# Engaging the Neurodivergent Producer

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AND AMBITIONS VIA DIGITAL INTERVENTIONS

**BY**
**PETKO ATANASOV KARADECHEV**

DISSERTATION SUBMITTED 2022

AALBORG UNIVERSITY
DENMARK

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## EXPLORATION OF SOCIO-TECHNICAL NEEDS AND AMBITIONS VIA DIGITAL INTERVENTIONS

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Petko Karadechev holds a Bachelor's degree in Cultural Studies from Sofia University, Bulgaria. He has been involved in work with socially vulnerable populations as well as the emergence and appropriation of digital tools in a broad social context, e.g., with his bachelor's thesis on online hate speech in Bulgaria in the 2010s. Petko also holds a Master of Science in Technology (Techno-Anthropology) from Aalborg University Copenhagen. His master thesis was a movie investigating the customization of a cognitive computing system and its socio-technical effects in an insurance company in Tokyo, Japan. Marrying Peter-Paul Verbeek's conceptualizations of post-phenomenology with video theory in a Danish context and a Posthuman Studies perspective, the thesis aimed to engage its video data into a more easily approachable visual dialogue. The main themes of the thesis were concerned with the viability of a cognitive computing or artificially intelligent system to replace human workers and the social and labor consequences of these early efforts to aggressively impose automated decision-making systems in a business environment. Petko received his master's degree in 2015 and became employed as a research assistant at the Department of Planning in Aalborg University Copenhagen. He joined the Techno-Anthropology and Participation Research Group whose main research focus is on emergent technologies, human-technology relations, and responsible technology innovation and use. Petko became a PhD Fellow in 2019 as he joined the "Digital communities for young people living with intellectual disabilities" project.

# ENGLISH SUMMARY

This thesis is the result of two and a half years of work as part of the "Digital communities for young people living with intellectual disabilities" (DiGi) project. With a specific focus on neurodivergent youth, it builds on a techno-anthropological academic background to explore the nature of the target group's interaction with familiar digital technologies and how these young people can be engaged as co-producers of digital content with the aim of learning more about their desires and ambitions within a digital context. The question of digital co-production was a central issue in this study. The key terms used throughout this thesis include disability and video tutorials, as well as digital creation and participation in digital practices. The study spanned two phases of fieldwork, namely, in-person and online only, and the insights gained offer theoretical contributions to the fields of human–computer interaction, critical disability studies, technology and inclusion, and more. The eight chapters of this work provide an overview of the academic context within which the study was situated, descriptions of the research design, the two fieldwork phases, and the study's theoretical contribution, a discussion to draw out the main points of the thesis and finally, my concluding remarks.

Drawing inspiration from the approaches of Brereton, Frauenberger, Seale, and more, the DiGi project addressed the often passive participation of neurodivergent people in society, in which they are often perceived as isolated recipients of resources rather than social actors with legitimate preferences. What this means in practice is that people who live with cognitive disabilities are a silent population that is dependent on municipal and state support to build, maintain, and engage in social relations. Digital technologies have changed this dynamic by offering another avenue of self-expression, skills development, social interaction, and support. In this study, I explored ways of engaging with neurodivergent participants by staging digital interventions with the participants as the digital producers of the content.

These digital interventions took the form of a two-phase methodological approach. First, we co-created participatory video tutorials (PVT), in which the participants were the co-producers: they decided on the type of content they wanted to present, demonstrated their digital skills, and were involved in the video editing process. This more normative approach was organized around a framework that was proposed by the researchers. Second, this normative approach was addressed by initiating an online-only fieldwork phase, which was focused on exploratory digital practices. Initially, this meant building on the foundation of the PVTs by attempting to recreate the tutorials in an online setting with the participants as the co-producers and correctors. However, the participants and researchers quickly moved into a more open space, where we experimented with digital tools, practices, and scenarios. Finally, the two approaches were merged, and I subsequently proposed a theoretical concept for researchers and professionals: the hybrid contact zone.

Both fieldwork phases provided interesting results. First, with respect to the PVTs, all the participants completed the tutorial process, during which we observed four types of reactions: (1) coping with ambitions, (2) show and tell, (3) connecting physical and digital experiences, and (4) enacting a performative role. Accordingly, we proposed four principles for engagement with digital technologies, which may be useful in special schools and sheltered residences. Second, the online-only sessions, during which the participants guided the process, offered examples of our exploratory approach to digital collaboration, including video compositing, placing oneself in a digital environment, and creating environments, inspired by the desire for others to feel what neurodivergent youth feel. As such, the main contributions of this thesis are the examples of digital engagement and digital co-production, which are situated within a theoretical framework. Ultimately, this thesis provides researchers and practitioners with specific suggestions on the theoretical and methodological approaches they could use to reimagine their existing practices, all with the goals of better learning from neurodivergent young people and supporting their social and digital ambitions to ensure their fuller participation in a reimagined society.

# DANSK RESUME

Denne afhandling er et produkt af to et halvt års arbejde, som en del af projektet, ”Digitale fællesskaber for unge med kognitive handicap”. Afhandlingen tager udgangspunkt i en teknoantropologisk akademisk baggrund, til at undersøge hvad denne målgruppe laver med velkendte digitale teknologier, og hvordan det er muligt at engagere disse unge mennesker i at samproducere digitalt indhold, for at lære mere om deres ønsker og ambitioner i en digital kontekst. Samproduktion er således et centralt emne, der bør være fordelagtig for både forskere og praktikere der arbejder med denne målgruppe. Nøglebegreber i denne afhandling er handicap, video-tutorials, digital kreation, og deltage i digitale praksisser.

Afhandlingen omfatter to faser af feltarbejde: personligt og online, og fremsætter et teoretisk bidrag til felterne; menneske-computer interaktion (Human-Computer Interaction), kritiske handicap studier (Critical Disability Studies), teknologi og inklusion (Technology & Inclusion), blandt andet. De otte kapitler i afhandlingen bidrager med et overblik over den akademiske kontekst hvori afhandlingen er situeret, en beskrivelse af forskningsdesignet, de to faser af feltarbejde, det teoretiske bidrag, en diskussion, og en konklusion.

Med inspiration i tilgange af Brereton, Frauenberger, Seale og andre, omhandler dette projekt den ofte passive deltagelse af neurodivergerende mennesker i samfundet, hvilket repræsenterer et ”problem med digital inklusion: medmindre borger med handicap har indflydelse på beslutninger som direkte påvirker deres liv, vil de forblive ekskluderet fra det generelle fællesskab, ekskluderet fra udviklingsmuligheder, og forblive passive modtagere af hjælp” (G3ict 2014). I praksis betyder dette, at mennesker der lever med kognitive handicap, forbliver en tavs befolkning, der er afhængige af støtte fra staten og kommunen, til at opbygge, bevare, og engagere sig i sociale relationer. Digitale teknologier har ændret denne dynamik og tilbyder en arena for at udtrykke sig, udvikle evner, sociale interaktioner, og støtte. Denne afhandlinger undersøger måder hvorpå man kan engagere neurodivergerende deltagere ved at iscenesætte digitale interventioner, der fokuserer på deltagerne som digitale producenter af digitalt indhold.

Disse digitale interventioner tager form af en tofaset metodisk tilgang. For det første ved at samskabe participatoriske video tutorials (PVT), hvor deltagerne fungerer som samproducenter ved at beslutte, hvilken type indhold de præsenterer, og derefter demonstrere deres digitale færdigheder og være involveret i videoredigeringsprocessen. Dette er en normativ tilgang organiseret omkring en ramme, som er foreslået af forskere. For det andet adresseres denne normative tilgang ved at indlede en feltarbejde-fase, der kun er online, fokuseret på eksplorative digitale praksisser. I første omgang betyder dette, at der bliver bygget videre på PVT-basen ved at forsøge at genskabe tutorials med online tilstedeværelse af deltagerne, som

fungerer som samproducenter og korrekturlæsere. Vi bevæger os dog hurtigt ind i et mere åbent rum, hvor vi eksperimenterer med digitale værktøjer, praksisser og scenarier. Endelig bringer afhandlingen de to tilgange sammen og foreslår et teoretisk koncept for forskere og professionelle: den hybride kontaktzone.

Begge feltarbejdsfaser gav interessante resultater. For det først, vedrørende PVT'erne, gennemfører alle deltagere tutorial strukturen og deres reaktioner kan inddeles i fire overordnede typer: (1) håndtere ambitioner, (2) vise og fortælle, (3) forbinde fysiske og digitale oplevelser, og via en (4) performativ rolle. På grundlag heraf foreslår vi fire principper for engagement via digitale teknologier, som kan være nyttige i specialskoler og botilbud. For det andet giver online-sessionerne eksempler på eksplorative tilgange til digitalt samarbejde med deltagere, der guidede denne proces. Eksempler inkluderer video komposition, placering af sig selv i et digitalt miljø, og skabe sådanne miljøer, hvor andre kan føle, hvad de føler. Derved er hovedbidraget i denne afhandling eksempler på digitalt engagement og digital samproduktion, sammen med en teoretisk ramme. De forenes for at kunne give forskere og praktikere konkrete forslag til, hvilke teoretiske og metodiske tilgange de kan bruge til at genskabe deres eksisterende praksis. Alt sammen med et mål om at lære fra målgruppen af neurodivergerende unge mennesker og understøtte deres sociale og digitale ambitioner for en mere fyldestgørende deltagelse i et genskabt samfund.

# ACKNOWLEDGEMENTS

The first and most heartfelt acknowledgement I need to make with regards to this PhD thesis goes out to every single participant I was lucky enough to work with for the better part of two and a half years. Spending time – far from enough! – with the sixteen young people who live with cognitive disabilities in the participating institutions of this project, has affected me deeply. I want to acknowledge how open and curious these participants have been with me, how they shared parts of their digital ambitions and aspirations with me, how they reflected on what their lives are and could be, with me – an outsider to their immediate environment, country, native language, and more. Overcoming all these differences together and being invited to continue our conversations even after the official fieldwork activities had ended, means more to me than I can adequately convey here. However, I want to acknowledge these shared experiences, as they matter. I would not presume to know if and how much they might matter to the sixteen participants I was privileged to work with, or if quantifying such a thing is necessary. Regardless, being an outsider – a Bulgarian in Denmark, a researcher in completely unknown special schools and sheltered residences – was no reason for disregard or doubt, or rejection. Rather, all sixteen participants and their caretakers, welcomed me as part of pre-planned activities, and extended their hospitality in physical as well as virtual environments. I cannot thank Henrik Søndergaard enough for his friendship, open and curious mind, and always being ready to dive in deep discussions. These experiences have already left their mark on me and will certainly continue to inform how I approach all research projects and everyday encounters with neurodivergent people from now on.

I want to extend my deepest gratitude to my supervisor and mentor throughout the PhD process - Professor Anne Marie Kanstrup from Aalborg University. Her relentlessly kind, insightful, and practical approach to the endeavor that is a PhD project has been a profound help for me. “We don’t do drive-by science” is a sentiment I heard from her and did my best to honor with my approach towards this project. I also want to thank my co-supervisor, Associate Professor Jacob Gorm Davidsen from the Department of Communication and Psychology at Aalborg University. His quick wit, inspiring professionalism, and infectious laughter have worked together to push me to question preconceived notions, and never forget the people who allow us to work with them. I also want to thank PhD Fellow Ditte Weber for sharing an unforgettable experience.

My PhD study has been part of the Digitale fællesskaber for unge med intellektuelle handicap project, or DiGi for short, which received its funding from the VELUX Foundation. I am grateful for the opportunity to conduct my PhD as part of DiGi.

While I could not physically travel abroad due to COVID-19, Professor Margot Brereton from Queensland University of Technology (QUT) in Australia welcomed

me into research group meetings, where I got to experience a different pace, rigor, considerations and engagement with theory and practice in an Australian context. Thank you to Associate Professor Laurianne Sitbon, Dr. Bernd Ploderer, Andrew Bayor, and the entire QUT team, as well as to Filip Birčanin, a true friend and colleague, for putting things into perspective and always inspiring me.

I also want to thank my colleagues from the Department of Planning at Aalborg University with whom I have shared many stimulating conversations throughout the years.

Last, but certainly not least, I want to thank my parents, sisters, and nephew for always supporting me. A special thanks to my partner Milena who makes it all worth it.

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# CHAPTER 1. INTRODUCTION

This PhD thesis is part of a larger project called *Digitale fællesskaber for unge med intellektuelle handicap*, which translates to "Digital communities for young people living with intellectual disabilities," or the DiGi project for short. In this overview, I present the stakeholders involved in the DiGi project, how the DiGi was structured and why, as well as how the project's goals were relevant to this thesis.

## 1.1. OVERVIEW OF THE DIGI PROJECT

The DiGi project is a collaboration between researchers from Aalborg University (AAU), young people (age 14-28) diagnosed as neurodivergent and staff from three institutions located in Aalborg, Denmark specialized for young people who live with cognitive disabilities. The three institutions are a school for children and young people between the ages of 6 and 18, a youth education for students between 16 and 25 years old, and a sheltered residence for neurodivergent young adults between 17 and 29 years old. The DiGi project took place from 2018 to 2021, with a final seminar and dissemination in 2022. Due to the duration of the project, some participants would transition between institutions during the different phases of DiGi. For example, students from the special school would move to the youth education as they turned 18 years old, and some residents would move to a fourth sheltered residence as they turned 28. The project received its funding by the Velux Foundation.

The project was organized around three main axes of stakeholders:

1. Researchers from Aalborg University
2. Neurodivergent participants and staff from all participating institutions
3. International academic cooperators

Furthermore, a steering committee was set up to ensure open communication between the researchers, management and staff, and participants. What follows is a brief overview of the roles and responsibilities within the DiGi project, starting with descriptions of the three participating institutions:

A special school for children and young people between the ages of 6 and 18 years called Kollegievejens has a capacity of 62. All the students live with cognitive and developmental diagnoses such as autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), and Tourette's syndrome. That means that all the students live with affected cognitive, motor, language, and social skills due to their conditions.

A youth education school that offers a special type of education for young people (*Særligt Tilrettelagt Ungdomsuddannelse* in Danish). The school is called VUK (short

for *Voksenskole for Uddannelse og Kommunikation*) and focuses on the age demographic of 16–25 years, with primary school education for those who struggle to continue with their education and/or employment. All students live with one or a combination of diagnoses of ASD, ADHD, learning disabilities, anxiety, acquired brain damage, and mobility impairments, among others.

A sheltered residence for neurodivergent young adults between the ages of 17 and 30 years who live with a certain degree of independence and self-sufficiency. The institution is called Sofiebo and supports a transition from youth to adult life, with social and practical activities for its approximately 20 residents.

A further residence for adults living with cognitive disabilities provided an additional site for the intervention sessions with the residents from the previously described sheltered residences who had moved while the DiGi project was in progress.

### 1.1.1. STRUCTURE OF THE DIGI PROJECT

The project consisted of three phases over a four-year period: two field studies and the implementation and evaluation phase. Each phase comprised video diaries and video interviews, with the addition of a workshop and theory seminar in field study 1, digital interventions and a theory seminar in field study 2, and a final workshop and theory seminar in the evaluation phase. Each phase took roughly two years to complete.

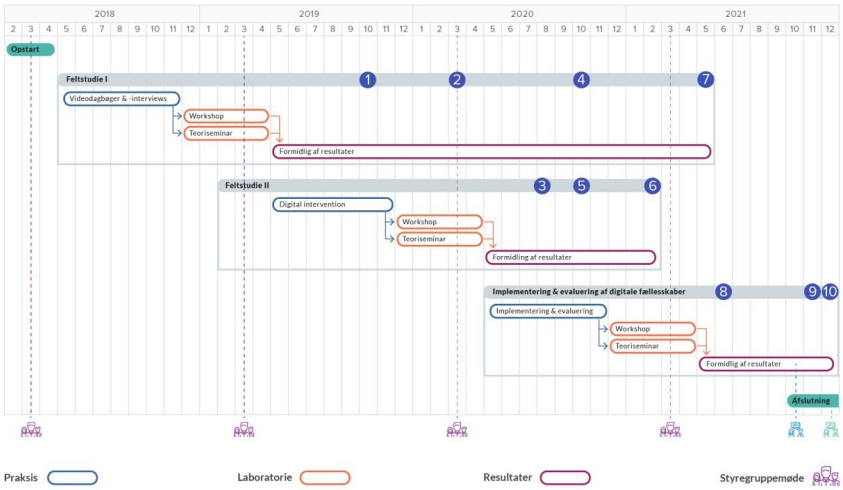



Figure 1. DiGi project structure. The legend reads practice (*praksis*), laboratory (*laboratorie*), results (*resultater*) and steering group meeting (*styregruppemøde*) (Kanstrup, 2017)

Figure 1. shows the three phases of the DiGi project. From top to bottom, it starts with field study 1 (FS1). The practical approaches used include video diaries and video interviews. A workshop and theory seminar make up the laboratory section where fieldwork with the participants and external academic support takes place. Finally, working on the results rounds up FS1. Next, field study 2 (FS2) is to develop digital intervention methods as its practical approach, carry out a workshop and a theory seminar for its laboratory phase, and work on summarizing its results in its final phase. The final phase of the DiGi project concerns implementation and evaluation of the. Steering group meetings between researchers and institution representatives take place once a year, where researchers would present results, and engage in discussions about the project's progress. A sense of continuity between all three phases is important, as it allows for cumulative knowledge to emerge.

### 1.1.2. A NOTE ON "DISABILITY"

The use of the term "disability" can be problematic due to different interpretations in different contexts and is a point of contention in the context of engaging neurodivergent young people in digital activities. To clarify how the term and its related concepts were understood and used throughout the DiGi project as a whole, and in this thesis in particular, I refer to the DiGi project's conceptualization of "disability," which was based in part on the second volume of The Collected Works of L. S. Vygotsky by Robert W. Reiber and Aaron S. Carton (1993).

The DiGi project drew inspiration from the work of Lev Vygotsky as his theory of defectology has to a large degree shaped the Danish pedagogy on working with people who live with cognitive and developmental disabilities. Defectology describes the discrepancy between the psychological constitution of an individual and the structure of their surrounding culture and society. As per Vygotsky (1993, as cited in Rieber & Carton, 1993), a child living with disabilities is not "less" developed than "normal" children, but rather differently abled (p. 30). As such, focusing research and pedagogical energy on disabilities makes little sense. Instead of narrowly defining people living with intellectual disabilities according to their medical diagnoses, this energy should instead be spent on better understanding the abilities of the individual, recognizing their uniqueness, and learning about them in the context of their environment.

Knox and Stevens (1993) pointed out that for Vygotsky, "the fundamental laws governing the cognitive and psychological development of an abnormal child are identical to those laws which guide the development of normal children" (as cited in Rieber & Carton, 1993, p. 12). Further on, they outlined one such law by describing two paths for development, which they call "the natural, 'physiological,' or biological and the historical, cultural" (Knox & Stevens, 1993, as cited in Rieber & Carton, 1993, p. 12). For children who live with intellectual or cognitive disabilities, inconsistencies are apparent in these two developmental trajectories. Historically, these

inconsistencies exist due to societal structures (e.g., institutions) and objects (e.g., physical and digital technologies) being designed for people with so-called typical development, which means in effect that they fail to address social groups with atypical development. Children's "disabilities" in this sense become an issue that affects how they participate in social activities and acquire relevant social skills and cultural cues, all of which have a significant influence on their development (Bøttcher & Dammeyer, 2012, p. 436).

### 1.1.3. A NOTE ON THE GOALS OF THE DIGI PROJECT

The DiGi project had two main ambitions. The first was to map the key digital abilities and practices that the project participants were engaged in on a daily basis and to learn more about their digital lives. This was achieved in field study 1 with the help of video diaries and video interviews. The second main ambition was to explore digital opportunities for practical engagement with the participants (i.e., what did they use their digital skills on, and how did they use their digital skills when engaged in a collaborative capacity as opposed to simply recording what they did?). To achieve this ambition, the researchers and participants were required to share responsibilities, to demonstrate their respective technological skills and socio-technical ambitions, and to commit attention, time, and effort to an exploratory process without any clear results or payoffs. As such, the exploration approach carried the inherent danger of not being able to include everyone. However, that risk was mitigated by the use of a workshop format (i.e., by premieres in field study 2, as described in section 4.5.5), in which we attempted to give back to the participants by organizing an event they would enjoy. Ultimately, field study 2—this thesis—was set up by the DiGi project to learn from the practical experiences gained in field study 1, to review the relevant literature, to develop and implement methods of engagement, and to do all that while maintaining an open outlook with respect to the co-creation, participation, and social relations emerging from and stimulated by the digital interventions.

## 1.2. OVERVIEW OF THE THESIS

This thesis is made up of eight chapters, structured as follows. The introduction outlines the academic context and structure of the thesis, discusses some relevant terms, and presents the rationale, goals, as well as academic and professional positioning of the thesis. The second chapter presents relevant academic literature and engages key terms in the larger context of the study, ultimately presenting the thesis' main research question.

Chapter three starts with academic influences to the research design of the project, how ethics has been considered, and offers an overview of the fieldwork. It then describes in depth issues of access to the field and the role of relevant stakeholders. The chapter concludes with a look into practical issues of how digital technologies and "disabilities" are engaged in the thesis, specifically outlining the role of video as

a tool for participant engagement, and introducing the idea of participatory video tutorials.

Chapter four is where that idea is developed further, discussing the importance of a video tutorial, what makes it participatory, and what its practical potency can be used for. The chapter continues with a deep dive into the first phase of the fieldwork, namely the sessions around the creation of the participatory video tutorials, with a five-step guide, and a discussion on the results of these efforts. The discussion includes reflections on the structure of the activities, an overview of the use of technology, four types of reactions to the tutorials from our participants, and four principles for the co-production of video tutorials.

Chapter five moves into the second phase of the fieldwork, which concerns online sessions. Here, vignettes are used to describe online-specific activities and convey key insights from participants regarding this approach. The chapter ends with a reflection on the usefulness of online sessions.

Chapter six builds on insights from the previous two chapters in order to present a theoretical concept that can be useful for researchers and professionals alike, namely the hybrid contact zone. The concept is defined, contextualized and discussed as a form of thirdspace, and is further developed via participant reflections.

Chapter seven is where I go back to the calls for research that this thesis is partly inspired by, and show how I have addressed them, and how I have answered the main research question. I revisit questions of care and knowledge that have been introduced in Chapter three and offer a critical discussion around why the approaches presented and used throughout the thesis have been chosen. The chapter ends by a reflection on the limitations of the project and opens questions about voice and control relevant to the target group of neurodivergent young people.

Finally, chapter eight concludes the thesis, and raises questions about future research, and how the work presented here can be expanded and take new forms.

Field study 2 was positioned at an academic crossroads. On the one hand, it had its roots in techno-anthropology. This is an international field of study, but the Danish tradition describes itself as having a multifaceted focus on technologies, experts, and users (Borsen & Botin, 2014) and the relationships between them. These general relationships represented a major part of the guiding principles of this thesis: to be grounded in specific activities with specific technologies, to consider how objects and subjects influence and co-construct each other, and when engaging in practical work, to consider more than just the immediate focus of the research (e.g., a technology, a user, or an expert) , but instead to approach the work with a nuanced perspective. On the other hand, field study 2 was inspired by a tradition of participatory design (PD), in which the tenets of working *with* instead of working *for* the participants influenced

the main ambition of the study. That is, we aimed to explore how the target group could be engaged in co-production and co-creation, to generate knowledge on what it means to pursue equitable, exploratory activities with neurodivergent young people, and to engage this target group as more than just participants who were present in the field, but rather as co-producers who could guide and shape not just the content, but the outline of the research process itself. On a very practical level, we asked: what would it mean to explore with this target group, and how could that be done?

### 1.2.1. NEURODIVERSITY

Before I approach the question of exploration with, I first have to be able to talk about the target group. One way to do so would be to offer an in-depth discussion on key terms like ASD (broadly characterized by difficulties in understanding social interactions), ADHD (issues with focus and maintaining attention), aphasia (difficulties with finding the right words to say or write), dyslexia (difficulties recognizing words), and dyscalculia (difficulties recognizing numbers). While such a discussion would undoubtedly provide information about the respective conditions that the members of the target group of this thesis were living with, it would mostly provide more information about the conditions themselves rather than the complex lived experiences of the people we were working with. Hence, a different approach was deemed more appropriate. In combination with Vygotsky's understanding of different abilities (1993, as cited in Rieber & Carton, 1993), I turned to the 2013 book by Joyce Davidson and Michael Orsini, Worlds of Autism: Across the Spectrum of Neurological Difference. In it, they refer to the concept of neurodiversity, which was popularized in the late 1990s and argues for "greater recognition of what Kathleen Seidel terms the 'variety of human wiring'" (Davidson and Orsini, 2013, p. 9). Recognizing such variety was an important step in addressing the participants in this project on their own unique terms. As such, this thesis was aligned with the position of Davidson and Orsini (2013) when they wrote that they were "part of a growing body of work that uses an abilities framework" (p. 13). This framework commits to engaging with people living with ASD and other cognitive and developmental diagnoses through "complex relational (dis)order that challenges deeply rooted stereotypes of what has long been regarded as normal human experience" (Davidson and Orsini, p. 13). This particular way of viewing participants is not neutral. It comes with an understanding of an unequal power balance between neurotypical and neurodivergent people, of complex intra- and inter-personal relations, and of stereotypes of normalcy, which can be used to exclude and isolate non-normal, neurodivergent people and more.

For the purposes of this thesis, it was important to elevate the question of the unique socio-technical abilities already displayed by the participants in field study 1, specifically, the large number of software applications and platforms used, as reported by Andreasen and Kanstrup (2019), in Table 1.

Table 1. Participants' use of digital technology in field study 1 (Andreasen & Kanstrup, 2019)

| **Applications and platforms** |
| --- |
| **Hardware**: Computer, phone, tablet, iPad, console |
| **Social media**: Facebook, Instagram, Twitter, blogs |
| **Messaging technology**: Messenger, Facetime, Skype, Discord, PlayStation Party, SMS, Viber, Snapchat |
| **Online and offline games**: Saints Row, Minecraft, Sandbox, Counter-Strike, 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, Bloons Bt6, Piano Tiles, UNO, Stickmuster Design, Pokemon Go, Candy Crush, Hay Day, Booble Shoot Pet, TikTok |
| **Video and music channels**: YouTube, Twitch, QR Code Generator, Spotify, YouSee, Title, Netflix, DR, Viaplay |
| **Others**: Github, Deviantart, Medusa, Javascript, Sleros |

I used this diverse range of technology across device types, international digital hubs, first-person shooter games, as well as game development environments (e.g., Roblox), programming languages, and more as an indicator of the many types of digital practices and social customs that could be referred to when engaging with the target group. Table 1 illustrates the more than 50 technologies that were used and provides a makeshift map of the personal and shared interests of the participants (e.g., over-representation of games and communication programs, as well as the creative tools for digital environment creation, game development, and programming). This formed an important aspect of the real people we engaged with, in addition to their living with medical diagnoses with support from special schools, sheltered residences, and more. This particular aspect—the engagement in socio-technical practices—was a major focus of this thesis.

### 1.2.2. WHO WERE THE PARTICIPANTS?

As I will be referring to the participants throughout this thesis (Table 2), a brief introduction is in order. These descriptions were my impressions from my first encounters with each participant, which all took place between September and November 2019. These impressions are based on my personal field notes taken during

or immediately after the fieldwork sessions at each institution. All the participants' names throughout the thesis are fictitious to respect the individuals' privacy.

Table 2. Participants of the study

| Institution | Participants | Age |
|---|---|---|
| Special school | 3 (Jens, Thomas, Andreas) | 14–15 |
| Youth education | 6 (Caroline, Hannah, Carl, Magnus, Lars, Rune) | 16–22 |
| Sheltered residences | 7 (residence one: Josephine, Alfred, Martin, Viggo; residence two: Klavs, Nadine, Linda) | 24–29 |

I heard **Jens** before I saw him as he was talking loudly to his caretaker as they entered the room for a video tutorial session. Jens was very talkative, gave his attention to everyone, and immediately engaged with the equipment in the room. He would go on to have noticeably long sessions in comparison to both his classmates and the other participants: where most would typically stay in person for around 60 minutes, Jens would easily remain twice as long. **Andreas** was much quieter than Jens and made much less eye contact. He would focus entirely on the technical tasks at hand and would only participate in or initiate a conversation after the sessions (and very rarely at that). **Thomas** appeared shy at first and did not speak unless spoken to. His demeanor quickly changed when he opened Blender—his software program of choice—and as his workflow, which included many YouTube tutorials references, unfolded. He was pleasantly surprised to learn that a researcher had had previous experience with this program and could engage him with it.

**Caroline** and **Hannah** arranged for a session where they jointly demonstrated how they had created a TikTok video. Caroline had asked Hannah to help her with make-up and to join a dance sequence. An interesting moment during this activity occurred when Associate Professor Jacob Davidsen and I were asked to leave the room, which left behind the only female researcher, Ditte Weber, as someone who could view the girls' performance. Caroline later asked Ditte and me to dance for a second video that she wanted to publish on her own. **Carl** was the first participant who stood out to me as he raised questions about fairness and responsibility and modeled his activity around issues of anti-cheating approaches in a game server. He was outspoken and directly engaged with the researchers on any and all topics that came to mind. **Magnus** was similar to Carl in that he was outspoken and initiated contact. He felt comfortable enough to offer handshakes, fist bumps, and even hugs. **Lars** stood out from all the participants as he wanted to film an historical reenactment and to use it for his existing

YouTube channel. As such, the digital practices were not front and center but were rather peripherally useful to his interests. It quickly became clear that **Rune** was close friends with Carl and Lars, and they played computer games together. He also had a YouTube channel, and he created humorous gameplay and compilation videos, which he shared with his friends.

**Viggo** was one of the older participants in this project. He was quiet and took his time before answering any questions. He took pride in the formidable amount of technology in his room, which included a large TV, a high-end desktop computer, and multiple game consoles. **Alfred** and **Martin** were friends and had a tradition of playing computer games together. They had inside jokes and were invested in sharing in-person gaming experiences with other people in their institution. **Josephine** laughed and sang and showed us how she used her smartphone to connect with loved ones. Her speech impediment did not appear to be an insurmountable challenge, and she lifted the spirits of everyone in the room.

**Klavs** and **Nadine** used to live in the same institution as Viggo, Alfred, Josephine, and Martin but moved to another housing facility before field study 2 started, and Nadine met Linda there. Klavs appeared to be shy and only engaged with us when his caretaker was next to him in the room. Nadine and **Linda** played mobile games and wanted to share their positive experiences with others. Nadine was also extremely hospitable and invited Professor Anne Marie Kanstrup and me on a tour of her room.

I have provided these brief character sketches to serve as small representations of the real people whose presence can never fully shine through this PhD thesis, but whose participation in it was an education in itself. These outlines are not meant to be definitive descriptions of their key characteristics, but simply to offer a glimpse into what it felt like to meet the participants for the first time.

### 1.2.3. WHAT WERE THE ACTIVITIES?

The fieldwork for this thesis consisted of two phases: in person (phase one) and online only (phase two). Phase one took place between September 2019 and January 2020 and directly engaged the participants as co-producers of participatory video tutorials (PVTs). All the activities took place at the participants' place of study or residence. The entire process is explored in depth in Chapter 4. As a brief summary, the creation and production of the PVTs included a combination of physical elements and digital activities. The physical elements included meeting in a dedicated room, with noticeable equipment set up (e.g., cameras, studio lights, audio recorders), sometimes even with a green screen, to visually highlight the researchers' commitment to the PVT creation process. The digital activities took place either on a computer or laptop provided by the institution or on a personal electronic device (e.g., tablet, smartphone, laptop, desktop computer) and included demonstrations of digital practices and tips and tricks for potential viewers.

Phase two took place between August 2020 and June 2021 and was exclusively online due to the COVID-19 lockdowns in place at the time. Using the video conferencing tool Zoom and given the less crowded, more personal online environment, I was able to explore more open-ended scenarios with the participants. These scenarios included semi-structured sessions where I would build on the experiences of the video tutorial sessions as catalysts for discussion and technological exchange with the participants. Additionally, there were sessions during which the entire list of activities was directed by the participants (e.g., the exploration of video compositing methods in an apocalyptic scenario with zombies, mixing 3D modeling with video editing to create a cyberpunk city). All these results are described at length in Chapter 5.

### 1.2.4. RATIONALE AND GOALS

In essence, the driving rationale behind this thesis was to attempt to explore the nature of the engagement with neurodivergent young people in their environment (either an institution or a shared virtual space) as digital co-producers. More specifically, I aimed to experience digital co-production and creation alongside this target group from the mixed position of a researcher who explores, as well as a learner who views the participants as experts in the activities they decide to share and treats them as such. This thesis was not structured around the idea of setting up experiments and measuring results. Rather, I endeavored explore the unique position of having access to a population that is stigmatized in different ways regardless of where they live. Pursuing an exploratory approach and learning about what this target group in Denmark creates, consumes, reproduces, and admires in a digital technology context is a research luxury that should not be taken for granted.

As such, a main goal of this thesis was first and foremost to establish a respectful, open, curious, and exploratory rapport with the participants, who agreed to share their time and expertise. A second goal was to actively give back relevant knowledge and digital skills to these participants and to not simply receive their inputs. Additionally, a goal of this thesis was to synthesize the shared experiences with these neurodivergent youth into questions for their support staff and caretakers to consider. As their work and efforts could potentially benefit from a reinterpretation of their positive experiences into their own strategies and classes, it is worth sharing all the lessons learned.

In this thesis, I found that despite many profound differences between my so-called neurotypical life and the participants' so-called neurodivergent lives, an approach that stimulated our interests with a simple label (i.e., "digital producer" or "digital content creator") and a simple structure (what is a video tutorial?) could engage a diverse group of neurodivergent young people. In this thesis, I aim to share a story about finding similarities between how the participants and I used digital technologies and how these similarities could be engaging for experts and offer deeper knowledge

regarding socio-technical participation from the position of a stigmatized, silent population that depends on personal and institutional care in Denmark.

### 1.2.5. ACADEMIC AND PROFESSIONAL POSITIONING

This thesis further aimed to contribute knowledge that could be useful to academics from related fields, such as human–computer interaction, critical disability studies, science and technology studies, communication studies, interaction design, design methods, ubiquitous computing, technology and inclusion, and anthropology. Any researcher with experience in PD, action research, and digital methods should be able to not just understand why certain practical choices were made in this thesis (e.g., the use of video tutorials as engagement techniques), but also easily modify the methods presented throughout this project in a way that would complement their existing work.

On a practical and theoretical level, this thesis additionally aimed to address the following two questions:

What should professionals working with neurodivergent youth take away from this thesis?

What should academics take away from this thesis?

While the expanded answers are given in Chapter 8, it makes sense to provide a few remarks here. First, professionals working with this target group can expand their existing pedagogic and teaching approaches to include more digital activities. This is in line with existing calls to center children as "protagonists" (Iversen, Smith, & Dindler, 2017) in PD and allow for another avenue that can support the nurturing of "constructive disagreement" and "agonistic design with neurodiverse children" (Frauenberger et al., 2019b). Practitioners in Denmark are usually highly experienced in in-person activities and have a strong tradition of engagement to build on. Leveraging digital activities in this environment should be approached in a respectful, caring, and exploratory manner with respect to strategy development so that the target group can ultimately benefit and make their own choices in this process.

Second, academics from related fields may also be able to benefit from this thesis. For example, scholars of critical disability studies may take inspiration from the agency and initiative demonstrated by the participants in the vignettes described in sections 5.2.2-6, and to update discussions around the term "disability" as well as the transfer of power in co-production roles during digital co-creation. Researchers of science and technology studies could refer to the hybrid contact zone (HCZ) and digitone concepts in Chapter 6 to revisit questions about technological appropriation from a socially vulnerable position and more. The next chapter, "Setting the Stage," better presents how this thesis relates to existing academic currents.

# CHAPTER 2. SETTING THE STAGE

Young people who live with cognitive disabilities occupy a precarious place in any society and are particularly vulnerable to social and technological shifts. The Danish context alone has seen profound changes in the 20th century regarding how physically and mentally disabled people are seen and treated. While a total of 11 state-operated asylums were built well into the 1940s and 1950s, an important shift was marked with the so-called Mental Retardation Act of 1959, which was drafted by the Danish advocate for the rights of persons with intellectual disabilities Niels Erik Bank-Mikkelsen. The Act promoted a principle of normalization that supported the closure of large asylums and a move toward smaller, decentralized living units for the disabled. It also codified Bank-Mikkelsen's call for the right of people with disabilities to have as "normal" living conditions and daily routines as possible (Derksen, 2021). Even though the Act of 1959 had positive effects overall, the practices and institutions did not change overnight, and interventions such as forced sterilizations and lobotomies were performed into the 1980s in Denmark (for additional information on disability policies in Denmark and the Nordics, see Derksen, 2021).

The purpose of this brief historical remark is to sketch a picture of the broad societal and governmental attitudes in Denmark toward people who live with cognitive disabilities. I further highlight the existence of medical justifications for certain approved methods (e.g., social control, medical interventions) and contrast them with the focus in the early 21st century of relevant parts of the academic community, their interests, and questions. This contextualization positions the current thesis in the lineage of engagement with and the involvement of people with cognitive disabilities in Denmark. It helps clarify what this project is and what it is not: it is an explorative study aimed at supporting digital social participation and skills development via digital interventions (in this case, participatory video tutorials [PVTs] and online sessions). It is not a prescriptive project aimed at justifying one set of approaches over another.

In contrast to governmental approaches from the past, current academic research has an imbalanced interest in how and why neurodivergent populations should be seen, represented, and play a role in research. How to improve performance on IQ tests (Sansone et al., 2014), how to increase physical activity (Rotta et al., 2022), how to assist in learning scenarios (Kauffman et al., 2017; Wilczynski et al., 2007), how to make choices available during shopping (Krummheuer, 2021), and how to design and deploy a planning system for calendar appointments (Rodil et al., 2020) are all research endeavors that have focused on learning from this target group as much as possible to help them solve one particular troubling, inconvenient, or practical aspect of their daily lives. In addition to these predominant areas, research trends indicate an interest in understanding and supporting direct socio-technical practices with the target group. Specifically, researchers have explored how the target group can be

involved in the design and creation of technological objects (Frauenberger et al., 2019a; Rajapakse & Brereton, 2019; Rodil et al., 2020), what constitutes "normal" technological use for them (Seale, 2017), the question of digital rights for people with disabilities (Alper, 2017), how technologies augment their practices (Alper, 2017), and more.

In this regard, an ambition of this thesis was to complement the more limited parts of this research by exploring direct engagement with a neurodivergent population and how they use the technological tools they interact with on a daily basis to create, modify, mix, and produce digital objects, scenarios, and situations with a direct social effect on their lives. This exploration was carried out via digital interventions, which were influenced by participatory design (PD) and co-design. Additionally, I referred to action research, design research, and video-based interaction research to investigate technology in action collaboratively with the target group. I turned my attention to all these design approaches and scientific disciplines in their specific capacity to foreground the participants in this study as active participants. Conversely, what I contribute to the ongoing PD research in this field is data and analysis on what happens when we engage neurodivergent participants as co-creators and co-producers of their own digital materials, interests, and ambitions (specifically with PVTs and online-only exploratory sessions).

The question of exploring rarely sought-after configurations (i.e., neurodivergent youth as co-producers and co-creators) is important to consider as it relates to PD's tradition of an "unshakable commitment to ensuring that those who will use information technologies play a critical role in their design" (Robertson & Simonsen, 2020, p. 2). Additionally, a specific characteristic of PD that I leveraged is its support of "mutual learning between multiple participants in collective 'reflection-in-action'" (Robertson & Simonsen, 2020, p. 2). I was also influenced by how action research "uses intervention into problematic social situations as a means to develop scientific knowledge" when I constructed and continuously updated my methodological approaches (Lewin, 1951; Rapoport, 1970; Trist, 1976, as cited in Iversen, Mathiasen, & Nielsen, 2004). This is because my research did not aim to merely describe results; instead, it was intended as an opinionated set of activities that continuously reflected on itself as it interacted and co-created with its participants. In the process of an intervention, positions must be taken and roles negotiated. In PD, there are typically two types of roles for participants, users and designers, where the designers' general objective is to understand as best as possible the users' lived realities, while the users generally attempt to communicate a preferred future scenario as well as obtain the (technological) skills to be able to achieve this (Robertson & Simonsen, 2020). While these roles are generalized and somewhat abstracted, they are sufficient to set up a process of mutual learning in which all the participants can conceptualize new (ways of using) technologies. The designer and user roles were not specifically pursued in the context of this thesis; however, their general outlines of mutual understanding and the exchange of (technological) skills emerged in the process of the fieldwork.

Researchers like Christopher Frauenberger (2011, 2013, 2015, 2016, 2019, in: Antle et al. 2020) and Margot Brereton (2014, 2015, 2018, 2019, in: Bircanin et al. 2020) have explored this question specifically in collaboration with children, adolescents, and adults living with cognitive and developmental disabilities who were engaged in the research as active and competent participants. Further, Greenbaum and Kyng (1991) viewed the users of IT systems as possessing competency and being competent practitioners themselves. I adopted this perspective to a traditionally marginalized social group that needs almost constant care and support. By looking into and actively building on their skills, I was interested in how their competencies (inherent and/or obtained) could be brought into the development of new social and socio-technical practices.

In related literature on human–computer interaction, there exists a call for another type of future research on ways to engage neurodivergent young people. Specific examples include authors like Frauenberger, Brereton, and Seale. They have highlighted the need for guidance for researchers and designers on productively engaging with conflict in the design process (Frauenberger et al., 2019b), the development of more lightweight methods, the need to disentangle power relationships when co-constructing experiences (Frauenberger, 2019a), and the supportive effects of positive risk-taking on educational practices (Seale et al., 2013). While my thesis does not aim to provide clear-cut, unambiguous answers to these issues, it directly addresses and engages with them via theory and methods. First, however, a few key terms that are fundamental to this thesis need to be clarified.

## 2.1. KEY TERMS AND DEFINITIONS

When a social scientist or medical professional uses the word “disability,” both will undoubtedly be in general agreement over some of the word’s characteristics (e.g., the inability to act in broadly acceptable social ways, and the need for niche support from pedagogical, medical, municipal, or other kinds of staff). Similarly, the term “intervention” may mean different things to a nurse and an anthropologist. Asking these different professionals to provide definitions for the word, however, will reveal the different considerations they hold as a result of their expertise. To minimize misinterpretations as much as possible, I have provided a short list of three key terms and definitions used throughout this thesis, namely “disabilities,” “participation,” and “digital interventions.”

### 2.1.1. DISABILITIES

According to data from the World Health Organization (n.d.), disabilities are the results of interactions, and they are not inherent to an individual or a group of people. Consequently, this project acknowledges that its target group is viewed as disabled in the context of functioning in social and physical environments, both in the locality of Denmark and to a different degree in international, internet-mediated contexts. Additionally, the American Association on Intellectual and Developmental Disabilities (AAIDD, n.d.) has described intellectual disabilities as “a condition

characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22" and adaptive behavior as "the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives." The AAIDD (n.d.) has also listed the following characteristics of adaptive behavior:

(1) conceptual skills (e.g., language, literacy);

(2) social skills (e.g., interpersonal skills, social responsibility, self-esteem);

(3) practical skills (e.g., daily living activities, occupational skills, travel); and

(4) standardized tests being used to determine limitations in adaptive behavior.

At this point, it is important to note that the definitions provided by the World Health Organization and AAIDD apply to the target group of this thesis to varying degrees depending on the type of interaction (physical or digital) that the individuals in the target group are involved in.

A long list of umbrella terms is used to encapsulate what is meant by cognitive disabilities, including Down's syndrome, autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), and Tourette's syndrome. For example, in 1911, the term autism was coined as a description for a severe type of schizophrenia (Evans, 2013), but in 2013, the fifth revision of the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychological Association combined it with Asperger's syndrome and childhood disintegrative disorder under the term autism spectrum disorder (American Psychological Association, n.d.). Similarly, all other terms are regularly revised by medical and social science communities to better address the lived experiences of the people who live with the said conditions. Possibilities for development for people living with ASD (as for all humans) are influenced by the dynamics between the individuals and the social groups they interact with. For example, "social coordination with others is enacted within and through differentially attainable social relationships, institutions, activities, spheres of knowledge, ideologies, emotional paradigms, and moral frameworks" (Ochs & Solomon, 2010, p. 72).

Regardless of exactly what is meant by one type of disability or another, all such terms should be used in accordance with the right of people to decide how they would like others to describe them (Alper, 2014). A debate on terms should never lose sight of whom those terms are describing, what these descriptions can influence, and how such terms permeate both a broader social perception of people living with disabilities as well as an individual's sense of self.

Furthermore, disabilities, regardless of how they are defined, are perceived differently offline and online. While cognitive and mental disabilities are often associated with problematic face-to-face communication, shyness, and anxiety, being online alters

these concerns. It allows individuals a different kind of control over social situations and exposes them to new kinds of challenges. Alongside these conditions, to be online in the 2020s involves a particular type of relationship with the dominant digital practices, which are focused around (personal) data sharing and digital creation via social media, technological literacy via digital tools, and direct contact with fast- and ever-changing social trends.

### 2.1.2. PARTICIPATION

Participation is another key term used in this thesis, and it may have an even richer network of related meanings than *disability* as it can be linked to many different areas of research. For example, *political participation* would have political scientists pointing out that the term has to do with "citizens' activities affecting politics" (van Deth, 2014). *Labor force participation* can be used to describe emerging technological advances like automation to investigate individuals' attachments to the workforce and participation in established work practices (Grigoli et al., 2020). Additionally, *women's participation* is another subfield of research interest where participation in labor, social, political, and other organizations is viewed through a gender perspective (Stoloff et al., 1999). Oser et al. (2012) discussed how *online participation* is distinct from offline participation in a political context; the authors concluded that there are distinct forms of online participation (e.g., contacting public representatives, spreading petitions and forms, organizing offline protests). On a critical note, Oser et al. stressed that they did not observe online-*only* political participation, which indicates that the term is not confined to a physical or virtual environment. All these different conceptualizations ambiently affected the research interests of this thesis: the project's participants were considered (1) not just as individuals, but as citizens, (2) not just as recipients of welfare, but as equal labor force participants, and (3) not just as witnesses to online trends, but active participants in their enactment.

To further clarify what conceptions of *participation* influenced this thesis, a brief outline of the PD field is necessary. PD emerged in the 1970s in Scandinavia in response to the introduction of information technologies in the workplace (Bødker et al., 2022). Over the years, PD has shown the importance and difficulties of engaging non-technical experts in conversations about present and future digital technologies (Kensing, 1991). Simonsen and Robertson (2012) outlined two fundamental aspects of PD that are relevant to better understanding the term *participation*.

The first aspect ensures that users of technology have the opportunity to have a voice in its design "without needing to speak the language of professional technology design" (Simonsen & Robertson, 2013, p. 2). This marks a shift in understanding about where useful knowledge resides. Instead of highly specialized technical vocabularies from experts, participation demands that input from all technology users be considered by designers and developers. Importantly, this shift also means less reliance on mediating and interpretative parties (e.g., caretakers, parents) and a focus on direct input from study participants, who are usually not asked to represent themselves.

The second aspect of PD acknowledges that non-expert users of technology may not be able to communicate the desired outcomes of design processes without knowing what is possible with the help of these technologies. Simonsen and Robertson (2013) argued that a need exists for a mutual learning process between users and designers, which can ”inform all participants’ capacities to envisage future technologies and the practices in which they can be embedded” (p. 3). Effectively, this PD characteristic highlights a shared responsibility regarding participation: engagement in an exploratory mutual learning process, which should be somewhat new to both the participants and researchers and can lead to better ways for the participants to communicate the desired process outcomes.

Participation in a digital context needs further defining as its meaning can differ depending on the focus of the researchers. For example, it may refer to the digital version of social activities that the participant already has experience with (e.g., remote communication, as per Buchholz et al., 2020; social inclusion, as per Chadwick et al., 2022). It can also mean participating in digital-first or digital-only activities, such as video manipulation, game development, 3D virtual modeling, and sending text and images, as is presented in Chapter 4 of this thesis. In any reading, however, digital participation, as conceptualized in this thesis, was inspired by the tradition of PD. According to Bødker et al. (2022), PD is sometimes used to engage future users locally in a particular context. The authors also highlighted PD’s relation to political and public organizations, where actions are needed on many levels. This characteristic of PD is relevant for the current thesis as somewhat organized action was very much not in the parlance of our target group, whose daily lives depend on their support staff and parents. However, the specific dependencies of their physical lives did not translate unchanged in their digital lives.

### 2.1.3. DIGITAL INTERVENTIONS

A medical intervention is often associated with medical or surgical procedures, and the social sciences would broadly define an intervention as the interposition in a practice or process. An intervention is also an interruption in an ongoing process or practice. It always originates from outside that process or practice and engages it with a disruptive force. The goal of developing a digital intervention approach with a target group whose daily activities, at home and at the institutions in which they reside, should not be unnecessarily disrupted in any way is thus a tricky one. However, situating those requirements in a digital environment is a relatively new practice with benefits and drawbacks that are still under consideration.

Digital interventions are also well-documented in the health and medical literature where they have been used to contribute to the knowledge on promoting self-management (McLean et al., 2015; Morton et al., 2016), managing hypertension (Bradbury et al., 2018), recovery from psychosis (Bucci et al., 2018), treating pediatric ADHD (Davis et al., 2018), developing therapeutic digital games (Kraemer et al., 2018), virtual reality (VR) music therapy to reduce social anxiety (Adjorlu, 2019),

promoting physical movement and countering sedentary behaviors (Schwarzer et al., 2018; Wang, 2019), and enhancing empathy (Chung & Ghinea, 2020; Wormald & Melia, 2020). Some researchers have observed and been present for the ongoing activities (Ringland, 2017, 2019b), with their only intervention being their presence as a visible and known witness to the process or practice. Other interventions have focused on research- or expert-developed digital tools or environments while participants with cognitive disabilities have interacted with them and were observed for the purpose of obtaining results (Chung & Ghinea, 2020; Tan et al., 2019). Digital interventions can be carried out via approaches like storytelling (Parsons et al., 2020), focusing on personal and intimate topics (Löfgren-Mårtenson, 2008), and self-management supported by telemonitoring (Morton et al., 2016).

In this thesis, I understood digital interventions as a practical, engaging, and appropriate way to use digital technologies for co-creation with people living with cognitive disabilities. A digital intervention can simultaneously be the tool (e.g., a digital workflow inquiry), the environment (e.g., a video call), and the theme (e.g., video tutorials) of an intervention process. In my work, I focused on the creative, expressive, and collaborative aspect of digital interventions and tested their applicability and limits as an approach that could be used with a socially vulnerable population.

## 2.2. PUTTING KEY TERMS TO ACTION

To ensure active participation, the research design was based on interventions that come as a concept from action research and PD, alongside the idea of *staging* (Binder & Brandt, 2008), which allows participants to not just show and tell what they consider important, but also to engage with and *enact* it (Sanders, Brandt, & Binder, 2010).

In the next two sections, I present how these three key terms relate to the DiGi project and thus what role they play in the conceptual focus of this thesis.

### 2.2.1. DISABILITY AND THE DIGI PROJECT

As mentioned in Chapter 1, the DiGi project bases its understanding of the term "disability" on the work of Lev Vygotsky (1993, p. 30). This conceptualization was shared with the practitioners from the participating institutions, and in a professional Danish context, disability is understood as a disparity between the individual's psychological composition and the structure of the surrounding culture/society. In an effort to better understand this disparity, the DiGi project team looked for more active approaches to engage the target group and was interested in exploring what specific technological contributions could be expected from the project participants. What this meant is that they were not to be treated as fragile recipients of research and innovation as they had social and technical ambitions and desires in their daily lives, which in turn meant that we could pursue strategies that supported them. The

diagnosis of disabilities the study participants lived with did not make digital production impossible as the available tools were malleable enough for them.

In Field Study 2, this conceptualization of what "disabilities" is had a direct effect on the methodological engagement and the following questions: How was our target group to be approached? What activities could be reasonably set up and carried out with them? What level of expertise were we ready to work with from their side?

### 2.2.2. PARTICIPATION AND THE DIGI PROJECT

Participation is a well-suited approach that worked to engage our target group as, in a Scandinavian context, it carries a particular tradition of democracy, direct engagement, practical use, and involvement. It implicitly and explicitly validated the expert position our participants held. This was important as it (1) invited them, (2) got them on the table, and (3) incentivized them to share their expertise from a more equal position.

Complicating the term, however, was the documented history of "passive participation" (Bøttcher & Dammeyer, 2012), which keeps volunteers from effectively making decisions that can have a direct impact on their lives. Additionally, other relevant stakeholders, like family members and professional support staff, may speak on behalf of a target group, thus altering and minimizing their participation (Benton & Johnson, 2015; Brereton et al., 2015; Frauenberger et al., 2011). The DiGi project team recognized that participation in a digital co-creation process could also be interpreted as simply delegating "testing" roles to the target group. Greenbaum and Kyng's (1991) early perspectives on users of IT systems as competent practitioners highlighted the differences between conceptualizing users who passively produce data for researchers and people who are experts in their own practices. The DiGi project researchers looked into and actively built on the skills of the target group and were interested in how their competencies could be brought into the development of new social and socio-technical practices.

The ways in which Field Study 2, as part of the DiGi project, addressed the concerns outlined in this section were as follows:

- Passive participation was avoided by structuring the fieldwork around not just ideas, but actions, reflections, reactions, and input from the participants.

- Speaking on behalf of our target group was minimized as the participants could choose the digital technologies they felt like presenting and could do so in a way that they were familiar with, thus negating the need for translation or interpretation input from other stakeholders. (The support staff could *support* the activities but were neither invited nor expected to elaborate on what our participants wanted to say.)

- Testing roles were avoided as the principal focus of the fieldwork was not digital solutions developed by someone else for the use by our participants but was rather the co-production of digital objects as a collaboration between the participants and researchers (Davidsen et al., 2021). The testing necessary in this process was shared between the two roles.

### 2.2.3. INTERVENTION AND THE DIGI PROJECT

The use of video tutorials in Field Study 2 was interventionist as they introduced recording, editing, and (co)producing components to the study, which were not part of the everyday activities of the target group. This disruption, however, built on the previously described understandings of disability and participation.

It is important to highlight that the objectives of Field Study 2 were to develop appropriate interventionist approaches and to operate within this framework. As such, a clarifying note on "intervention" is necessary.

In this thesis, I applied an "intervention" definition that was specifically built on the DiGi understanding of "disabilities" and how "participation" is conceptualized. This means that an intervention should consider the unique, individual characteristics of each participant's conditions without reducing the person to their diagnosis. This was achieved by expecting the participants to meet the researchers (1) inside their comfort zone of a specific digital technology use case and (2) outside their comfort zone while collaborating with an unfamiliar research crew. An intervention should also consider the specific social arrangements around any activity (e.g., the number of support workers and parents needed when setting up a local area network [LAN] party), the type of technical knowledge support workers needed when arranging an online video session between researchers and participants, and the question of technical parity between the researchers and participants (it is impossible to know how much everyone knows about any given topic, thus balancing that disparity is a critical characteristic of a successful intervention).

### 2.2.4. CURRENT RESEARCH AND RELEVANT PROJECTS

Frauenberger and his research colleagues engaged in the design of both tangible technological projects. These included a smart kaleidoscope using a Raspberry Pi computer, a headband for reflection on social situations, and a sound explorer (2016) as well as methodological tools (e.g., a critiquing tool in the ECHOES project, 2013; design exposès, 2016; the concept of *Handlungsspielraum*, 2016). While these projects introduced new technologies to the target group, they left space for researchers with an interest in the practices of co-creation, collaboration, and skills development, which is where my project makes its contribution. Conversely, Brereton (2015) also published research on designing technologies with this target group. However, space remains for exploration of their role as active producers and creators

of their own (digital) content, their own (digital) tools, and their own scripts. Another area in which my research deviates from that of Frauenberger and Brereton concerns the expression (i.e., verbal, visual, digital) of future ambitions and ideals. While the research by Frauenberger et al. (2013, 2016) could be characterized as having provided the majority of the tools (e.g., fabric, Raspberry Pis) and assisting the participants in making a type of product (e.g., headband, storytelling device), in this project, the neurodivergent participants brought all the hardware and software tools, acted in an expert manner, and had the researchers mainly support their exploration of digital skills development and ambitions.

There are two main knowledge gaps that I address directly in this thesis. The first concerns Frauenberger et al.'s (2016) focus on the production of physical and digital technological objects. They initiated a co-creative process whose characteristics, deliverables, and details were strictly top-down controlled and did not go further into more creative engagement with the target group. The PVTs and online sessions presented in this thesis address this aspect directly.

Second, Brereton et al.'s (2015) work on *design after design* supported the study participants in the "concrete expression of likes, dislikes, capabilities, emotional wants and needs and forms of expression that hitherto had not been fostered." (2015, p. 1). While this research focus produced critically important practical tools for expression, more could be done in the way of facilitating first-hand self-reflection by study participants: *why* they consider some things and practices important, and *why* others should pay attention to that. The physical and online stages of the digital interventions in this project provide insight on these topics, which leads to the thesis's main research question.

## 2.3. RESEARCH QUESTION

To arrive at the primary research question of the thesis, I followed three main concerns: (1) the DiGi project's goal of gaining a better understanding of how digital technologies can be used to support digital social relations among young people who live with cognitive disabilities; (2) the research interest in the target group's digital abilities, as seen in recent works by relevant researchers (e.g., Frauenberger et al., 2016, 2019a; Brereton et al., 2015; Seale, 2007); and (3) personal observations during fieldwork with the target group. To address all three points, I arrived at the following formulation:

*How can a digital intervention approach be co-developed and used as a research design technique to support digital co-production and social engagement through active participation, digital skills development, aspirations, and knowledge exchange between neurodivergent youth and researchers collaborating as co-producers and co-creators?*

As evident from relevant research globally (Frauenberger, 2016, 2019a, 2019b; Brereton, 2015) and in a Danish context (Rodil, 2020; Krummheuer, 2021), neurodivergent participants can be engaged as experts in their own experiences where they can provide meaningful information and translate their desires and needs to trained researchers. My research question clearly indicates the driving interest behind this thesis: to explore what emerges when members of the target group are engaged as equal collaborators who (in addition to their desires and experiences) use their own technological skills, narrative ideas, and social instincts to express themselves and their digital aspirations.

# CHAPTER 3. RESEARCH DESIGN

The purpose of this chapter is to introduce the reader to the research design of the thesis by presenting the initial theoretical influences, their effects on the research process, the role of the participating institutions, caretakers, and participants, how digital technologies were used throughout the fieldwork, and an in-depth description of video tutorials and their place in the thesis.

There is always more knowledge a researcher can acquire about the participants they are about to design their study around, and that was certainly true in the case of this thesis. As such, the research approach for this project was heavily inspired by the methods developed and used by Frauenberger et al. (2011), Makhaeva et al. (2016), and Brereton et al. (2015). Specifically, an adapted version of Frauenberger et al.'s use of blank comic strips (in this thesis, a blank tutorial structure), Makhaeva et al.'s Handlungsspielraum concept (a conceptual creative space for collaboration; in this thesis, the video tutorial creation process and hybrid contact zones), and Brereton et al.'s *design after design* (the appropriation of newly developed technologies for new uses; in this thesis, the appropriation of digital creation tools to reveal digital skills and ambitions). The combination of this blank tutorial structure around a video tutorial creation process to explore how digital creation tools can reveal the digital skills and ambitions of young people who live with cognitive disabilities and came together to form the methodological focus of the thesis.

As outlined in Chapter 1, this thesis constitutes field study 2 of the DiGi project and as such has a predetermined place and function: to design, carry out, and analyze a series of digital interventions with young people living with cognitive disabilities. These interventions were built upon the knowledge gained in Field Study 1 and provide methodological and theoretical contributions to the academic field as well as to practitioners.

To situate the research design choices as transparently as possible, first I will introduce two concepts that influenced the areas of interest and the practical steps that were considered and taken.

## 3.1. DESIGNING RESEARCH AROUND MATTERS OF CARE AND TACIT KNOWLEDGE

### 3.1.1. MARIA PUIG DE LA BELLACASA'S *MATTERS OF CARE*

The first real push to design the research for the digital interventions that formed part of this thesis was influenced by and based on the work done by Maria Puig de la Bellacasa in her 2017 book *Matters of Care: Speculative Ethics in More than Human*

*Worlds*. In the book, Bellacasa discussed Bruno Latour's notion of *matters of concern* (Latour, 2004) in which he challenged the dominant *matter of fact* perspective and defined it as "an amazingly narrow, specialized type of scenography using a highly coded type of narrative, gazing, lighting, distance, a very precise repertoire of attitude and attention, of which historians of science . . . have made a careful inventory" (Latour, 2008). Latour's *matters of concern* problematized this specialized and somewhat straitjacket-like perspective by offering a space, *gatherings* as he called them, where "ideas, forces, players and arenas in which 'things' and issues, not facts, come to be and to persist, because they are supported, cared for, worried over." (Neil, 2017). Bellacasa (2017) recognized the charge brought about by Latour's ideas and pushed it further by calling for a *matters of care* perspective, which "inscribes care in the materiality of more than human things" (p. 18). Bellacasa's particular conception of care placed it as a "force distributed across a multiplicity of agencies and materials and supports our worlds as a thick mesh of relational obligation" (p. 19). This particular notion of inscribing care in more than human things resonated with me while I was familiarizing myself with the practices in the institutions that participated in this research. Our participants demonstrated a breadth and depth of interests and skills—55 different digital applications and platforms were used between 25 participants (Andreasen & Kanstrup, 2019)—which indicated a deep level of care for the practices and the more-than-human participants in them. Less than a year into the fieldwork, these observations and ideas made a certain amount of sense as they seemed to demand a focus on the relationships between the young people and the technologies they were using, not just as mere tools for communication, creation, and consumption, but as physical and digital objects and subjects with agency. Research by Alper (2014, 2017a, 2017b) on social media use, Ringland (2016, 2019a, 2019b) on (dis)abled embodied experiences, Smith (2010) on disabilities in virtual worlds, and Ghougassian (2020) on avatar-based support tools for people with intellectual disabilities. among others, has shown that neurodivergent people can have a strong and particularly embodied relationship with the digital technologies they use. Building on this literature, Bellacasa's *matters of care*, and my initial meetings with the participants from the four institutions, it seemed appropriate to pursue interventions with the following characteristics:

- Per Alper: a focus on the relationships between the members of the target group and digital technologies they cared for;
- Per Bellacasa: a focus on the instances of care and lack of care in these relationships;
- Per Ringland and Ghougassian: the development of interventions that directly engaged the participants with digital avatars, when applicable; and

- Per Bellacasa: the development of interventions that invite the participants to share what (if any) place does care for the more-than-human things that they have in their digital practices.

These initial ideas, however, proved to be too constraining and normative for the reality of meeting our participants for the first time and beginning to explore what it might mean to (co)develop digital interventions with them. Regardless, Bellacasa's deep understanding of care had already influenced how I would develop the research design of the project. Specifically, in the third chapter of *Matters of Care*, "Touching Visions," Bellacasa contrasts a "touch"-first perspective on knowledge creation with a perspective focused on "vision."

In the same way that Donna Haraway (1988) critiqued how "vision" is used to establish objective truths with a *god trick* and a *view from nowhere*, Bellacasa also offered a compelling view of focusing on touch as a mode of knowledge making:

> [T]ouch's unique quality of reversibility, that is, the fact of being touched by what we touch, puts the question of reciprocity at the heart of thinking and living with care. What's more, the reciprocity of care is rarely bilateral, the living web of care is not maintained by individuals giving and receiving back again but by a collective disseminated force. . . . Care is a force distributed across a multiplicity of agencies and materials and supports our worlds as a thick mesh of relational obligation. (Bellacasa, 2017, p. 19)

These conceptualizations of care, touch, and reciprocity influenced how the thinking behind setting up all the fieldwork sessions throughout this project was effected (see Chapters 4 and 5). Specifically, early in the fieldwork process, it became crucial to structure the activities in a way that highlighted the role of touch (per Bellacasa). What that means is that it would not have been enough to simply observe what the participants were doing, how they were interacting with their smartphones, laptops, desktop computers or other devices, or indeed just watching what they created, remixed, and played within a digital environment. We as researchers needed to play an engaged, haptic role, where our presence would leave a mark and where we would have a reciprocal relationship in the development of digital interventions with our neurodivergent participants.

For the concept of touch to challenge vision as a knowledge-making paradigm in this type of fieldwork, the activities had to be shared between the researchers and participants in a way that would not just be acceptable but make sense and be somewhat familiar. This is partly what gave rise to the idea of co-creating video tutorials as a format that would allow for:

(1) a reciprocity of responsibilities, where the participants and researchers were engaged in co-creative activities;

(2) a shared sense of ownership with the potential to strengthen individual autonomy, as our target group members were rarely in the position of being creators and producers of content; and

(3) distributing care across a variety of situations: as researchers, we did not care about the project only when we needed data or when our participants were displaying something we found valuable.

Touch is tricky when setting up digital interventions with neurodivergent participants as physical contact can, ironically, be less intuitive than digital contact: while handshakes and other physical pleasantries are mostly off limits, interactions around software (in a shared in-person or online environment) were well received by our target group. When addressing a poem by Susan Leigh Star, Bellacasa (2017) wrote that "Computers are more than working prosthesis; they are existential companions for people trying to keep in touch with dislocated networks of loved ones" (p. 107), and that applied to all the participants in this project.

### 3.1.2. MICHAEL POLANYI'S *TACIT DIMENSION*

How should researchers plan engagement with participants about whom they know very little or nothing? How can space be created for the participants' tacit knowledge to not just appear, but to be discussed, visualized, and made consciously into something? I approached this question by combining a diagnostic perspective that outlined the capabilities of the participants (e.g., some people were living with ADHD and therefore could not remain focused for long periods of time; others were living with ASD and therefore operated equipment in very particular ways) with a tacit perspective that did not expect clear verbalizations and visualizations, but could use the visual medium of video tutorials to communicate knowledge that could not otherwise be shared. The diagnostic perspective implies a prescriptive approach, which not what this thesis is about. The tacit perspective, however, was much more central to the thesis as self-expression of any kind is a central characteristic of the social difficulties faced by neurodivergent people and exploring ways to support this self-expression was of great interest to the project. Nevertheless, the essence of even knowing what we were doing was a difficult question all on its own.

In 1966, Michael Polanyi wrote about tacit knowledge in his book *The Tacit Dimension* to problematize human knowledge. His work on this type of knowledge was relevant in the research design of this thesis as it acknowledged and directly engaged with a critical part of our participants' lives: (1) their desire to create and communicate something via digital technologies that they otherwise might not be capable of communicating and (2) their mechanical issues with speech because of cognitive impairments.

"We can know more than we can tell" is Polanyi's (2009) oft quoted phrase that encapsulates his way of thinking regarding the nature of knowledge. In a famous example, he said that people can know a person's face and be able to recognize it among many others, perhaps millions, and yet not be able to tell exactly *how* they recognize it. Polanyi complicated this situation by coming up with a scenario: a potential witness has seen the face of a person of interest but has no way of describing it with enough specificity to the police. The police, however, may have a large collection of photos of different facial features (e.g., noses, mouths, eyes), and by using them as a visual tool, the witness can construct and form a reasonably good likeness of the face in question. "This may suggest that we can communicate, after all, our knowledge of a physiognomy, provided we are given adequate means for expressing ourselves" (Polyani, 2009, p. 4). Moreover, Polanyi pointed out that the existence and application of the photographic police method do not provide the witness with instructions on *how* to put the facial features together, which allowed him to conclude that the "very act of communication displays a knowledge that we cannot tell" (p. 4). This basic description of tacit knowledge was useful when designing digital intervention activities with our target group as it demanded a strong focus on the appropriate kind of tools, as well as a sense of what they were meant to help communicate.

## 3.2. ETHICS OF RESEARCH AROUND DISABILITIES

Designing research with neurodivergent participants comes with a host of ethical considerations. Questions about, for example, autonomy (or "informed consent"), inclusion, justice, no harm, precautions, and privacy (Børsen, 2021, pp. 178–179) may not arise directly as specific topics during fieldwork, but the research structure must allow for participants, caretakers, researchers, and any other relevant stakeholders to address these questions openly or indirectly, if necessary. Additionally, ethical considerations must not be reserved exclusively for the fieldwork stages of the project but should rather be woven into all research practices: from literature gathering, through private research discussions, work with participants and stakeholders, communicating results, and anything in between.

A systematic literature review study by Van Mechelen et al. (2020) called "18 Years of Ethics in Child-Computer Interaction Research" supports the need for more robust ethical considerations during research. The authors identified eight types of ethics in their review of 157 papers from the Interaction Design and Children conference and the International Journal of Child-Computer Interaction. I have condensed these eight types, defined by Van Mechelen et al., in table 3 for brevity:

Table 3. Eight types of ethics found in 157 papers from the Interaction Design and Children conference and the International Journal of Child-Computer Interaction by Van Mechelen et al. (2020, pp. 6–7), adapted in a table form

| No. | Type of ethics | Description |
|---|---|---|
| 1. | Formal procedural research ethics | Protecting participants from physical/psychological harm; obtaining informed consent from children and parents; preventing the invasion of privacy; argumentation of the use of deception |
| 2. | Informal procedural research ethics | Similar to no. 1, but less formalized, occurs both before and during research. No express need for institutional approval. |
| 3. | Situational ethics | "In-action" and "micro" ethics (e.g., often unexpected events in the course of fieldwork), which demand on-the-spot reactions by researchers in ethical ways |
| 4. | Participation ethics | Concerns the value of participation and representation, and the active engagement of children in the research and design process |
| 5. | Design ethics | Actual or potential impact of an existing technology or technology under development on the lives of all relevant stakeholders |
| 6. | Everyday ethics | Ethical concerns arising during daily situations and social interactions between people without an explicit link to technology |
| 7. | Teaching design ethics | Raising critical awareness about the impact of technology on people's lives and society at large |
| 8. | Teaching everyday ethics | Teaching children to be ethical actors who deal with ethical challenges in their daily lives |

The authors noted three underdeveloped areas of ethical consideration by the child–computer interaction community, which they summarized as (1) definition and theoretical basis, (2) reporting of formal ethical approval procedures, and (3) the extent to which design and participation ethics are dealt with (Van Mechelen et al., 2020, p. 1). All three areas are reflected in this thesis.

First, as Van Mechelen et al. (2020) observed, a lack of definitions is not surprising since child–computer interaction has "emerged as an interdisciplinary research area" (p. 9). As mentioned in Chapter 1, the current thesis also comes from an interdisciplinary field with its techno-anthropological background. As such, the definitions about ethical categories (e.g., autonomy, privacy) that influenced how we approached our work with the neurodivergent participants took inspiration from the work of Børsen and Botin in general (2013), and specifically the definitions provided by Børsen in his "Quick and Proper Ethical Technology Assessment Model" (2021, Annex 1, pp. 178–179). Second, this research project received approval from the National Data Protection Agency in Denmark and thus followed all the national rules and regulations regarding ethical conduct and was compliant with the General Data Protection Regulations in the European Union. Third, to support a shared understanding of the project and in an effort to make participation as frictionless as possible, we (1) obtained written consent from the neurodivergent participants with the assistance of their caretakers; (2) informed the participants of the overall goals and ideas before and during each research session (e.g., we wanted to learn from them how they created videos for social media with the goal of co-producing a video tutorial that others could follow); (3) provided repeated reminders that their identities would remain anonymous and that their participation in the study was something they actively had to agree to (i.e., their participation was voluntary), as opposed to being unwittingly used for data gathering; (4) provided repeated reminders that they could choose to leave the study at any point; (5) explained that all the data gathered in the sessions would only be used for this project and nothing else, and that it was subject to General Data Protection Regulations, which include deleting it after a period of time.

While all these measures strove to foster and maintain an open environment where any potential ethical issues could be discussed and resolved, there were inherent challenges that need to be acknowledged. For example, gaining written consent from the neurodivergent participants was not unproblematic as it demanded that their agreement required a very specific understanding of legal questions regarding data gathering, data retention, and data use, as well as free participation in the research, which they should be able to leave at any point should they choose to. While any potential issues in comprehension were addressed by the participant's caretaker, who was able to assist with the written consent, we as researchers could not assume that we knew what our participants were actively agreeing to. For example, they may have understood that it was possible to leave the work sessions but may have decided that this did not apply to them. Such speculations highlighted the importance of regularly reaffirming the project's ethical stances.

Ultimately, these reflections are meant to underscore the following point: ethical research with neurodivergent young people demands careful and ongoing discussions with all the participants at all times. Ethical research in a co-producing context means finding a level of respect between the participants and researchers that offers all the

parties the space, tools, and opportunities to challenge themselves in the research process and to be challenged by everyone involved in a consensual way. If the participants want to try something that could result in perceived failure, they should be able to do so, and the researchers should be able to follow these same choices.

## 3.3. FIELDWORK OVERVIEW

What follows is an overview of the stakeholders, domains, and activities throughout this thesis. First, the stakeholders who were present during the fieldwork sessions were the participating volunteers (p), the researchers (r), and the caretakers (c).

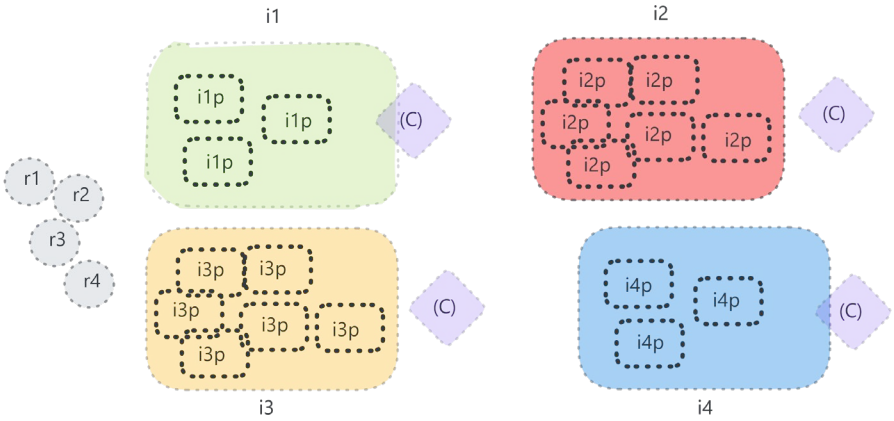



Figure 2. Stakeholder overview

After the end of Field Study 1, some of the participants chose to not continue with the research project, while others volunteered to remain for the next phase (i.e., Field Study 2). Figure 2 presents an overview of the four participating institutions (i), namely, i1, i2, i3 and i4, each with the respective number of participants (iXp), which were three in i1, six in i2, six in i3, and three in i4. The caretakers were either present during some sessions (in i1 and i4) or available when needed (in i2 and i3). In total, four researchers (r) from the DiGi project carried out or participated in the fieldwork.

The fieldwork took place in two phases: in-person meetings and online sessions.

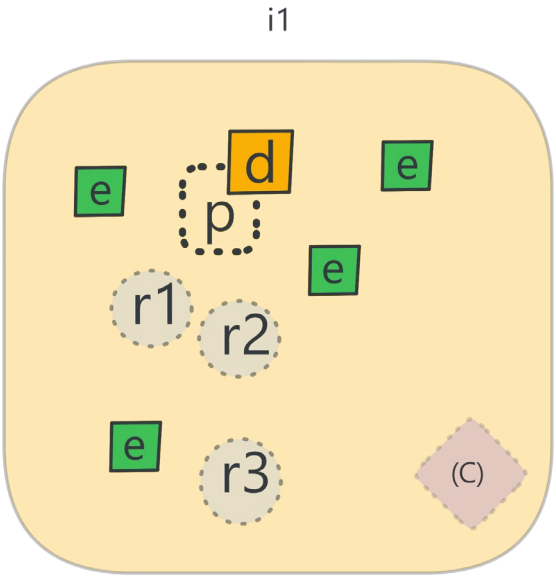



Figure 3. Overview of phase one: in-person meetings

Figure 3 is a visual representation of phase one of the fieldwork for this project (i.e., the in-person meetings). All the sessions took place in a dedicated room inside each respective institution. The figure shows i1 with the following configuration as an example: one participant (p) is working on a device (d) with equipment (e) (e.g., video cameras, studio lights, and voice recorders all around). Two researchers (r1 and r2) are interviewing the participant, while r3 is sitting further back, ready to contribute to the conversation should the need arise, and making sure the equipment is in order. A caretaker (c) was present at some but not all the sessions and could engage in the activities depending on the participant's needs.

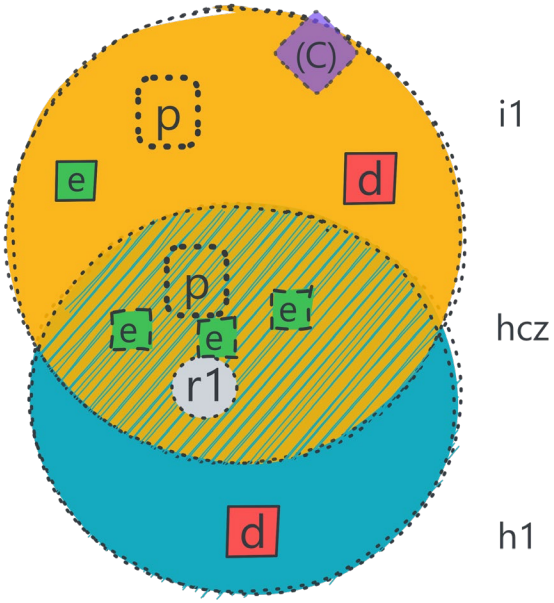



Figure 4. Overview of phase two: online sessions

Figure 4 is a visual representation of phase two of the fieldwork for this project, the online sessions. All the sessions took place remotely over the video-sharing service Zoom, which is visualized in a third space between the institution (i1) and the researcher's (r1) home (h1). The participant (p), their caretaker (c), and devices (d) were always located in their respective institutions (in this case, i1). Additional devices and equipment (e) were available for their use at the institution (e.g., desktop computers and laptops and a green screen room for additional video recording, which was made available by their caretaker). All the activities occurred online via digital equipment (e) using software tools like Roblox Studio or Blender, which were shared between the participant and researcher. In contrast with phase one, where the participant predominantly used a device and the researchers would occasionally interact with a laptop or desktop computer, either to set it up or to illicit a particular interaction with the participant, phase two was very different. Due to the digital nature of the shared space, all activities occurred in what I have called the hybrid contact zone (HCZ), which will be properly introduced and elaborated on in Chapter 6. In the HCZ, the participant and researcher simultaneously co-created and explored digital objects and practices. This could either be achieved through verbal and visual coordination or through direct takeover, wherein the participant would take over the researcher's mouse cursor and execute an action instead of explaining how it should be done. This level of freedom distinguished phase two from phase one.

## 3.4. INSTITUTIONAL BORDERS

In this section, I delineate how the organization of an institution can determine what researchers and participants are allowed to do and are prevented from doing in a digital intervention context.

### 3.4.1. ACCESS TO THE FIELD

A major administrative border that regulated how we interacted with the participants in our project also offered a way to access the field (i.e., special schools and sheltered residences) as well as to directly contact the participants. This access was ensured by the project agreement between Aalborg University, Kollegievejens Skole, VUK, and Sofiebo, in general, and in practice by the DiGi project primary investigator Professor Anne Marie Kanstrup and one contact person from each institution.

What this meant in practice was that there was a clear and agreed upon procedure for spending time with the participants. This, in combination with the fact that I am physically based in Copenhagen and not Aalborg compounded the sense of distance, so the opportunity for me to spend unstructured time in the institutions was greatly diminished. Additionally, the support staff (i.e., contact people, pedagogues, caretakers) carried out the traditional gatekeeper role, which means that we relied entirely on them to help select which neurodivergent students and residents would be approached to participate in the project, as well as when and where we could carry out our research activities. As the outcome of this project was partly meant to directly support the daily work of these gatekeepers, they were naturally supportive of our approaches, which is precisely what we experienced throughout the multiyear collaboration.

### 3.4.2. CARETAKERS AS A SCAFFOLD OF DIGITAL INTERVENTIONS

We designed and carried out all the project activities with the participants within the institutions and in a digital form with the explicit consent and (often) physical presence of and mediation by their caretakers. The caretakers provided us with information about which activities had been used in the past to engage the participants (e.g., a tour of the computer rooms and MakerSpace engagements at Kollegievejens Skole; diaries and guided walks in woods at VUK; photos of past experiences on the walls and LAN parties at Sofiebo).

Physical activities play a critical role in the institutions; the youth have to be together and be able to study in a classroom-like environment, play in sports rooms (e.g., volleyball at VUK, inner courtyard in Sofiebo, game area in Kollegievej), have recreational areas (e.g., couches, chairs, and a main lounge in Sofiebo; a music room with instruments and a cafeteria for shared post-class activities at VUK; game rooms at Kollegievej). These activities did not exhaust what our participants wanted to do,

however. They had legitimate and deep needs, which could only be addressed via digital practices. Neither institution at that time had staff dedicated to digital practices. A caretaker from Kollegievejens Skole had set up MakerSpace initiatives, where he would work with youths on 3D modeling and try out different digital tools. He managed to channel and support these initiatives and the interests of a number of students who joined his initiatives voluntarily. Additionally, the caretakers at Sofiebo supported LAN parties, assisted the neurodivergent residents in setting up a space for gaming, and encouraged their leisure activities.

While examples exist of caretakers supporting digital practices in their respective institutions, these are not part of strategic, long-term administrative action. However, it is critical to highlight a basic point: should any more serious attempts be made in the future to support our target group's digital practices, their caretakers would have to play a crucial, scaffolding role both in traditional, offline settings, as well as in a digital context.

## 3.5. DESIGNING RESEARCH AROUND DISABILITIES IN INSTITUTIONS

In this project, I did not engage directly with the medical diagnoses of the participants. To avoid any confusion or misunderstandings about how I accounted for the cognitive disabilities our participants lived with, I need to make the following point: all the researchers were aware of the participants' cognitive and developmental disabilities at all times and discussed them with the participants at certain points, sometimes with the assistance of the caretakers. We were, however, not conducting research *about* cognitive disabilities, but rather about co-creating and co-producing digital activities while *acknowledging* the unique perspectives of our participants. Our approach was to focus on the production side, namely, acting, making, and engaging, with elements of reflection, during the interview sessions. More specifically, the research was designed *within* the institutions, where the participants' disabilities were less likely to be problematized, taken out of context, or considered an issue. In this environment, the disabilities did not reside solely within the participants; they were *diffused* by the structure of the institutions. We took this into account in the research design by not foregrounding what was not in the foreground. We focused on learning about the practices and experiences *made possible by the environment* that we were working in.

## 3.6. DISABILITIES AND DIGITAL TECHNOLOGIES

No one in the participating institutions initiated a conversation with me regarding the cognitive and developmental disabilities the students and residents there lived with. This question was addressed in the formulating phase of the DiGi project. However, the few times I raised the question of medical diagnoses with staff at the institutions, the responses I received were vague and general in nature and included no specifics regarding the participants. This was understandable on multiple levels: this thesis was

not a medical project, and I had no ambitions to competently incorporate a medical understanding of cognitive and developmental conditions in its approaches. Additionally—and importantly, I did not consider cognitive and developmental disabilities as a participant characteristic around which to build the entire research focus. The theoretical and methodological frameworks of the thesis were thus not based on diagnoses, but on people. At the same time, the following question emerged as an interesting one in this environment:

How is one supposed to design an intervention, and a digital one at that, without specific knowledge of a diagnosis that is used by the state and society at large to define, to a large degree, the lives of the project participants?

My particular approach was to take hold of what I considered the lowest common denominator, in this case, digital visual approaches (e.g., the participatory video tutorials and online sessions described in Chapters 4 and 5), and to design around them. Specifically, this meant the consideration of four key criteria that any initiated research activity should address: (1) the activities should be related to something familiar: new topics and information may be scary and may take a lot of time to process, and it is not possible to know how the participants may react to them; (2) the activities should have a central visual component: considering the language barrier (Danish/English, but also the slang of the person in a special school/university), the activities must be visualizable (i.e., something people can see, be able to point at, and change); (3) the environment should not dictate the activity: as this was a digital intervention, it should not be bound to either a physical or an online environment; (4) the participants should be seen and interacted with as producers: they should be able to direct what is being shown, how it is being shown, what it should look like, what tools should be used to present it, and how long they would like the production to continue for, as well as be able to leave at any point, to abandon the effort entirely, and to change every single thing about the result via their collaboration with the researchers.

Thus, we were not designing for or about disabilities or divergence, but for abilities and cooperation. We also incorporated safety planning as much as support: the activities needed to be specific (i.e., to not overwhelm the participants, but also to provide clear choices), to be visual (i.e., to not trigger verbal difficulties, but also to facilitate a more digitally natural medium), and to be reversible (i.e., to not lock the participants in a specific situation and to enable creative endeavors).

### 3.6.1. THE DISABLED PRODUCER

In this section, I address what considerations were embedded in this research when approaching the neurodivergent participants as (co)producers of digital content.

Ensuring vibrant, meaningful "producer" and "co-producer" roles is never a straightforward process and knowing *how* to ensure this is not an obvious thing to do either. A level of trust is necessary in shared interests (e.g., social media, daily practices, 3D modeling), and this should be strong enough to support the participants' instincts to show, present, demonstrate, and dictate. As such, the physical and digital spaces have to be set up in a way that asks questions like: What is the thing you are interested in? How do you make it? Is it like this or like that? Are you inspired by X or Y? In other words, show, tell, and lead.

That said, what played into the role of a producer with disabilities? What made (co)producers out of our participants? First, they were already volunteering, creating, sharing content, and in a lineage and system that supported this behavior (e.g., on an online platform like GitHub, in discussions on Roblox forums). The disabled producers were self-taught. There were no classes for this type of online behavior in the participating institutions. They supported some activities but did not push boundaries like our participants could. The disabled producers pursued a vision; there were specificities that mattered, like a particular set of digital plug-ins (e.g., to extend the functionality of Minecraft) or popular aesthetic qualities (e.g., using specific background music, fonts, and colors when editing a TikTok video). The producing role came with a responsibility to the vision, to the potential viewers, to faithfully represent it, to collect, arrange, and display all the necessary parts of what made their interests important. The disabled producers were guided by a faithfulness to a perceived vision and responsibility to truthfulness. It was also a particular type of powerlessness: the impossibility *not* to create and co-produce content as a somewhat natural way of self-expression, and this was much easier compared to existing social norms in neurotypical society (e.g., by verbalization, argumentation, confrontation).

The disabled producers assembled physical, digital, and performative artifacts. Jens searched for relevant Minecraft plug-ins, studied them, and tried them out. Thomas and Andreas explored the limits of their available digital tools by developing games and creating environments. They assembled what was available into configurations of sense (i.e., what would work best with what). They relied on a network of support, from the technical aspects (i.e., the availability of hardware and software that would get the job done), through to the administrative (i.e., time, lessons, educated personnel who supported their needs) and the personal (i.e., caretakers who stayed with them and left them when needed).

The producers with disabilities communicated via aesthetic methods: the style of the tutorial, the relationships between the segments, what *felt natural* rather than what *was understood to be rational or to make sense*. The neurodivergent producers sometimes communicated the differences in perception, but that was of less importance than actually performing, sharing, and expressing. The role of producer kept everyone in check that what was important was to search for the expression of

truthfulness and to arrange it in such way that what could not be verbalized/communicated had a place and was acknowledged.

All these characteristics (self-taught digital skills, pre-existing technical interests, the pursuit of truthfulness, and the need to communicate that to others) applied to all the participants and researchers engaged in digital co-production throughout this project.

## 3.7. USING VIDEO AS A TOOL FOR PARTICIPANT ENGAGEMENT

When considering how to create an environment supportive of participant engagement, a decision was made early on that video would play a major role in all the activities. As mentioned previously, video was consumed by all the participants on a daily basis (predominantly via YouTube and social media), and some of the participants had experience with creating videos for their own social media channels. The medium of video is malleable as it allows for quick and easy capture (e.g., with a smartphone), easy manipulation, if needed (e.g., with free and open-source video editing software for desktop/laptop use, or with built-in video editing smartphone features), as well as easy sharing (e.g., with built-in messaging services like Apple Messages or the simple upload routes in YouTube). We utilized both the creative and consumptive aspects of video (e.g., as a medium for recording, editing, and building, as well as watching content). The malleability of video was a critical characteristic as it is meant to be adaptable to all individual preferences.

Engagement with video comes with certain roles. While a basic mode is to passively watch content, another intuitive mode is to watch videos collaboratively. We built on this by setting up sessions where the participants were invited to act out, record, and re-order what they wanted the researchers and others to see. All these activities instinctively demanded that the participant engaged in a particular role—as a performer when acting out and as a producer when deciding which parts were to be selected and edited into the final video.

While the participants eased into their roles, the researchers were tasked with offering a blueprint for the video structure, filling it out alongside the participants, actually editing the video, and later, bringing a draft version for corrections and changes, before carrying out a second edit and finalizing the video tutorial. The roles the (co)producers and participatory video tutorial (PVT) format were meant to offer were simultaneously to empower our participants (as the main drivers behind the activity and its interpretation) and to highlight existing and important interdependence aspects of the format. In other words, this type of interdependence (which was built on shared interests, existing skills, and a desire for self-expression) held the possibility of starting a loop: watching videos to sharing videos, to recreating videos so that others could watch, share, and potentially recreate. This possibility was part of the reason for

using video to engage our participants even though it was not something that was actively pursued.

Another important question regarding video concerns its form and actual production. As mentioned, the PVT format was proposed, and later, all the videos were edited by the researchers. A potential strategic downside of this research approach was that we used video as the lowest common denominator shared between all the digital tools and platforms that our participants had used during Field Study 1, and in the interests of time, we did not source ideas about other shared formats. While a PVT was positioned as a proposal, which each participant could choose to ignore or adapt in any way they preferred, ultimately no one expressed a desire to drastically change the format. We acknowledge that we may have unwittingly siloed our participants into using their devices and performing actions without spending time on meta-topics, like the format of the activities we could have engaged in. However, the ultimate use of video for engagement was dictated by its familiarity, malleability, and ease of use by our participants, whose individual conditions may have posed challenges to other kinds of approaches that require more verbalization or the acquisition of new technical skills.

## 3.8. PARTICIPATORY VIDEO TUTORIALS

In an effort to actively engage the neurodivergent students and residents in the four participating institutions, as well as to address the research question presented in Chapter 2, I introduced the idea of a PVT. The rationale for its use, structure, and implementation, examples of its use, and results are presented in Chapter 4. Here it must be said that the PVT was one part of the idea of digital interventions (the second part, online sessions, is presented in depth in Chapter 5). The use of video makes PVTs both malleable and rigid in specific ways: (1) methodologically, PVTs can be adapted to individual scenarios, requirements, reactions, and uses on the fly, and (2) technologically, PVTs are rigid due to the “minimum system requirements” needed for engagement. What this means is that the participants needed to have access to the right kinds of devices and software that would run the software of their choice well enough.

### 3.8.1. INITIAL VIDEO TUTORIAL SETUP

The initial contact with the participants was centered around the importance of two aspects: (1) their own digital skills and desire to share their digital abilities and (2) video as the medium of expression. The video tutorial format was proposed as a narrative aid to be used by the participants when talking to the researchers about their skills, as well as an avenue for technologically challenging the participants. We imagined that the narrative aid would be needed if the participants were struggling to explain what they were interested in or good at as it would allow them to simply visualize it. The technological challenge around video was based on information from

Field Study 1, which showed that the participants had experience with a large variety of digital tools and platforms; as such, proposing a video tutorial format could potentially build on their existing skills and act as an incentive for some of the participants to further develop their technical abilities with support from the researchers. Put simply, a technological challenge with low stakes of failure offered opportunities for technical growth for the participants and allowed the researchers to share technical knowledge and skills beyond the limits of the fieldwork as a sign of gratitude to the participants who had agreed to devote their time and involvement to this project.

### 3.8.2. COVID-19 AND A SILVER LINING

When COVID-19 spread to Denmark in early 2020, it profoundly affected the lives and work of the entire population. We likewise needed to adapt the fieldwork to the new conditions. Losing direct, physical access to the participants meant losing irreplaceable knowledge and sense-making. All the relationships that had been developed in the span of a few months had to be paused, and we needed to rely on the initial rapport established during the filming, editing, and presentation of the PVTs.

This shift in everyday life forced the researchers to lean heavily on another available opportunity: to look into digital interventions through purely digital channels, which meant video calls and digital fieldwork. The conditions for this choice and its specific development are presented in greater detail in Chapter 5.

## 3.9. DIGITAL INTERVENTIONS IN RESEARCH WITH NEURODIVERGENT YOUTH

While the research in this thesis has no medical focus or aspirations, it is meant for use by pedagogues and professionals who provide general healthcare services to neurodivergent youth, and specifically professionals who can utilize digital interventions in their practices. Hermaszewska (2020), who referred to Eysenbach's (2001) "What is e-Health?" paper, wrote that online interventions "otherwise known as eHealth or digital interventions, are defined as healthcare delivered to patients and carers using the internet" (p. 4). As will be discussed further in this thesis (specifically in Chapter 5), using the internet does not mean that digital interventions are carried out from afar. As shown in Chapter 4, they can be set up and initiated in an in-person setting, and to that end, digital interventions can also be defined as socio-technical interactions that use digital tools in hybrid (online and in-person) environments.

Hermaszewska (2020) further pointed out the following characteristics and advantages to digital interventions:

> Complex online interventions which comprise multiple components, such as psychoeducation, self-care, and peer-support, are seen as providing a

> probable cost-efficient alternative (Sin et al., 2018). Complex online interventions are advantageous as they enable users to individualise their usage and content choice suiting their own needs and preferences (Sin, Henderson, Woodham, Sesé Hernández, & Gillard, 2019; Todd, Jones, & Lobban, 2013). (p. 4)

The two points, cost and individualizations, should be considered by pedagogues, caretakers, and researchers alike. Throughout this thesis, I make the argument that another characteristic of digital interventions exists with neurodivergent youth, specifically, that digital interventions can be set up alongside familiar, existing digital practices in configurations that support the autonomy, self-perception, and abilities of the participants by positioning them as co-producers of content meant to be beneficial to unknown recipients.

To that end, I offer the following characteristics of digital interventions, as enacted throughout this thesis:

- Digital interventions are rooted in personal rapport, which can be obtained physically on site or digitally via video conference.

- Digital interventions are suited to the specific technological realities of the participants and their specific use of hardware and software.

- In the current project, digital interventions were not used to *deliver* healthcare, but to *explore* issues of agency, involvement, interests, and ambitions, which can be important for researchers (to gain knowledge about the target group) as well as for caretakers and policy makers (who can use these cases as data to improve existing policies and develop new policies to better serve and support the target group).

# CHAPTER 4. PARTICIPATORY VIDEO TUTORIALS

In this chapter, I unfold the journey to co-develop and co-produce participatory video tutorial (PVTs) as part of the digital intervention approach of the thesis and highlight the inspiration, design, intervention, evaluation, and further improvement of the PVTs. I present in detail the role of video in the thesis and the initial reactions to a video-first format, which is a methodological approach that relies overwhelmingly on video data, specifically, screen-recorded, screen-shared, and screen-occurring data that encompasses interviews and digital activities. Both focus on what is displayed on screen, which defines the video-first format. Later in the chapter, I address why video was chosen as an approach and what it was expected to reveal (section 4.3), the details of how it was used in practice (section 4.4), what our participants' reactions to the PVTs were (section 4.5), and how they would determine the next phase of the project (section 4.6).

## 4.1. WHAT IS A TUTORIAL?

The origins of the word "tutorial" can be helpful in answering the question: what kind of methodological approach can directly address the inherent and inescapable power imbalance between a researcher and a neurodivergent participant? One might assume that when researchers engage with their target group, they would act as tutors (from the Latin *tutorem*, which is related to a *guardian* or *watcher*, or *tutus* [to] "watch over, look at" (Vaan, 2008, p. 632). While this kind of arrangement has certainly been used throughout academia, an approach inspired by participatory design (PD) would instead compel the researcher to see their participant as the guardian of their lived knowledge and experience, and look to be taught by them and learn as much as possible about their practices, thought processes, and desires. The evolution of "tutorial" starts from a notion of protection "and suggests connection with [the] Sanskrit *tavas*—'strong, powerful,' Greek *sōs* . . . from a root meaning 'to be strong'" (2008, p. 632).

In this sense, a tutorial has the potential to help researchers better understand the power of the tutor. This is especially useful when working with a socially vulnerable population, which is traditionally and almost exclusively perceived through a label of diagnosis and thus automatically triggers pre-existing social and policy reactions (e.g., a particular kind of disability is to be treated in a particular kind of way, at a particular kind of place, by specific types of specialists—pedagogues, caretakers, administrators, etc.).

Working with young people who live with cognitive disabilities and being seen as a tutor also triggers a particular viewpoint and frames a person in a certain way. From

a philosophical standpoint, a tutorial offers a deterministic approach (e.g., certain conditions exist, which necessitate that if I do *X*, then *Y* will necessarily follow). A tutorial also comes with embedded roles: the tutor (or the source of information) and the recipient of said information, namely, a pupil, student, or simply someone who lacks that particular information. The tutor is not and should not be considered a source of *pure* information or *pure* knowledge, however. Rather, the source provides a *unique packaging of information* that the recipient desires to engage with. The tutorial is a snapshot of the tutor's abilities, complexion, and understanding of a practice, sense, or perception. This snapshot is broken down into steps and taken apart for the benefit of an (imagined) recipient's consumption and understanding. The tutorial is a modus of creation and presentation: a specific type of creation that has the explicit goal of being useful, of serving others, and of sharing understanding and knowledge; it is a creation that is inclusive by design—it can hold more than one source of knowledge; it is a mixture/mixing of knowledge, worldviews, and understandings. Why is that? It is because funneling information and sharing are activities meant for others, not for oneself. The *packaging* of information and knowledge is the tutor alone. It is a revealing activity, not necessarily of the true self, but nevertheless, it reveals *a self* that wants to be seen and wants to be engaged with and used by others. The act of packaging is revealing in itself.

The tutorial concept was intuitive for our participants in this study as it was not out of line with their daily institutional experiences of following step-by-step suggestions, procedures, and guides from the caretakers and staff. We also confirmed in Field Study 1 that, in their personal time, the participants searched for and used video tutorials online. We did not disrupt the deterministic character of the tutorial simply to introduce fewer frictions in its meta or conceptual phase; rather, we focused on the usability of the tutorials: how our participants were engaging with the tutorials, what they liked and disliked about them, what they were interested in showing, what circumstances allowed them to reach a state of *flow* where they felt like they wanted to engage others with their own skills and understandings, and under what conditions they ran into a wall that broke their flow?

To that end, the specific idea of a tutorial underpinning this thesis can be summarized as such: a tutorial is a quasi-deterministic process (i.e., there are logical links that are intuitive to follow but not impossible to abandon if needed) where a source (tutor) repackages parts of themselves into a snapshot of information that they unfold to a recipient (student) in an easy-to-follow manner.

*A note on roles: Tutors and students*

Who is the tutor, and who is the student in a PVT? The roles are not attached to individuals. Rather, they are characteristics that can simultaneously be inhabited by participants and researchers.

## 4.2. WHAT MAKES A PARTICIPATORY VIDEO TUTORIAL PARTICIPATORY?

In Chapter 2, I outlined two main vectors of inspiration from PD adopted in this thesis, namely, (1) users of technology should have their voices heard in technology design without needing to speak the language of a professional designer, and (2) users of technology may not be able to express their desired outcomes without knowing what is possible with the help of technology. I will expand on these two points to clarify how I used them.

The first vector of inspiration could be understood by some to mean that since the end user should not need to speak a professional language, it is up to the professional to explain and clarify, and work with the end user's language. This was not the case in my thesis. Instead, what I worked toward was the co-development of a shared language with the project participants in the following ways:

- By using information from Field Study 1 to narrow down the participants' fields of interest;
- By using support from co-researchers and caretakers to reach out and ask for volunteers to create video tutorials.
- By providing each participant with a single sheet of paper where they themselves wrote/indicated what they would like to make a tutorial about
    - The sheet was written out in their mother tongue and asked for very specific input in an effort to minimize potential points of confusion.
    - The participants could fill out the sheet alone or with the help of their caretaker.
- By using this sheet to prepare thematically for the video tutorial recording
- While a Danish co-researcher led the interview at the recording sessions, by using keywords related to the area of interest to indicate familiarity with the process, but only if I had prior experience with it
    - For example, when a participant was working with Blender, which is an open-source software program for 3D modeling, animation, and rendering with which I am familiar, I referred to my own experiences with the program and asked to be taught the parts of the participant's expertise during the recording process.

- By using the shared understanding of the program as a technical language foundation with which to explore deeper questions at a later stage in the project

Following this strategy, the participants were not required to engage in an unfamiliar language practice but were instead incentivized to extend their existing understandings in a way that would interface easily with the researcher's understandings.

The second vector of inspiration was directly related to the first one as it built on the established shared language between the participant and researcher in order to reach an understanding of previously unknown possibilities when using a specific piece of technology. To expand on this point, I will stay with the example of the 3D modeling software Blender. The program is capable of executing a vast array of actions: from using geometry nodes to model virtual objects in 3D space, computational fluid graphics to produce fluid simulations (e.g., of smoke, rain, dust, cloth, hair), or a keyframe framework that allows for non-linear animation, to using both the graphics and central processing units of a computer to render video graphics, and so on. Each of these technical domains can be explored in great depth. One's interest in them can be easily aroused as Blender is used by professionals in fast-developing fields, for example, the automotive industry (e.g., to design and test cars and car parts before production starts), the film industry (e.g., to create visual special effects), and the VR industry (e.g., to design virtual spaces and interactive 3D applications). It is even heavily used in the video games industry, which was of huge interest to some of our participants (Andreasen & Kanstrup, 2019). This technological and domain complexity is relevant as it denotes a large horizon of possibilities toward which a participant and researcher can work together. It is very likely that almost any interest expressed by a participant can be explored with the researcher, thus achieving the following:

- The participant and researcher use shared interests to display mastery in parts of a technological artifact (hardware or software).

- The technical mastery of the participant and researcher highlights the vast knowledge they do not yet or may never possess with regard to the technology in question.

- Using the established shared language, the participant and researcher can identify areas of interest where they would like to cross a border of ignorance into a place of shared knowledge (e.g., how to use Blender for more than the specific routine performed by the participant).

- This border crossing can provide first-hand evidence to the participant that new knowledge mediated by technological skills is achievable, thus extending the knowledge horizon further.

- The participant can now use their acquired knowledge and experience to express more of their desired outcomes for the technological design.

Drawing inspiration from these two core principles of PD, as outlined by Simonsen and Robertson (2012), we aimed to achieve a high level of active participation by the project's target group members when involving them in the creation of the PVTs. I have outlined what characterizes a *tutorial* in the context of this project, and I have outlined the specific understanding of participation that influences it.

## 4.3. THE ROLE OF VIDEO: HYPERVIDEO AND DIGITAL MOULDING

To clarify why video plays a central role in this thesis, I will cite an insight from Ylirisku and Buur's seminal 2007 book *Designing with Video*:

> [Video] can capture activities as they unfold in time; it can portray the personality and feelings of people; and it can show a fictitious future. To emphasize this quality of video we prefer to talk about video as clay rather than data. Data carries the notion of objective research, of truth that cannot be questioned. Design challenges are open without a limited set of right (or true) solutions, and approaching design from the point of view of truthfulness presents a misconception of the pursuit. Clay, rather than data, can be shaped by a designer until he or she is satisfied with the form. Moreover there is a certain intensity to the shaping itself: the very process of moulding is a process of coming to an understanding of the conditions and possibilities of a particular design. (p. 26)

The fusion between how this project understood what a *tutorial* is and viewing video as *clay* can be very powerful. It can be used to simultaneously explore what young people living with cognitive disabilities want to teach and/or share with others, as well as present them with a malleable digital object that can be easily molded in an effort to highlight the following point: the results of the PVTs in this case were not the produced video files, nor were they the quality, depth, and breadth of information, condensed in them. Rather, the results were the processes of the shared digital moulding itself.

I have been inspired by Ylirisku and Buur's (2007) conceptualization of video with regard to the recording, sharing, and direct engagement with digital objects. In the case of the video tutorials, we intensified the characteristics of video via digital technologies in terms of (1) how we filmed the participants with cameras, (2) how we

used software to record their screens, and (3) how we co-edited and edited the tutorial itself. As such, video was not just a process of recording or editing. It was the mode through which the practices were enacted, and to a degree, it represented the practices themselves. I would make the case that these three characteristics of the use of video in this project equate to a specific type of saturation with video. These levels were somewhat entangled as they coalesced to bring a nuanced image of the environment (e.g., where we filmed), the action (e.g., what our participants did on their devices), and the results (e.g., what they wanted the edited material to look like). In a sense, we engaged in a relationship with a stacked video, which I call *hypervideo*, since it touches on a variety of levels. These levels can range from the immediate and practical (e.g., where to place the video cameras), through the inner and unexplainable (e.g., how and why certain participants wanted their video tutorials to look a particular way), to the speculative and potential (e.g., seeing these video tutorials as vessels that could carry certain meanings from our participants to potential viewers). The term hypervideos has traditionally been used in educational contexts to mean a specific type of visual and dynamic artifact related to "individual or collaborative annotation and automated feedback" (Sauli et al., 2016), for developing instructional scenarios (Cattaneo et al., 2017, 2018), or simply to mean the linking of different kinds of media into a video object (Chambel et al., 2015). However, this is not how hypervideo should be considered in relation to this project. Here, it stretched the notion of clay onto a digital canvas and borrowed the idea of moulding from Ylirisku and Buur (2007) to conceptualize digital moulding as a general description of the video tutorials themselves.

Digital moulding should also be considered a process that shines a light on the practice of production (by a person living with cognitive disabilities). In this project, it indicated showing instead of saying or writing what the interests and ambitions of our participants were. It further reflected the power of revisiting and re-editing past choices, desires, and aspirations. These were explored through the practical language of technologically mediated actions, where semantics were different in comparison to the symbolic language of words, which the participants knew could mean very different things to different people.

Ylirisku and Buur (2007) continued:

> Video material – as clay – allows the designer to then mould interactions as they unfold in time and space: both the interactions between people and between people and technology. Video materials allow the interactions to turn into catalysts of a dialogical learning process rather than as static sources of objective user data. (p. 26)

This dialogical learning process was the fundamental reason for using video when working with the participants in our study. Denmark already has a rich history with regard to expanding the rights of marginalized and socially vulnerable populations, as

well as a sustained interest in practices of inclusivity. Exploring the use of video to further these efforts can therefore be seen as a worthwhile effort as it can be better understood in academic and social contexts that have historical experience with this kind of experimental engagement with traditionally silent populations.

Video plays another important role that made it indispensable for this thesis: it can act as *social glue*, which Ylirisku and Buur (2007) defined as something that "helps understand how the video equipment and the situations of shooting, editing and showing of video support the social process of design: how people collaborate and develop ideas together" (p. 20). When taking into consideration that people living with cognitive disabilities have mostly been approached with assistive technology agendas (where the main efforts were centered on producing a solution to a specifically defined problem perceived to be experienced by the target group), video has the potential to focus on collaboration and idea development rather than a utilitarian data-gathering process.

Keeping in mind the *social glue* potential of video, it is important to connect it to the inherent role play of a tutorial framework, and the participatory ideas rounding up the three main characteristics of a PVT. What can be said about the format at this point is that it was set up in a bare-bones manner to spark interest among the participants and make them curious about trying it out. While we could not know their actual thoughts about it, we can certainly say that the PVT format is such that it would have fallen apart without their active participation. It was made clear at the video recording sessions that it was up to the participants who volunteered for the experiment to determine whether it would be worth it. The stakes for participation were low and the gains unknown. We saw that this combination of incentives led to high retention in our case: not one person chose to drop out of the PVT sessions after having started them, and only one person chose to not engage entirely as they were not feeling well on the day of shooting.

Having described what makes up a PVT, it is important to go one step further and ask: what kind of data can such a format produce, and what even qualifies as data?

## 4.4. IN-PERSON RECORDING SESSIONS: WHAT IS THE FIELD, AND WHAT IS DATA?

To present what constitutes data as the result of a PVT, I will first situate it and present the field within which the data was generated and collected in detail.

### 4.4.1. WHAT IS THE FIELD OF THIS PROJECT, AND HOW DID I APPROACH IT?

A field is a distributed environment across physical and digital domains. A total of 16 participants living with cognitive disabilities (accompanied by their caretakers) joined

our team of four researchers for fieldwork. Spanning from mid-2019 to early 2021, the fieldwork was divided into 34 in-person sessions (further broken down to pre-production, production, feedback, and premiere phases) and six online digital activities. Figure 5 presents a general overview of the field.

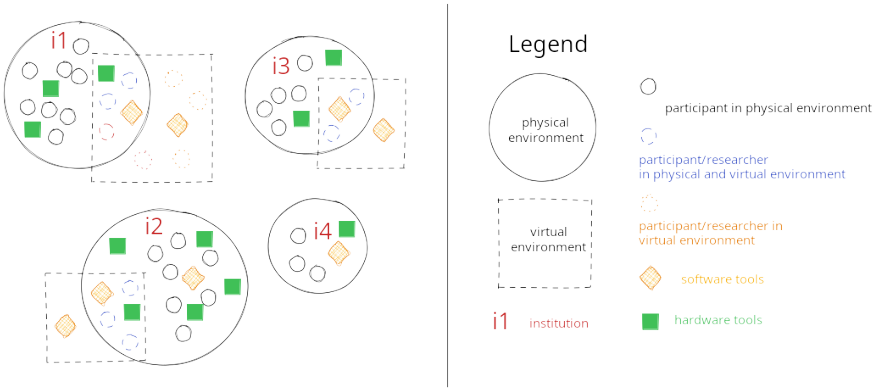



Figure 5. Overview of the project field. All the physical environments refer to locations within the participating institutions. All the virtual environments refer to video conferencing and virtual meetings from two Danish cities

The physical domain was spread out across four institutions in Denmark: two special schools and two sheltered residences. The research team was offered rooms in which to spend more focused time with the participants. These rooms were equipped with hardware and software solutions that were appropriate for the participants during the sessions. Additionally, the researchers brought extra equipment to both film and edit on site. Each session, except one, took place in a shared space, either a repurposed office, common area, classroom, or a canteen. The one exception was a participant's private room in a sheltered residence, where we filmed on two separate occasions (primary shooting and a second take).

The physical domain was characterized by a high degree of control exercised by the primary investigator and caretakers/administrative staff from all the institutions. This meant that at all times the responsible parties were aware of who was visiting which institution, when, for how long, with whom, and for what purpose. This was especially true for me as a non-native speaker with the additional disadvantage of living and working in a different city. Every physical meeting had to be arranged by the project's primary investigator (a co-researcher). They would get in touch with the administrative and support staff in advance via email, text, or phone calls and initiate a negotiation process. After the caretakers had confirmed that the participants had indeed expressed a desire to join the fieldwork, further arrangements (e.g., type, duration, location of the activities) could be made. This gatekeeping did not feel out of place in the institutions for younger children, where the staff appeared to almost match if not completely outnumber them. Having such a presence and taking ethical

and moral reservations into consideration, it was easy to understand why a strong gatekeeping tradition was in place.

While the overall setup generally confined the researchers to a single room, some of the participants opened up during the fieldwork by offering a view into their homes. Some lived in sheltered residences, while others lived in buildings adjacent to their special schools.

The online domain was mediated by the video conferencing tool Zoom and enacted through two types of screen sharing: (1) traditional, where both the participants and researchers could view and interact directly with the software on each other's computers, and (2) virtual, where both the participants and researchers had a virtual avatar presence as they created digital objects. Thus, the video data from the screen recordings constituted the entirety of the data corpus for the online sessions.

The importance and use of hardware and software tools within these sessions, as well as a fuller description of the activities carried out during them, is explored in Chapter 5. First, however, I will address the question concerning data with regard to the project field.

### 4.4.2. DIGITAL DATA IN PHYSICAL ENVIRONMENTS

In practical terms, co-producing the PVTs resulted in video files. However, as mentioned in section 4.3, the main results of this thesis concern *the process of digital moulding*, in which the participants and researchers explored together how a digital intervention can support social relations among the target group. In this sense, the video files represent a critical but inconclusive part of the data corpus.

Another important piece of the data puzzle is what the participants were actually saying when they co-produced the PVTs. Their opinions and ambitions (e.g., what the topic of a tutorial should be, what styles should be used, who the intended audience would be, how their work should be engaged with) were as critical as the recording of and produced video itself. However, moving images and thematic interpretations did not exhaust the data corpus. The ongoing self-reflection by us, the researchers, on our biases, how our interventions were morphing into a different kind of power dynamic, and the nature of our place in the history of academics whose desire for inclusivity could result in shutting out participants' voices, all provided another element of the gathered data. No intervention can occur from a neutral position, and we strived to acknowledge as many of the biases we carried as possible and offered practical suggestions to the other researchers and caretakers regarding what considerations they could take when attempting to support digital practices and social relations among this target group.

## 4.5. PARTICIPATORY VIDEO TUTORIAL: A FIVE-STEP GUIDE

### 4.5.1. STEP ONE: COMMUNICATING THE GOALS AND METHODS

The first step to co-producing a PVT with neurodivergent young people concerns the manner of communicating what a video tutorial is. Ylirisku and Buur (2007) provided a useful metaphor to convey how one can conceptualize a method:

> Method may be understood as organising a party. People do not plan precisely what the guests need to do step-by-step, but they put all their energy into organising the space, the lighting, the food, the decoration, the songs and the music. If the party organiser achieves the right atmosphere, the participants will make sure that the party is a success. (p. 34)

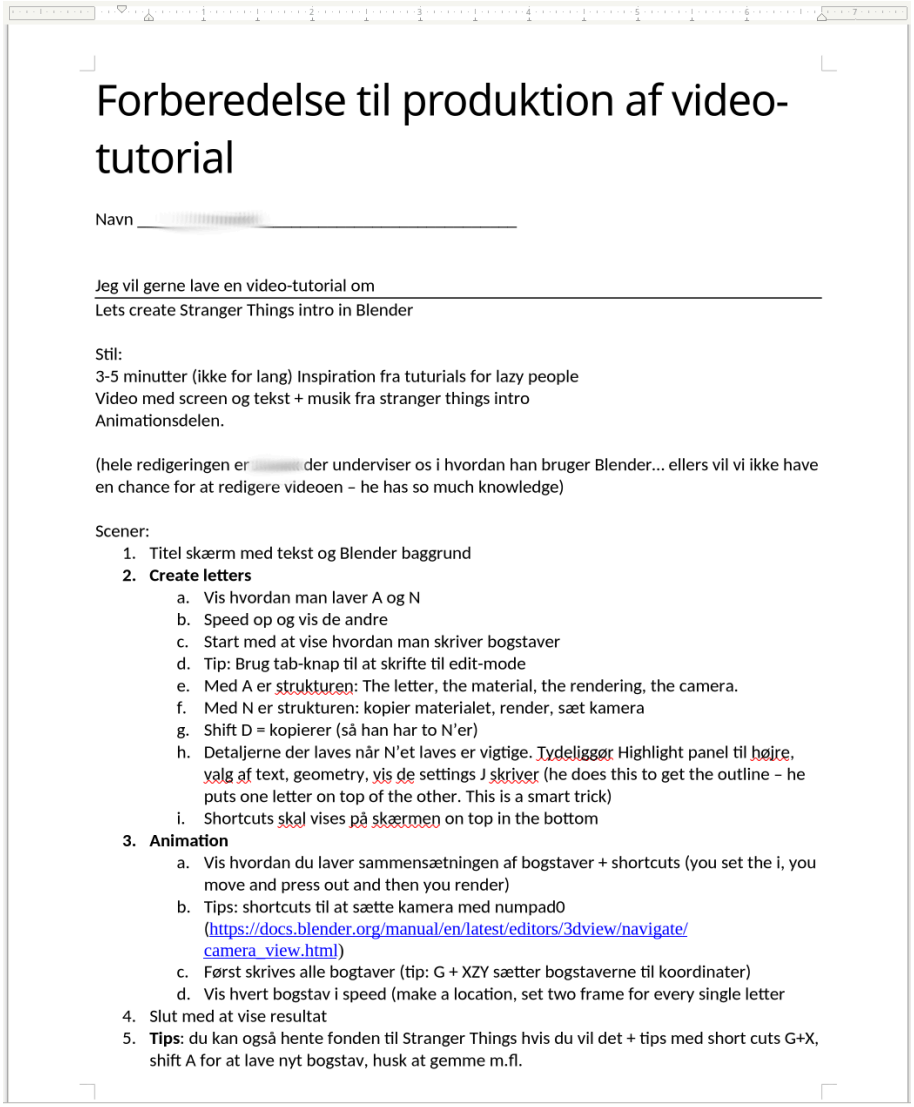
A "party" approach can achieve two things in a socially vulnerable context: (1) it can be low on or even free of anxiety, which was an issue for our target group, as the focus is on participation instead of production, and (2) it supports a feeling of shared responsibility toward the activities as all the stakeholders are visibly expected to contribute to the ("party") environment. This first step of co-production started in mid-2019 when the researchers approached the participants from Field Study 1 with proposals for Field Study 2 to build on that positive experience.

To create a PVT, we first introduced the concept of a video tutorial as the lowest common denominator that tied together all the digital activities observed during Field Study 1 and an unused method that only works with active participation. This was enough for 16 volunteers from four institutions. They were specifically told that if the tutorials did not work for them, they could indicate their displeasure or other preferences, and the researchers would adapt to those. However, the format proved to be non-divisive as no one questioned it directly.

The PVT, as implemented, carried a dual meaning: on the one hand, it had a very specific, clear, and easy outcome, namely, the video files themselves; on the other hand, the researchers repeatedly communicated to the participants that the process was exploratory, and there was no specific outcome that had to be reached. In that sense, the freedom to show exactly what they might want to share was built into all the PVT sessions. There were two additional characteristics of the PVTs that were made clear to the participants. First, the sessions should ideally be enjoyable, meaning that the form and focus of the videos should be about something that brought joy to the participants. Second, the sessions were presented as having a specific type of educational charge. In other words, the researchers were not present to simply collect data but to learn how the participants did specific things (e.g., the steps required to create a virtual landscape or to move from raw video footage to a TikTok post with all its aesthetic stylings, linguistic codes, etc.). Put simply, we should learn from each other and see what we could do to support each other.

To approach that ideal, the researchers and participants ideally needed to share certain technological experience and expertise—enough so that we could communicate using the same language. In practice, that meant that we used the findings from Field Study 1 to familiarize ourselves with the digital practices of the participants so that we could be specific about the technology use at hand: what is it (e.g., an app like Apple Messages, a game like Destiny 2, a process like a LAN party), what is it used for (e.g., Roblox Studio can create digital environments, TikTok can film, edit, and distribute video to a large group of people), what does it require (e.g., an internet connection, a sufficiently powerful laptop/desktop/VR), and so on. In summary, we needed to be able to use a technology-focused language to establish a rapport.

Communication cannot be a one-way effort, however. To offer a non-intrusive avenue for contact, we offered our participants a script, which invited them to share what they would like to create a video tutorial about.



# Forberedelse til produktion af video-tutorial

Navn _____

Jeg vil gerne lave en video-tutorial om
Lets create Stranger Things intro in Blender

Stil:
3-5 minutter (ikke for lang) Inspiration fra tuturials for lazy people
Video med screen og tekst + musik fra stranger things intro
Animationsdelen.

(hele redigeringen er [illegible] der underviser os i hvordan han bruger Blender... ellers vil vi ikke have en chance for at redigere videoen – he has so much knowledge)

Scener:

1. Titel skærm med tekst og Blender baggrund
2. **Create letters**
   a. Vis hvordan man laver A og N
   b. Speed op og vis de andre
   c. Start med at vise hvordan man skriver bogstaver
   d. Tip: Brug tab-knap til at skrifte til edit-mode
   e. Med A er strukturen: The letter, the material, the rendering, the camera.
   f. Med N er strukturen: kopier materialet, render, sæt kamera
   g. Shift D = kopierer (så han har to N'er)
   h. Detaljerne der laves når N'et laves er vigtige. Tydeliggør Highlight panel til højre, valg af text, geometry, vis de settings J skriver (he does this to get the outline – he puts one letter on top of the other. This is a smart trick)
   i. Shortcuts skal vises på skærmen on top in the bottom
3. **Animation**
   a. Vis hvordan du laver sammensætningen af bogstaver + shortcuts (you set the i, you move and press out and then you render)
   b. Tips: shortcuts til at sætte kamera med numpad0 (https://docs.blender.org/manual/en/latest/editors/3dview/navigate/camera_view.html)
   c. Først skrives alle bogtaver (tip: G + XZY sætter bogstaverne til koordinater)
   d. Vis hvert bogstav i speed (make a location, set two frame for every single letter
4. Slut med at vise resultat
5. **Tips**: du kan også hente fonden til Stranger Things hvis du vil det + tips med short cuts G+X, shift A for at lave nyt bogstav, husk at gemme m.fl.

Figure 6. Screenshot of a filled-out PVT script. The first three sections were filled out by the participant prior to filming. The remaining sections were completed during filming by the primary investigator, who led the interview and prompted the participant with questions about types of scenes (Scener), visual styles, desired result, and tips and tricks

The script was provided more than a month in advance of the filming sessions to all the participants and began with open-ended prompts (e.g., "Jeg vil gerne lave en video-tutorial om"/"I would like to make a video tutorial about. . .") as well as standard questions (e.g., "Hvem kunne du godt tænke dig skal se din video?"/"Who

would you like to have view your video?") It then provided open questions about (visual) style and specific scenes. The answers and reactions to these questions constituted the background knowledge we had when we met our participants physically for the first time and started filming.

As verbal and written communication were both avenues with which the neurodivergent participants had issues, when carrying out the PVTs, we made sure to pay attention to how we visually presented the activities. In that regard, the equipment we brought (two cameras, two studio lights, microphones, voice recorders, etc.) may have seemed overwhelming from an outside perspective, and we did not exclude the possibility that some of the participants may have somehow been surprised or even scared by it, even though we received no such direct or indirect feedback. On the contrary, a few of the participants used the equipment as a shared topic of interest, while most did not react to it. However, all this technology was meant to communicate our level of commitment and to capture the results of the PVTs while avoiding quality issues.

### 4.5.2. STEP TWO: WHO DOES WHAT AND WHY

*Participant, caretaker, and researcher roles*

All the participants who joined the PVT sessions were neurodivergent students and residents of the institutions. The role we had in mind for them was one of a decision-maker and co-producer (i.e., someone who shares what digital practices they think others should know about and benefit from). As a result, the participants with a specific interest in technology but who lacked sufficient support at home or at the institutions they lived in tended to engage more with the PVT process.

The caretakers were responsible for the access to and use of the physical spaces. They arranged the participants' schedules, made sure they had ample breaks, and on rare occasions, acted as interview relays between the researcher and participant.

The researchers initiated the tutorial format and conducted all the filming and recording activities, interviews, and video editing. The latter was first undertaken on the spot with direct involvement from the participants, then alone at home, then at feedback sessions, and then at home to apply corrections. The researchers also helped set up and support physical activities (e.g., LAN parties). The researchers were further responsible for the logistics of the sessions (i.e., time, place, and duration of the meetings) and provided the technical equipment and support.

In the PVT format, both the participants and researchers were co-producers. In that regard, the participants were responsible for showing up and allowing the researchers to record how they performed their digital activities; they demonstrated their digital skills while simultaneously answering questions from the researchers, who tried to roughly follow the script. The participants were responsible for expressing their

preferences regarding which parts of the recorded videos should be kept, in what general order they should be presented as a tutorial, what tips and tricks should be highlighted from the video material, and what general visual styles should be used. Additionally, they provided feedback on the draft video tutorials, either approving the choices made by the researchers or disagreeing with said choices and leaving specific notes on what had to change, how, and why.

The researchers as co-producers had the responsibility of arranging the physical recording area, sometimes with assistance from the caretakers, and ensuring all the technologies worked as expected (e.g., the cameras and microphones were recording, the screen capture software functioned properly). They tried to adhere to the agreed upon script in ways that supported the participants' self-expression (e.g., if a participant had not indicated a preferred visual style for their video tutorial, the researcher would nudge them to make a decision in that area). Importantly, it was the researchers' responsibility to not cannibalize the co-operation space. They had to leave the participants to find their own tempo, style, and sense of comfort, such that the participants would want to not just show what they had done, but offer reflections on why.

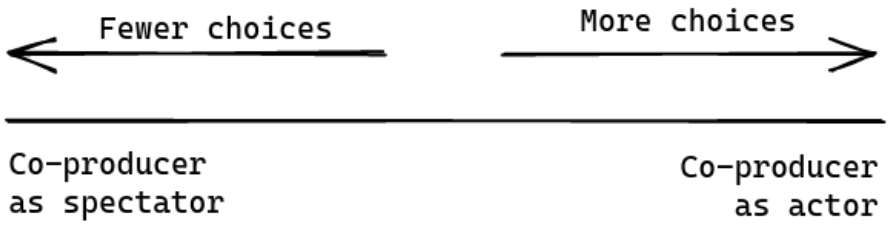



Figure 7. Spectrum of participation

The PVT format included a long list of activities, chief among them were the physical set up, recording, demonstration, interview, first round of video editing, feedback, second round of video editing, and premiere. At any one of these points, the participants and researchers needed to make choices about how to set up the equipment, what to demonstrate and how, and so on. The more choices they acted upon, the more active their co-producing role was, and conversely, the fewer choices they acted upon, the less active their co-producing role was. We proposed a spectrum of participation to situate these types of co-production anywhere between the spectator and the actor. More specifically, the participants and researchers were directly engaged in the following three-step process when co-producing a PVT:

1. Problem/area of interest

The participants presented an issue they had encountered in their digital lives or an area of interest they found important for themselves or others. Examples included questions about how to gain popularity on social video platforms (TikTok), how to ensure fair play in online gaming (Space Engineers), and how to build digital environments (in Roblox Studio).

2. Solution/skills demonstration

The participants demonstrated how they solved the presented issue or what skills they found most useful (for themselves or others) when engaging the area of interest. Examples included using messaging services to communicate with people you love (via Apple Messages), setting up physical LAN events for shared gaming experiences or reconstructing digital objects in 3D space (via Blender).

3. Tips and tricks

In the final step, the participants were encouraged to synthesize the most important points about what they had presented so far. We encouraged anything between three and five tips to ensure that real choices were made and that the step was not too overwhelming. Another focus in this step was to remind the participants that these tips and tricks should be useful both to them and potential viewers.

These three steps completed the PVT framework as enacted during the in-person sessions of the project.

To film, we met physically at the institutions and used approximately one hour to record each video tutorial. The researchers arrived with cameras (a primary camera to film the participant, a secondary camera to focus on the relevant activities and objects, and a 360-degree camera for different viewpoints), studio lights (better light supports a more professional look), and microphones. Additionally, we set up screen recording software to capture the digital activities. The caretakers provided a room and ensured that the schedules were in order, there was sufficient time for filming and breaks, and the participants left on time so as to not have their regular activities suffer. The participants chose what program or digital activity they would showcase and were reminded that they could supplement the basic recording setup with anything they liked. The main question of the activity therefore needs to be revisited: what were we filming and why?

While interesting and unexpected results inevitably emerged from this format, it also clearly marked the limits of what we were able to focus on, what comprised the video filming, video production, and digital manipulation, and how they came together. To practically acknowledge this limitation, we encouraged experimentation and were

open for unplanned activities based on the tutorial format. Examples of experimentation included a showcase of Second World War German foot soldiers' equipment, as well as the set up and carrying out of a LAN party. One particular type of unplanned activity emerged as a request from two of the participants after the last session of the fieldwork. They asked that we continue our sessions online, which inspired the second phase of this thesis's fieldwork. More details will be presented in Chapter 5.

### 4.5.3. STEP THREE: FILMING AND EDITING

Filming a scene is never an innocent activity. A gaze directed at something has an inherent power over it as it shapes what is being seen into what the perceiver will act toward. The double-slit experiment, which demonstrates the fundamentally probabilistic nature of quantum mechanical phenomena, offers physical evidence of the ways in which the act of observation affects what is being observed. That change takes one type of form when the observer is human and a different one when the observer is a hybrid (human/machine). Why this matters in the context of filming a PVT with neurodivergent participants relates to the issue of control. More specifically, it is about who watches and records whom, how the filming is set up and enacted, and the kind of power dynamics to which it is conducive. To unpack these questions, it is necessary to explore the practical details regarding how we filmed the PVTs.

Heath and Hindmarsh (2010, p. 40) provided descriptions of *roving* and *fixed* camera approaches. A roving camera can be used in multiple ways, for example, in a mobile, participant-guided manner (reference is made to Sarah Pink's fieldwork (2004) where she was guided by her study participants while discussing questions of home design and organization) or for *guerrilla-style filming* (Shrum et al., 2005), where the researcher follows mobile participants as they actively engage in mobile activities. A fixed camera can offer meaningful benefits as well. For example, it lends itself better to more formal or constrained environments and allows the researcher to adopt an observational and less obtrusive role during the filming process. We adapted aspects of these two camera approaches and mixed them with the specific requirement for a PVT: filming via a digital camera.

This methodological necessity presented us with a challenge: how could we use film to record the physical and digital environments in a fluid manner that was unobtrusive and stayed out of the way of the participants' activities, but at the same time be visually present, not awkwardly hiding, and signal a tangible interest in the activities? We addressed these challenges via a dual-filming approach.

Figure 8. The A-cam filming a participant while a researcher is setting up Open Broadcaster Software Studio for screen recording

This means that we combined physical and digital filming in the following manner: the two physical cameras we used (main camera: A-cam; secondary camera: B-cam) had their own places. The A-cam was stationary and fixed on a tripod. It looked directly at the participant and whoever was next to them. The B-cam was mobile: it could be on a tripod, and a researcher could move around, pan, and zoom with it. It could also be fully hand-held so that the researcher could more easily focus on a particular detail or interest.

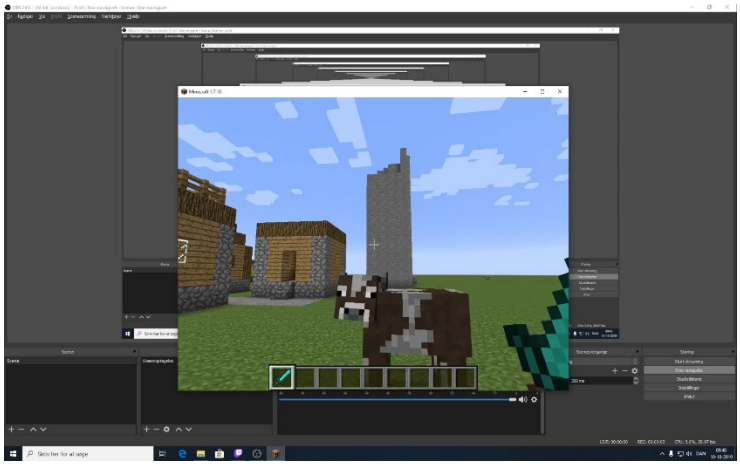


Figure 9. Setting up Open Broadcaster Software Studio to record a participant's screen.

The virtual camera recorded the digital activities and could take two forms: first, a third-party program called Open Broadcaster Software Studio (OBS for short), which offered extensive filming control, and second, a built-in screen recorder. With OBS, we had the ability to record only one window on screen, which allowed a kind of privacy for those participants who did not wish to have all their digital activities recorded. We could also record custom sections of the display or everything on it and choose whether or not to record audio. Because this was third-party software, which was not present by default on the participants' computers, we had to engage in a technical conversation with the participants and/or their caretakers to explain what we were using and why. OBS is easier to use in a stationary environment, either on a desktop computer or a laptop. In other cases, where the participants used a mobile operating system on a smartphone or a tablet, it made more sense for us to use the built-in screen recording solution. This allowed less friction due to technologies during filming as we did not have to install additional software.

Using physical and digital cameras simultaneously raises the question: why film in two domains? When recording a video tutorial of a digital activity, screen recorders are practically mandatory. The format demanded that we manipulate the footage somehow so as to (1) shorten it, (2) stress points of interest for our participants, and (3) aim for a specific aesthetic not present in the raw data recording.

Filming requires more than just cameras. We brought studio lights to each tutorial recording session to provide adequate ambient lighting. We made sure to have audio redundancy by providing the participants with "lav microphones," which could be easily attached to the collar of their shirts if needed or simply placed nearby without obstructing their movements. We complemented these small microphones with larger voice recorders, which provided better audio quality as well as audio redundancy in the event of a technical failure.

The filming tools, software for recording, physical configuration of the room, and positioning of the participants, researchers, and caretakers all came together in the unique staging of the filming process. We positioned the A-cam such that it always centered the participant, and we moved the B-cam around to capture activities that were invisible to the A-cam. What we chose to include in the video footage and how we chose to arrange it mattered for what we later saw and worked with as co-producers of the tutorial.

*Editing and co-editing practices*

When we filmed our participants, we expect some sort of self-correction, an adjustment to the social environment from their side, while we attempted to establish a rapport. This adjustment was also visible in the digital practices we observed. While some of the participants remained within the confines of the program they were showcasing, others would branch out, unprompted, and use other programs (e.g., a

web browser, file manager) to show more of their practices. We viewed these adjustment practices as a lower level kind of editing as they addressed specific choices on what to show, what to interact with, what to hide, and so on. We called them type 1 editing.

The next level, type 2 editing, concerned more active engagement with the digital content. We could not have known the degree to which our participants had planned what they demonstrated to us, but while interviewing them, we noticed that they consciously decided to focus on different aspects of what was being shown. For example, one participant wanted to demonstrate "how to play Space Engineers," a first-person shooter game; however, we were surprised that what he meant was an hour-long exploration of the in-game menu options. Conversely, other participants showed us how to make a TikTok video with a greater focus on social trends and social cues than the technical aspects (e.g., the choice of fonts, language use, friends lists).

The final level, type 3 editing, was more reflective and was about the relationship between the participant's editorial preferences and the researchers' need for structure. To that end, after each session, we immediately imported the recorded screen footage from the participant's device into a video editing program and invited them to directly cut, slice, and play around with the videos. The purpose of this activity was to end up with a rough idea of structure of the video tutorial (e.g., which specific views did we need to make sure to include, which ones were less important).

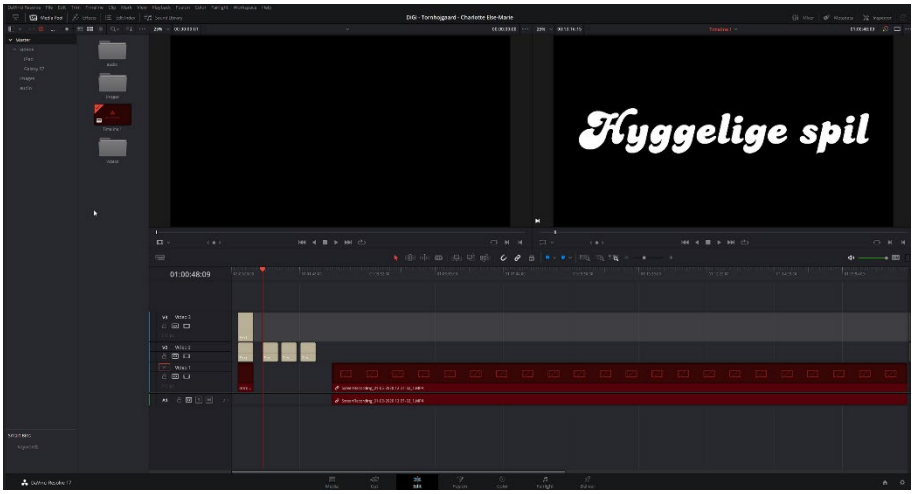



Figure 10. Example of a video timeline with basic video editing immediately after filming a tutorial session

Figure 11 demonstrates a basic type of editing, which included choosing the names of specific video sections and their font and font color. This was subject to change at the feedback sessions.

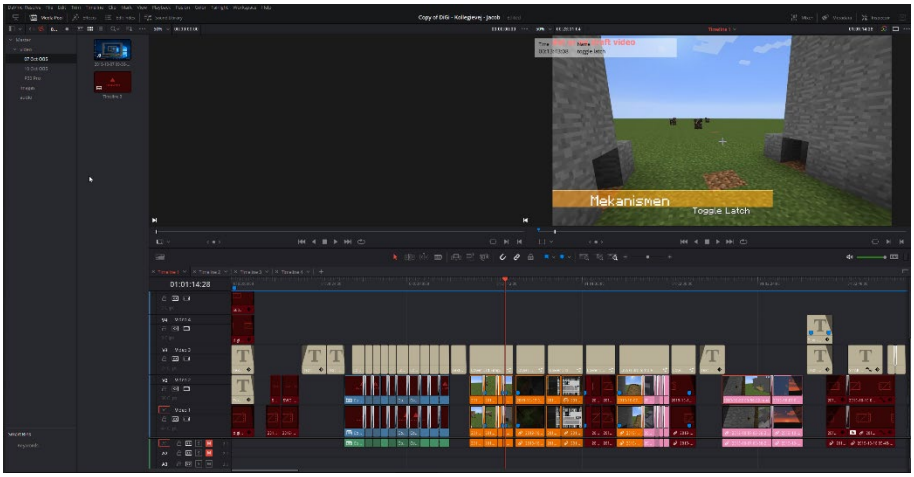



Figure 11. Example of a timeline before a feedback session

Figure 11 shows a video timeline in which the researcher had visually interpreted all the requirements from the filming session and prepared them for critique and further editing by the participant at the feedback session. Ultimately, the timeline was used as a methodological tool for engagement and stimulating feedback.

With this in mind, the question remains: what does it meant to edit video and data in a PVT? Editing is a multilayered process that has individual dimensions (e.g., when a researcher interprets the participant's requirements offsite) but is profoundly collaborative as it is a digital manipulation of one stakeholder's ideas using another stakeholder's technical skills. Achieving any kind of agreement in this setup demands a collaborative environment.

### 4.5.4. STEP FOUR: ENSURING FEEDBACK

Feedback is the direct response to a shared activity or action, where one side reflects on the choices and decisions made. In a tutorial context, feedback is critical in ensuring a sense of belonging to the project. This means that the filming session with its focus on demonstration and answers did not exhaust the entirety of contributions that our participants were capable of. In addition, creating a space for reflection, change, and/or reversal of opinion was important to strengthening their sense of belonging to the process.

Feedback is not a rehearsed response given once; rather, it is a continuous process that starts with the filming itself as the participants reflect on what is occurring. We

initiated two types of feedback during the PVTs: preliminary and considered. The preliminary type was carried out immediately after the filming session concluded. The researchers added the raw video footage into a video editing program with the participant next to them, scrubbed through large chunks of video, and asked for rough, general reactions regarding which parts should definitely be removed and which ones should be retained, as well as what general visual style should be pursued (e.g., what fonts and colors should be used). The more considered type of feedback occurred weeks later. The researchers used the draft timeline from the previous section to create a semi-finished video. Each draft was shown to the participants, and they were encouraged to make changes on their own by taking the mouse and marking/showing what they approved and what they wanted changed. Re-recording and applying any changes indicated by the participants were done on the spot.

While one feedback session may not be considered exhaustive for a PVT, it at least signals a structural commitment to getting as much as possible from this format.

### 4.5.5. STEP FIVE: PREMIERES AND NEXT STEPS

After all the feedback had been addressed and the draft videos reworked, the researchers organized premieres at the special schools and sheltered residences, where everyone was invited to a screening of the video tutorials.


Figure 12. A photo collage from two premieres showcasing the participants with honorary diplomas for their participation (top right), an audience at a special school (bottom left and bottom right), props (top left: a red carpet and a banner with the project logo), and popcorn (middle)

The premieres were intended to support a festive environment, and small props like a red carpet and snacks helped in that regard (Figure 12). Honorary diplomas for participation were created, printed, and laminated for each video tutorial creator. After their video had been shown to the audience, the participants were presented with a diploma, received an ovation, and made way for the next tutorial. After each premiere, there was a small social gathering where reactions and opinions were shared. These events proved an important aspect of this step, as during one of them, the researchers were approached by the participants from one of the special schools with requests to exchange Twitter usernames to be able to keep in touch. The outcome of this interaction is described in Chapter 5.

## 4.6. RESULTS AND REACTIONS TO THE PARTICIPATORY VIDEO TUTORIALS

Earlier in this chapter, I described the results of the PVTs to be a *process of shared digital moulding*. I will substantiate this claim by describing the digital expression of this process, the structure, style, and tips and tricks of the tutorials, and four types of reactions that they elicited in our participants, which led us to formulate four principles for the development of PVTs. Before that, a brief overview of the technical results of the in-person sessions is in order. The PVTs were made up of three sessions: filming, feedback sessions and premieres. All together they resulted in 235 hours of footage (including video from four different types of camera sources and audio from a voice recorder) and total 2.8 terabytes of storage.

### 4.6.1. STRUCTURE, STYLE, TIPS AND TRICKS

The digital result of the PVT process was the creation of 16 tutorial files (13 tutorials and three additional versions: two without end credits, and one dubbed in Danish instead of English). Each tutorial is between two and five minutes long. They were co-produced between 16 participants from four institutions and a total of four researchers. Each video tutorial began with a title screen and consisted of anything between two and seven distinct sub-sections. For example, a tutorial on how to create a drawbridge in Minecraft had the following sub-sections: (1) materials, (2) mechanism/drawbridge, and (3) modifications. All the videos included with some form of tips and tricks for viewers (e.g., “choose music without copyright” when choosing music for a video, or “write the text in English” when including text on a TikTok video that was intended to illustrate a point and be understandable to more people), and concluded with an end screen with production roles. The final structure of all the tutorials did not diverge substantially from its initial conception. The only major changes concerned the addition of narration.


Figure 13. Example of an introduction screen from a tutorial. “Hvordan man laver en LAN party” or “How to host a LAN party” by Magnus


Figure 14. Example of an end credit screen with roles of all participants. “Idea and TikTok video” by Caroline and Hannah, TikTok venner (*friends*) and kamera (*camera*) by three researchers

What follows is a table with overview of the pseudonyms of the participants, the title of their tutorials, and the intended audiences for each video, as specified by the participants themselves.

Table 4. The titles of the produced video tutorials with the participants' descriptions of whom should they be viewed by.

| Participant(s) | Tutorial title | Intended audiences according to the participants |
|---|---|---|
| **Andreas** | How to create beautiful landscapes in Roblox Studio | "Folk med interesse for emnet. Både børn og voksne" (People interested in the subject. Both children and adults) |
| **Caroline, Hannah** | Sådan man laver en video i TikTok (Let's make a video in TikTok) | "Alle" (Everyone) |
| **Jens** | Sådan laver du en vindebro i Minecraft (Let's make a drawbridge in Minecraft) | N/A |
| **Josephine** | Sådan laver du en video til dem du holder af (How to make a video for the ones you care about) | "Alle som gerne vil lære at lave YouTube video" (Anyone who would like to learn how to make a YouTube video) |
| **Thomas** | Let's create the Stranger Things intro in Blender | N/A |
| **Carl** | Hvordan man spiller online i Space Engineers (How to play online in Space Engineers) | "Alle" (Everyone) |
| **Magnus** | Hvordan man laver en LAN party (How to host a LAN party) | "Alle der vil lave et LAN party" (Anyone who wants to have a LAN party) |
| **Lars** | Tyskerne udstyr som fodsoldat under 2. Verdenskrig 1940 – 1943 (German foot soldiers' equipment from World War | "Alle med interesse i historien om 2. verdenskrig" (Everyone with an interest in the history of World War Two) |

| | | |
|---|---|---|
| | Two 1940–1943) | |
| **Rune** | How to edit videos in ShotCut | "Alle som gerne vil lære at redigere video" (Anyone who would like to learn how to edit videos) |
| **Alfred, Martin** | Sådan laver du et LAN party (Let's make a LAN party) | "Alle der vil lave et LAN party" (Anyone who wants to make a LAN party) |
| **Viggo** | Sådan du bliver god til at spille Destiny 2 (How to get good at playing Destiny 2) | "Alle som gerne vi spille PlayStation med andre" (Everyone who wants to game on PlayStation with others) |
| **Klavs** | Nyheder med Klavs (The news with Klavs) | "Alle" (Everyone) |
| **Nadine, Linda** | Spil der er hyggelige at spille med venner (Games that are fun to play with friends) | "Alle" (Everyone) |

Besides these structural points, each video had its own stylistic feel. For example, all the videos (except one) included background music; two videos had voice narration (one narrated by a participant, another by a researcher), while the other nine participants chose to use text on-screen to direct the viewer's attention in their videos. The other two videos had timestamps to make it easier for viewers to navigate the content of the tutorial. An interesting stylistic choice for most of the tutorials was the unprompted use of the English language: four of the 13 videos were fully or partially in English in an attempt to make the videos more appealing to a broader audience (Table 4).


Figure 15. A screengrab from Lars' video tutorial where he is holding a sign that reads "not political" in Danish. Visual and political styles could co-exist in how the participants co-produced their tutorials

Finally, the participants had their own understanding of the tips and tricks they wanted to share with their viewers in their tutorials. Most (eight) preferred to have the tips written out on-screen throughout or at the end of the video. Two preferred to opt out of a tips-and-tricks section in favor of more detailed descriptions on-screen and an emphasis on specific practices via text or images. One participant did not provide any tips and tricks at all and instead opted to end their video with a frame of them holding a political sign.

### 4.6.2. OVERVIEW OF TECHNOLOGY USE

As a contribution to the technology overview of Field Study 1, I compiled a list of all the digital technologies, platforms, and related hardware used throughout the in-person phase of the fieldwork. In sum, the 16 participants showcased their engagement by using the following:

- four digital creation platforms
- five communication and entertainment apps
- six games presented in tutorials and many more played at LAN parties
- five types of ambient technologies
- three specific types of hardware and software for support and recording

- **Digital creation platforms**
  - Minecraft [**Sandbox video game development program**]
    - Skinseed for Minecraft [Mobile application available on the Google Play Store]
    - Modifications to Minecraft
      - Pistronic 2
      - Project Red - Base
      - Project Red - Compat
      - Project Red - Fabrication
      - Project Red - Integration
      - Project Red - Lightning
      - Project Red - Mechanical
      - Project Red - World
  - Roblox Studio [**Digital environment creation program for the online game platform Roblox**]
    - Building Tools by F3X Plugin
  - Blender [**3D computer graphics software toolset for creating animated videos, visual effects, motion graphics, virtual reality (VR) and more. Free and open-source**]
  - ShotCut [**Cross-platform, free and open-source video editing program**]
- **Communication and entertainment**
  - TikTok [**Video-focused social media platform**]
  - DR Nyheder [**News section of the national Danish broadcaster DR**]
  - DR Radio [**Public radio service by the national Danish broadcaster DR**]
  - Facebook [**Social media platform**]
  - iMessage/Messages + Camera [**Default messaging service on Apple devices**]
- **Games**:
  - Space Engineers
  - Destiny 2
    - Ishtar Commander for Destiny 2 [Mobile application available on the Google Play Store]
  - Candy Crush
  - Hay Day
  - Funky Bay
  - Cross-Stitch World
  - LAN parties (console, virtual reality, desktop computer, and iPadOS games)
- **Ambient technologies**
  - Operating systems (Windows, Android, iOS, iPadOS)
  - Digital stores (Apple AppStore, Google Play Store)
  - Web browsers (Google Chrome)
  - Digital game distribution systems (Steam)
  - Search engines (Google, YouTube, TikTok)
- **Others**
  - Cables, TVs, monitors, console game controllers, headphones, laptops, computers, network routers, speakers
  - HTC VIVE - VR headset
  - Screen recording software (OBS)

Figure 16. An overview of the digital technologies and their related physical instances used by the participants grouped into five categories

Figure 16 provides a detailed overview of these digital technologies. This summary of the physical and digital technologies used strengthens the findings from Field Study 1 by providing more examples of the digital platforms and the types of digital skills and ambitions. While Field Study 1 showed evidence of a variety of digital practices (from games to programming), this technological overview of the PVTs includes events like LAN parties and shows the participants' depth of engagement (e.g., the participants did not contain their attention to the default program layout; they reached out to collect and experiment with third-party plug-ins).

### 4.6.3. FOUR TYPES OF REACTIONS TO THE TUTORIAL CO-PRODUCTION PROCESS

All the participants had their own way of reacting to the process of the video tutorial co-production. In our 2021 INTERACT paper (Karadechev et al., 2021), we outlined four strategies observed during the PVT process: *coping with ambitions*, *show and tell*, *connecting physical and digital experiences*, and *performative role*, which I will describe in depth here.

***Coping with ambitions*** describes participants who are frustrated that there are practical, technical barriers preventing them from showing exactly what they have in mind. In the INTERACT paper, we gave the example of Jens who knew he wanted to build a virtual drawbridge in the video game Minecraft, as well as a virtual avatar of himself, which would be giving a tour of the building process. The avatar idea was borne out of a conversation between Jens and a researcher, and Jens went out of his way to find, download, install, and use a mobile application to streamline the process of Minecraft avatar creation. He modeled himself in that application and urged the researcher, who would be doing the draft video edits, to include and animate the avatar. This clear idea of what should be included in the video and how it should behave hit a wall of frustration when (at the feedback session) Jens saw that his avatar did not mix seamlessly with the surrounding environment and stood out in a visually displeasing way (Figure 17).

Figure 17. Jens's Minecraft avatar stood out in a visually unpleasant way that created issues for Jens

Having created not just the avatar, but a virtual library with the project logo (DiGi TV) in the background, Jens felt disappointed by the lackluster technical result as the researcher could not reproduce in time and to a satisfactory degree what Jens had in mind. Later on, he tried to fix the image to his liking on his own but was ultimately not successful and voiced his displeasure at the tutorial premiere. However, he reached out after that to ask if he could use one of the researchers in an online session, where they would play with the video editor used in the tutorial production sessions.

Another frustration was voiced by Carl, one of the two participants who requested a voice-over for their video. While initially he had wanted a researcher to record the audio of the text they had agreed upon, Carl was provoked during the feedback sessions by the audio quality and requested that he do the voiceover for the video himself. We highlighted these examples as reactions to the tutorial format to shine a light on some of its limits: namely, that it is difficult, if not impossible, to achieve perfect alignment between the mental model or idea that a participant would want visualized and what the technical capabilities at the time actually allow for. The main point in such a situation does not concern the technical (or imaginative or other) discrepancy, but rather the ways in which this format makes coping strategies attenable, inviting, and desirable by the participants. While Jens could not fix his avatar as much as he had wanted, he did use the tutorial as a stepping-stone to engage with technical questions (presented in greater detail in Chapter 5) and to create more digital objects at that point. Carl, on the other hand, simply re-recorded, on the spot, with the researcher the parts of his tutorial that did not sound as he wanted them. Substituting the draft audio with Carl's take was an easy step that made coping with his ambition of just the right words unproblematic.

***Show and tell*** is the second approach we identified through the video tutorial co-productions. Its main characteristic appeared to contrast with the *coping with ambitions* strategy. Where participants like Jens and Carl struggled to precisely visualize their ideas, others, like Josephine (Figure 18), seemed to roll with whatever was available to them. They were the focus of the tutorial, not the digital representations. Josephine co-produced a video about using Apple Messages to send video clips to people she loved. The relative technical simplicity (compared to Jens's ideas, for example) may have helped create an easier visualization. However, Josephine's demeanor stood out as a much calmer one as she was not bothered by the technologies (her smartphone, the video recording process, embedding a video in a message, etc.); rather, she was entirely focused on her own performance. Josephine sang for the primary investigator and appeared to generally enjoy herself.


Figure 18. Josephine demonstrates how she attaches videos to a message

We contrast this *show and tell* approach, where the participant is less involved in every single technical step but instead keeps their focus on the activity, with the more antagonistic *coping with ambitions* approach. In Josephine's case, the co-producer role set the mood and engaged in social activities, which were recorded by technologies, instead of focusing on technologies and having social relations as a by-product.

***Connecting physical and digital experiences*** constituted the participants' third strategy for co-producing a PVT. Its main point lies in the interpretation of the tutorial as not just something that happens between a person and a device, but rather a larger activity where social and technical environments intertwine and mix constantly. In practice, this was exemplified by two distinct groups of participants in two separate institutions, who, independently of each other, decided to set up and record a LAN party. A LAN party is a specific type of social engagement, in which various participants bring their devices (anything from a large desktop to a VR setup, to smaller tablets and smartphones) to a larger room and spend time playing many different games together (Figure 19).


Figure 19. LAN partygoers from Magnus' tutorial on how to host a LAN party. Two people play, while four others hang around and watch/engage with them

While this activity certainly shifts the focus away from the question of "how do we make a tutorial about a LAN party" to "let's enjoy this party and record it," it also demonstrates how participatory a video tutorial process can be. In i2, where the first LAN party was held, only four participants decided that they would stage such an event, which ultimately brought together more than 20 young people with even some of their parents joining in. The flexibility and looseness of the tutorial structure allowed for such interpretations. While some may raise valid questions about the substance of video tutorials basically showcasing a LAN party, we would argue that the effects of a tutorial are manifold. While Jens's video had a specific goal (i.e., to show viewers exactly what steps should be taken if to create a drawbridge in Minecraft), the mixing of physical and digital environments leans more heavily on an aspirational note. It creates more of a focus on "wouldn't you like to be a part of something like this" as opposed to "act in this exact specific way if you want to achieve this exact specific outcome."

Finally, we observed what we called the ***performative role***. This can be seen as a combination of the first two approaches albeit with a few important differences. Just like *coping with ambitions*, the performative role is focused on presenting a specific sequence of steps and showcasing a precise vision of what has to be shown. However, it also shares qualities with the *show and tell* approach, namely, that the participant is in total control of the situation, performs what they have in mind, and is not bothered by any technological hiccups. For example, Thomas, a participant who created 3D models in Blender, sat down with us and spent the entire time explaining to us what he was doing, why and how, and showing us YouTube video tutorials, which he watched for inspiration (Figure 20).

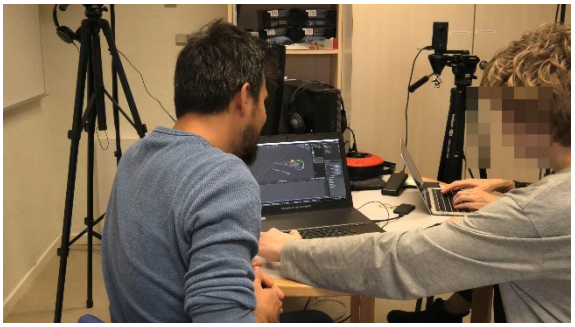


Figure 20. Thomas demonstrates how he navigates 3D space in Blender

This particular type of reaction to the tutorial sessions revealed different co-production motivations and desires. As we later found out, Thomas had prepared prior to the filming session by rehearsing the model he demonstrated for us multiple times. This did not take anything away from his technical and co-producing abilities but indicated to us the importance of preparation when engaging in a tutorial recording. From one perspective, Thomas may have felt awkward if he had to look for help in the presence of unknown researchers. On the other hand, he may have just wanted to be as helpful to the filming process as possible. While we do not know this definitively, we can say that this performative approach stood out as a unique way of engaging in the co-production of a PVT.

### 4.6.4. FOUR PRINCIPLES FOR CO-PRODUCING PARTICIPATORY VIDEO TUTORIALS

When considering the 13 co-produced video tutorials and the four types of reactions we observed during their filming and editing, we gained new and practical insights into the tutorials. In the aforementioned 2021 INTERACT paper, we referred to four specific principles for co-producing PVTs.

The first principle, **socio-technical belonging**, refers to two aspects: the physical and conceptual places of the tutorials. Each participant in our fieldwork had watched videos on how to do things. They had prior practical experience with the concept of following steps to achieve a goal—in their institutions, at home, and online. Thus, the idea of a tutorial and its practical enactment already belonged in the place where we carried them out. We argue that if they were to be taught and imported, their engaging power and methodological potency would be greatly diminished.

Second, the principle of **technical accessibility** is related to the previous idea of belonging in that every co-producer of a tutorial should already be familiar with the technical tools required for its enactment, filming, editing, and presenting. Although we introduced cameras on tripods, studio lights, microphones, and more, the same

effect could have been achieved entirely with the devices already owned by our participants. Had we taken that route, the only items we would have sacrificed would have been time and convenience.

Third is the principle of **methodological elasticity**. What we mean by methodological elasticity is that the structure of the tutorial should never negatively constrain or prevent a participant from whatever tutorial-related activity they want to pursue. No matter how they act (e.g., in a somewhat passive *show and tell* manner or experimentally setting up a physical LAN party), the tutorial format should allow for these activities while never losing its core structural rigidity (i.e., the three-step structure).

The final principle is **material reusability**. While different co-production sessions were received differently (some more favorably than others), it was critical to ensure some form of future reusability of these activities. If any positive parts of the sessions were to endure and be developed into more appropriate practices at each institution, they would need to be deconstructed by the caretakers and participants in their daily practices and the relevant parts adapted and reused in contexts we cannot predict. For example, Jens's frustration with technical tasks and desire to follow up on potential leads for technological development could be referred to as part of the homework for regular classes, as well as in more experimental MakerSpace environments, which are available at some Danish institutions.

These four principles can be used by researchers in the fields of human–computer interaction and child–computer interaction, whose work involves practical engagement with young people (with or without cognitive and developmental disabilities). Additionally, these principles may be useful to administrative staff at special institutions (e.g., schools, sheltered residences) where neurodivergent young people study or live and can be used as guidelines for institution-specific activities. Finally, the pedagogues and caretakers in these institutions could use the four principles when considering how to engage neurodivergent youth in digital activities.

It is also important to note that not all institutions will necessarily have the resources for the technical setup presented in this chapter, which should have no effect on the benefits of the four principles. They can, however, serve as reflection points for how available and already-in-use technologies could be reconfigured around the principles to better support digital activities for this target group.

### 4.6.5. METHODOLOGICAL TRANSITION

The premiere sessions took place in January 2020 and marked the end of the in-person phase of my fieldwork. I did not expect that all 16 relationships with project participants would evolve at the same rate, or indeed evolve at all, but the different reactions at the premieres gave me reason to expect more from some of the

participants. For example, three of them approached me after the screening of the tutorials at their institution and asked for my contact details as they wanted to share other digital activities they had been engaging in. With the full knowledge of the relevant caretakers, I initiated online contact and began planning the next phase of the fieldwork. While I knew this next phase would revolve around a mostly online-first approach and would build on the digital skills and ambitions witnessed throughout the in-person phase, I was not prepared for the amount of change brought about by the COVID-19 pandemic.

All the data gathered between mid-2019 and early 2020 naturally raised more questions than answers, and the first one—in relation to the practical activities shared between the participants and researchers—was "and so, what now?" In the next chapter, I present the second phase of my project, which took place entirely online and uncovered a much greater wealth of perspectives, insights, and data than I could have anticipated.

# CHAPTER 5. ONLINE SESSIONS AND DIGITAL MOULDING

In Chapter 3, I introduced the idea of digital moulding to describe the results of the participatory video tutorial (PVT) creation process. In this chapter, I describe my use of digital moulding to explore what took place during the second phase of my fieldwork when the digital creation processes moved entirely online due, in large part, to the effects of COVID-19 in Denmark, which comprised a swift and comprehensive set of lockdown measures. I describe why and how we set up six online sessions, offer a detailed overview of each activity (its structure, goals, and results), and use them to ask questions about the combination of in-person and online-only activities, which I explore in Chapter 6.

To begin, it would be beneficial to outline the evolution of the digital moulding process. During the in-person phase of the fieldwork, digital moulding was confined to the normative structure of the video tutorial. As described in greater detail in Chapter 4 (section 4.3, "The Role of Video"), digital moulding emerged as a result of using video in three ways (i.e., hypervideo, clay, and social glue), as well as the PVT sessions themselves. These sessions followed a clear goal of recording and co-producing the videos based on the known interests that our participants shared. In contrast, going online-only challenged the digital moulding process by stripping it of its normative methodological structure. As I reveal later in the chapter, we addressed this methodological issue by embracing the benefits of an online-only environment, namely, a different kind of rapport-building, the greater ease of digital tool use, and a singular focus on digital scenario exploration by our participants. We explored what we could do together through various digital tools and, in the process, learned more about each other.

## DIGITAL MOULDING

Digital moulding is constituted by an interplay of technologies (e.g., all the programs described in section 4.6.1 plus all the technologies used by the researchers) and socio-digital scenarios (e.g., all the social interactions that took place during the fieldwork both in the physical and virtual environments). There exist different power dynamics in virtual compared to in-person sessions: while the participants were in the spotlight during the in-person sessions, we almost exclusively recorded them (except for during the editing and co-editing process) during the online sessions, and there was no spotlight. However, the shared process of moulding took on a new meaning when the constraints of the physical settings were lifted in favor of much more direct digital interaction. I expand further on this in six vignettes later in this chapter.

## 5.1. ADAPTING TO A PANDEMIC

On March 11, 2020, Danish Prime Minister Mette Frederiksen talked about *samfundssind*, which roughly translates from Danish to *community-mindedness*, when announcing the first set of measures aimed at limiting the spread of COVID-19 in Denmark. From March 13, 2020, all workers with "non-essential functions" in the public sector were to stay home for two weeks (Danmark lukker ned, 2020) in a display of social care for a difficult, dangerous, and rapidly changing health situation. The gradual expansion of the measures (e.g., closing down childcare centers, schools, and similar institutions) directly affected all the institutions participating in this project. It meant that no in-person contact was possible, with a strong indication that the implemented measures would not be short-lived. In this sense, displaying *samfundssind* dictated that I adopt a fieldwork strategy where I was never physically with any of the participants, their pedagogues, caretakers, administrative staff, or even my own colleagues. On the one hand, pre-COVID, I would have engaged with more participants after the video tutorial sessions regarding further digital production setups and used video in more direct ways to build on the work done up to that point. On the other hand, the COVID-19 lockdown measures forced me to rethink what makes fieldwork meaningful. In my case, working with digital interventions meant that I had no choice but to fully immerse myself in digital research and organize online-only activities for the participants.

It is worth noting that by mid-April 2020, a gradual reopening of Denmark had already been undertaken. I might have been able to travel to the participating institutions, and I could have attempted to organize entirely online activities while still being in the participants' physical vicinity (probably in a nearby building) to maintain strict social distancing. However, I chose not to pursue such a research route. Any potential positive effects it might have had on the rapport and social relations I had already built with some of the participants would have been undermined. This approach would have been considered insensitive and offensive given the associated health (COVID-19) and social risks (ignoring and disrespecting *samfundssind* and going against the Danish trend of social protection). Adopting an entirely online-first and online-only fieldwork approach therefore made sense on a human, citizen, and research level.

To that end, I was able to build on my previously established connections (at the video tutorial premieres) with the participants who—unprompted and on their own—had asked to exchange contact details so that we could keep in touch (all with the knowledge of their caretaker). The combination of the Danish lockdown measures against COVID-19 and the goodwill displayed by the three participants at one of the participating institutions made the adaptation to online fieldwork seem fitting. The benefits of this shift meant that I would be able to obtain a clean(er) slate for data collection and could set up new activities in new environments with little input from the institutions. It would offer me more direct and unmediated contact with these participants, which could potentially be seen as a better chance to interact with them

without a major behavioral filter (e.g., how they would have altered their behavior if we were physically in an institution, where they would have had to pay attention to their anxieties regarding in-person meetings).

The downsides of this shift to online-only research were necessarily reflected in the considerably more limited desire for participation. Any potential activities I might have initiated with more young people from the institutions could never be tempting enough to break through the strongly regulated health environments in the special schools and sheltered residences. This meant that only the participants who had been eager enough to initiate contact themselves would be the ones with whom I could work. This even smaller number could be seen as detrimental to any broader credibility with respect to the produced data. Additionally, moving to an online-only environment without prior agreement between the researchers and participants meant that new forms of misunderstanding and misrepresentation were an even bigger possibility. With these potential benefits and drawbacks in mind, I decided to make a proposal to the three participants who had volunteered to collaborate with me and to see what they thought.

## 5.2. ONLINE SESSIONS: STRUCTURE AND PURPOSE

A physical quarantine meant no direct contact with the participants, which prompted me to rethink the purpose of the digital intervention. What was it supposed to aspire to and why? The general direction of the digital intervention process motivated me to look into how our participants could be active digitally in ways that supported, enhanced, and benefited their social relations and could unfold in a virtual environment. In addition, I considered what digital activities I could set up that would allow a digital-first perspective of the participants' digital creation sides to become more visible while retaining a focus on *their* voices without imposing much of myself as a researcher. How could I learn as much as possible about their desires and ambitions?

My hypothesis was that having the participants lead the online sessions would be beneficial for their self-perception and support our established rapport (as outlined in Chapter 4), which relied exclusively on them being technological experts in their digital practices. The notion of having neurodivergent participants lead online sessions was supported by a few additional facts: (1) the participants had actively sought out future engagements with me, meaning that they already had interests, ambitions, and potentially, ideas, and (2) there were only three of them, and they were from the same special school, which meant that they knew each other and could engage between themselves without as many issues. They would thus be more likely to want to try something like leading an online session. I wanted all the participants to be as active as they wanted to be and to try anything they might want to try in an online context. To allow for that, I proposed a loose structure and invited the participants to play with it. Its specific form began with the idea of using the PVTs

we had co-produced during the in-person sessions as a foundation and building on them, thus strengthening the feelings of continuity, commitment, and exploration. The meetings would be online and would be recorded via Zoom and shared screens with the knowledge and consent of the participants and their caretaker. The participants would watch me follow the tutorial itself, step by step, and would help me practically as I try to recreate the final results (e.g., a beautiful landscape in Roblox Studio, a drawbridge in Minecraft). This idea constituted the starting point aimed at helping us explore digital practices together in a virtual environment.

While discussing this idea with the participants and their caretaker, it became clear that such an approach would be a somewhat controlled effort of "going native" on my behalf, where I would quite literally follow the participants' digital steps, doing what they were doing, and seeing what they were seeing. That meant that, in a sense, I would assume the role of their student (i.e., learning from their recorded digital practices and applying those lessons in front of them, ready to be scrutinized). This would rely heavily on a key aspect of any tutorial: I could fail at the task, and that would be OK! The point was not to succeed, but rather, to follow the provided steps with interest, respect, curiosity, and an openness to being wrong. Furthermore, it would require me to receive assistance and not just recognize the tutorial creator's skills, but practically rely on them to pursue a successful recreation of the video tutorial.

An important but easy to dismiss aspect of this methodological approach relates to the very practical, tangible tools we used. Specifically, the computer I would use to recreate the tutorial would be different than the one our participants had used in our previous sessions. The software they had used back then was very likely set up differently from mine, and their usage of the programs was certainly different from mine. Trying to recreate the tutorial necessarily meant that I would bump into small (e.g., the configuration of the software) and large issues (e.g., not understanding certain points of the tutorial). Thus, attempting to recreate the tutorial could be a good approach that involved our participants (as tutors) interrogating me (as the student). Before proceeding further, it is important at this point to address the question: why were we exploring this particular way of continuing work with the PVT format? The main reason concerns a deep interest in the directness that emerges in a digital environment (i.e., from having the ability to control our pointing devices without much friction). As mentioned previously, it was important that the researchers and participants engage with previously co-produced material because acknowledging and using it could support the retention of the beneficial parts of the tutorial sessions.

Setting up the online sessions meant that I needed help from the participants' caretaker. He would book a room, make sure there was an available computer for them, set it up and test the connection, and sometimes stay with the participants during the sessions, even briefly.

The initial plan for the online sessions was to focus on the process of shared digital moulding. That meant that the main digital activity (e.g., using Roblox Studio to create digital landscapes) was not entirely in focus. Rather, how we engaged with the previously co-created tutorial, what the participants focused on, and ultimately, the shared process of digital creation was what was interesting. A summary of the main structure and purpose of the online sessions is as follows:

- We still used a structure (I followed the tutorial, they corrected me), but only loosely, as a starting point, compared to the tutorials.

- The structure was open-ended as there were no requirements to exclusively adhere to what had been recorded in the video tutorial. Experimentation was not only possible but encouraged.

- This format was meant to support the exploratory goals of the project: what would happen and how would we interact and engage when we used digital technologies that could support the ambitions and desires of the participants?

### 5.2.1. GOING OFF THE SCRIPT: VIGNETTES FROM THE ONLINE SESSIONS

What follows is an overview of the second phase of the fieldwork, which consisted of six online sessions with Andreas, Thomas, and Jens, and took place between August 2020 and June 2021. I provide general outlines of the sessions and use vignettes to highlight key points pertaining to the focus of this chapter (i.e., differences that are registered between a mixed digital moulding process as a result of a PVT and an online-only digital moulding process). I combine sessions four and five, as they are effectively one conversation, split in two parts. Both follow a list of topics, prepared by Thomas.

The structure of each online activity was very much dependent on how each participant interpreted their digital ambitions on the day of recording, which means that the structures themselves were completely unique. However, they were all united by a principle of teaching and *going off the script*, where the participants were encouraged to indicate if and how they might want to build on the digital activities from phase one (e.g., everything taking place as part of the PVTs). The exploration of these ambitions, desires, and needs was then what would constitute the structure of each session. There was no pre-determined limit to the number of sessions we would have due to the open nature of the activities. Ultimately, school scheduling and work life ended up determining the total number of six sessions.

As mentioned, all six sessions saw the participants taking control of the structure of the activities. In contrast to the PVTs from Chapter 4, they could introduce more narrative and stylistic choices to the structure as this time they were not presented with

a strict script (e.g., Chapter 4, section 4.5.1, Figure 6.) but were expected to demonstrate more ownership in the process compared to the activities in Chapter 4.

While the online sessions were longer in duration, and there was more discussion, the main focus remained on the activities on-screen. It is for this reason that quotes are used sporadically in the vignettes presented later, and they mostly revolve around the visual representation of the activities (e.g., screenshots from the video recordings). This focus on visual material was chosen as verbal communication was not the main interest of the participants; the reason for seeking further contact and additional activities concerned digital practices. To that end, any verbal reflections were a benefit but not a demand of the research. However, focusing so much on screenshots can limit the interpretative scope of the data. Losing nuances from the data, in these cases, was inevitable. For instance, not engaging in a classic semiotic analysis deprives the vignettes of some depth. However, I chose the vignette format for precisely that purpose: to attempt to convey a richer picture of each session and thus communicate key points while remaining cognizant that other kinds of analysis remain an option for future engagement with the data.

A brief note on vignette as a method: they refer to "stimuli that selectively portray elements of reality to which participants are invited to respond" (Hughes in: Given, 2008, p. 918). I have chosen to use vignettes for two main reasons:

- They can be useful when exploring participants' "perceptions, attitudes, and behaviors in qualitative research" (2008, p. 918),
- "*Moving vignettes*" (2008, p. 918), which can use narratives and video extracts, e.g., PVTs from phase one, invite participants to react and reconsider prior choices and actions. The reflective potential of basing the online sessions on the PVTs opens a possibility for nuanced reflections and self-reflections from our participants.

### 5.2.2. ROBLOX STUDIO: RECREATING A TUTORIAL // ANDREAS AND THOMAS

Meeting Andreas and Thomas was an exciting moment because, due to COVID-19 lockdown restrictions, it was the first time in almost eight months that we had met and interacted. However, there were surprises from the very beginning.

Initially, the meeting was scheduled to be between me and Andreas, and last one hour over Zoom. I was to follow his Roblox Studio tutorial on creating a beautiful landscape. However, Thomas, who is a friend to Andreas, had decided that he would also join without telling me. This meant that I would no longer have the ability to follow the tutorial as intended with only Andreas there to guide and critique me. Further complicating the situation was the fact that Thomas had somewhat mentored Andreas in different programs, helping out when technical issues occur, creating

digital landscapes together, sharing them online, and generally engaging in the same socio-technical activities.

While we were setting up the online environment in Roblox Studio, we went over the roles for the sessions: I was following the tutorial and asking for help when necessary; Andreas was the principal tutorial co-creator and Thomas was supposed to simply help out if needed. Harry, their caretaker, was present in the room with Andreas and Thomas, but did not join the online activity.

Figure 21. Yellow circles mark the virtual presence of Andreas and Thomas inside Roblox Studio. The translucent objects allow virtual collaborators to see each other in 3D space

Once the virtual environment was prepared, I started following Andreas's video tutorial. Now, a few notable moments from the session:

- Thomas immediately took charge of the session, even though we were following Andreas's video tutorial. Thomas utilized a feature of Zoom where callers can take control of each other's mouse cursors on multiple occasions with my cursors, when it was easier to show me the location of e.g., a setting, than to explain it. Where the co-production process of a PVT was somewhat linear (e.g., we film and record, then we edit, then we collect feedback, etc.), this session was more hands-on, where three streams of activities took place simultaneously.
- Even though we agreed that Andreas and Thomas would generally correct me in recreating the tutorial, both immediately began creating parts of the landscape on their own. The question of realism emerged. We would spend time debating differences between pine trees and fir trees, and which ones would be realistically applicable to the scenario we have committed to.

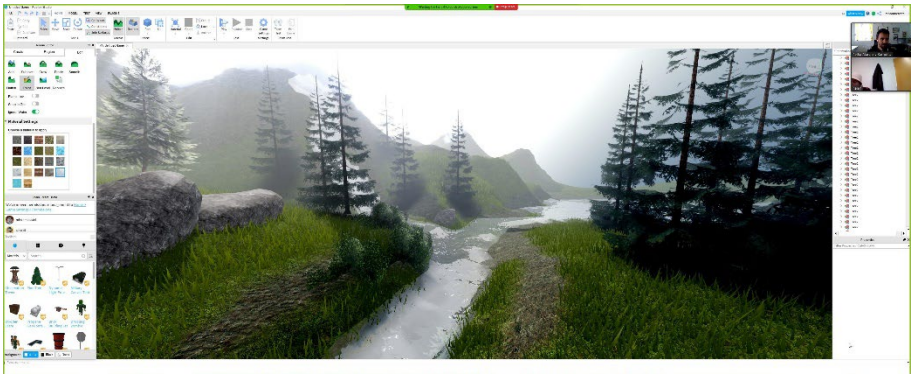


Figure 22. A view of the terrain we created by following Andreas' tutorial. Fir trees in a mountainous region surround a stream. Realistic water reflections and sun rays were a big point of focus

Both Andreas and Thomas have a keen eye for aesthetics. Visual elements like light reflections, realistic rock size and placement, etc., were important points of consideration for the two participants.

Figure 23. Researcher and Andreas's avatars, standing together by a river they made, enjoying the view

Another important aspect of this online activity ended up being the shared enjoyment and 'use' of the final result. While Thomas had to leave early, Andreas and I activated our Roblox avatars and took a stroll inside the result of the session. We ended up creating a ring of mountains with springs flowing from them and shaping a small island in the middle of the mountain ring, having fir trees and boulders all around. The scene was set with morning fog and was devoid of characters. Thus, Andreas' and my avatar could share a calm walk by the lake, where we said our goodbyes.

### 5.2.3. DAVINCI RESOLVE: TESTING THE LIMITS // JENS

During the filming and editing of Jens' PVT, he became interested in DaVinci Resolve – a video editing suite, - which was used by researchers and was unfamiliar to him. He had wanted to use a green screen and engage in video compositing (Chapter 4.6.3.), but was unable to, mainly due to a combination of the methodological approach and scheduling of the DiGi project. As such, meeting Jens online for the first time presented a surprise, as he had been working with DaVinci Resolve unbeknownst to me and wanted to share what he had learned. His technical focus was still engaged with green screen and video compositing, which was thematically explored in a zombie apocalypse scenario. Throughout the session we both applied what skills we had and, more importantly, together searched how to perform certain tasks (e.g., extracting objects from one video and insert them in another one, thus compositing a scene). All activities occurred simultaneously and enabled both of us to see each other's screens.

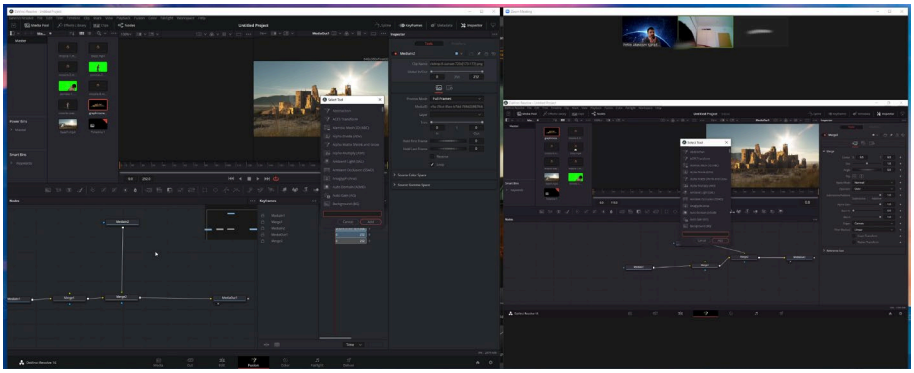


Figure 24. Both Jens and I are using local versions of the DaVinci Resolve program and are in Fusion – part of the program that deals with 3D modeling, animation, and video compositing

On the window to the left in Figure 24 is my instance of DaVinci Resolve, and on the right – Jens'. We are sharing each other's screens via Zoom, looking at each other's progress and talking about it as it unfolds or stumbles. In Figure 24, Jens and I are replicating steps for video compositing in DaVinci Resolve's Fusion section (where 3D modeling and animation can be designed) as seen in a YouTube video tutorial I had found online. The practical goal of the activity was to cut out an object/subject successfully and fully from one video and transfer it into another video.

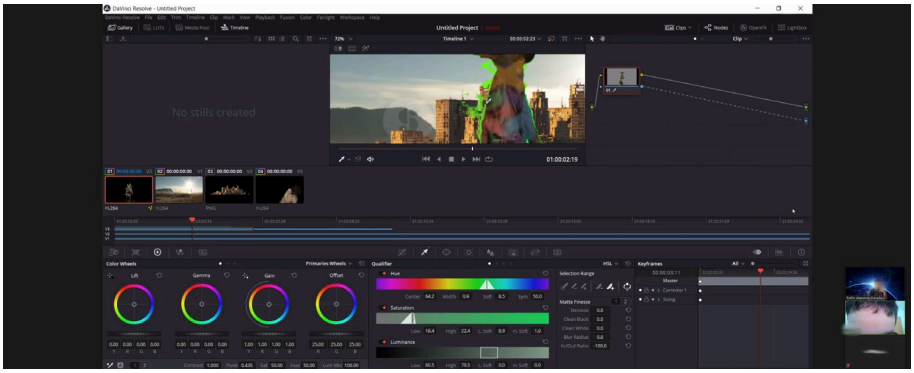


Figure 25. Jens is cleaning residual green spots from a video composit inside DaVinci Resolve's Fusion section

A key moment in this session related to the actual digital materials we had to use. As Jens had settled on a zombie apocalypse scenario, we had to find footage that he approved of, which would also be free. This led us to using whatever video worked and ending up with watermarks over the zombies Jens wanted to use. This increased the digital clean-up workload in the video editing process, as seen in Figure 25. It also forced us to search – in our own ways – for ever more efficient ways of cleaning up the footage, which contributed to an environment where everyone could be useful in teaching the other on how to use a somewhat new program.

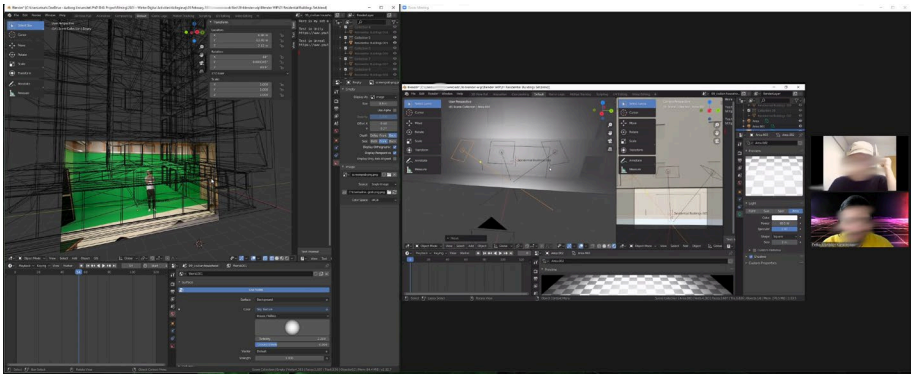
The session lasted for just over two and a half hours, and a considerable amount of time was spent searching for digital materials, a trial-and-error process of finding what videos work and what do not.

### 5.2.4. BLENDER + DAVINCI RESOLVE: TOURIST IN A CYBERPUNK CITY // THOMAS

In contrast with the previous two sessions, where participants and I would meet, and engage in a digital exploration process on the spot, this activity with Thomas was qualitatively different. Thomas came prepared with footage of himself he and his caretaker Harry had taken in preparation for the meeting. Months later I would find out from Harry, Thomas' caretaker, that the footage (see Figure 26.) was recorded in a room at the special school, which was usually reserved for staff to record educational resources for blind and deaf people. Due to COVID-19 and local lockdown measures, Harry could allow Thomas to "hijack" he room and play around inside with cameras.

Figure 26. Thomas being filmed in front of a green screen in his school, posing as a tourist with a camera

At the beginning of the session, Thomas outlined the objective for the day: he wanted me to help insert footage of himself as a tourist in a cyberpunk city, which he would create. One of the standout features of the activity was the collaboration between Thomas and me around questions for the actual design of the environment. What exactly does this cyberpunk city include? Do we have a virtual camera that moves between digital buildings, will the viewer ever go inside? Where do we place the footage of Thomas and why? Does he have a backstory to be there? Thus, we return to the focus of shared digital moulding, as it is the result of the session and not necessarily a finished and polished video result. While some of the choices we made may not be visible (e.g., Thomas being a tourist in an unfamiliar cyberpunk city, and being overwhelmed by it, starts to record it with his camera), it was important to discuss them and suspend our disbelief together, so we inhabit the same virtual space.



Footage 27. On the left: footage of Thomas in front of a 3D model a building. On the right: Thomas experiments with light sources to support a sense of realism

Digitally molding this space meant making very specific choices. For example, in Figure 27. Thomas and I discuss where to position his footage. The left screen shows Thomas walking by a 3D model of a building, stopping, taking out his camera and filming as a tourist would. The right screen shows different angles for virtual light to hit Thomas in front of the building. All these technical activities should not be perceived as flawless and taking place without issues. Dealing with problems is a central element of all online sessions, and this one is no exception. With a running time of just over three hours, there were plenty of issues to solve, as demonstrated in Figure 28.

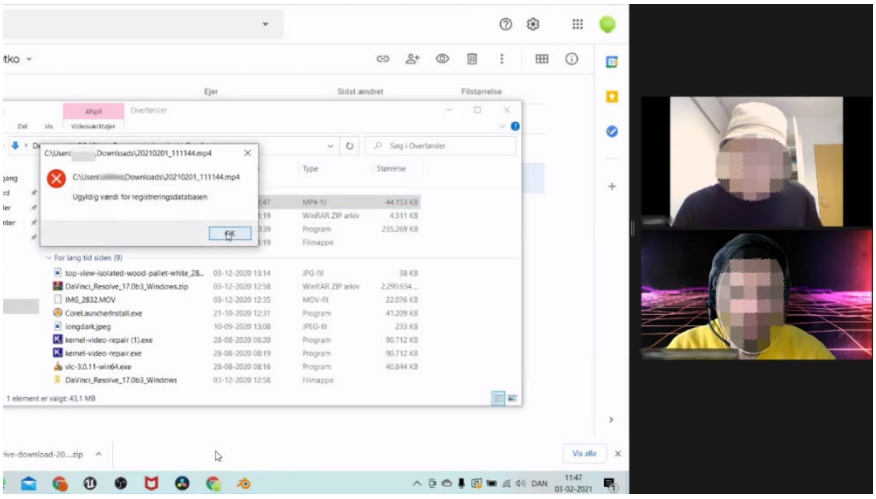



Figure 28. Thomas and I troubleshoot a technical error with a video file

Thomas suddenly received an error message when managing a video file and the error code describing the issue was not helpful, so both of us engaged in troubleshooting, until we could continue using the file. As Thomas' system was in Danish, we had to use a translation function from Google Translate to first convert the error message to English, and then decipher what the message actually meant in practice.

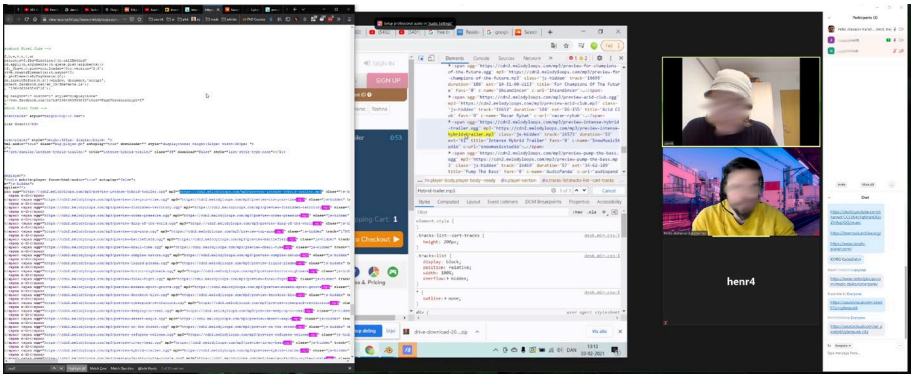



Figure 29. Exchanging technical tips and tricks on how to find an embedded audio file in a webpage

Throughout this session, Thomas was teaching me how to use Blender much more than I was sharing knowledge on how to use DaVinci Resolve, as he had already tried it on his own. However, a principle of reciprocity is always important, which is why relevant tips and tricks must be shared at all times. For example, while searching for an appropriate music to go along with the cyberpunk theme, Thomas stumbled upon an audio file in a website, but there was no obvious way to download it. In Figure 29 I share how to use a developer tool in the Firefox web browser to confirm if this audio file is available for download, and then collect it, which Thomas found quite useful.

Jens' storyline of a zombie apocalypse in 5.2.3. had a singular, dominating focus: to play around with and use video compositing. In this session with Thomas, the exploration of digital technologies was more diffused and with twists. Thomas also used video compositing, but in this case to insert *himself* into a scenario he created. Thomas and I also solved technical issues, but instead of staying with the technical solution, we engaged in a conversation about the meaning of language while using Google Translate and searching for error descriptions (Figure 28).

### 5.2.5. TALKING POINTS IN TWO SESSIONS: THE LONG AND SHORT OF IT // THOMAS

During the cyberpunk city exploration (5.2.4), Thomas and I exchanged a lot of practical tips – he taught me how to work with 3D objects in Blender, and I taught him how to composit videos in DaVinci Resolve. Developing that rapport contributed to the desire to continue exploring interesting themes. Thus, the following two sessions – in March and May 2021 – were directed by Thomas and entirely revolved around a list of discussion topics that were important for him. The list changed between the two sessions. Figure 30 shows the first part, which Thomas had prepared and shared with me for the March 2021 meeting:

1. - My experience with core
2. - Little nightmares 2
3. - Story in video games
4. - Techno anthropology
5. - What job do you want after you are done studying
6. - World building?
7. - Bear note app
8. - How have you been
9. - Tell me more about Bulgaria
10. - Hunt showdown
11. - Rick and Morty
12. - Show a little more gumball?
13. - I met an Indian girl in here in Denmark and she spoke Danish rather well
14. - The last of us 2
15. - Year walk
16. - Sea of thieves
17. - Have you ever been around Europe?
18. - Resident evil 8

Figure 30. Part one of a discussion list prepared by Thomas.

While the previous session (5.2.4) still had a somewhat standard structure (i.e., meeting to create a specific digital environment and place footage of Thomas in it), the March and May 2021 meetings were much more open-ended. As evidenced by the discussion topics prepared by Thomas in Figure 30, the field of interests has been greatly expanded from strictly technical questions about software practices in, e.g., sections 4.6.3. and 5.2.4, to an exploratory discussion focused on personal questions and interests. For example, Thomas asking about my personal (point 9.) and academic (point 4.) background, and willing to discuss the origin story of the online moniker he uses (point 15.). As a result of this open-ended approach undertaken by Thomas, a boon of additional topics emerged during these sessions, which I have compiled in the following table:

Table 5. Summary of talking points and notable characteristics in the March 2021 session with Thomas

| N | Topic | Theme | Notable characteristics |
|---|---|---|---|
| **1** | Metahumans (3D modeling software) | Digital manipulation | Ease of access to software and ease of use |
| **2** | The Amazing World of Gumball (TV shows) | Animation | Feelings of belonging, ”real family”; realism |

| | | | |
|---|---|---|---|
| **3** | Two Minute Papers (YouTube channel) | Knowledge sharing / Style | Preferred format of communication |
| **4** | Pinterest (image-based platform) | Visual inspiration | Broad access. Repository. Compilations and collections. |
| **5** | Den Skylding (Movies) | Conveying feelings | Using light to ”transport” viewers |
| **6** | Night in the Woods (Video games) | Relaxing | Being ”in the middle of nowhere”, headspace |
| **7** | What Remains of Edith Finch (Video games) | Deep experience | How to visualize humanity? |
| **8** | Firewatch (Video games) | Aesthetics | Story-driven? |
| **9** | Pirates of the Caribbean (Movies) | Realism | Davy Jones character – most realistic. What’s the role of stories? |
| **10** | 3D scanning | Tangibility | 300 photos into a 3D scanner? |
| **11** | Gravity Falls / Game of Thrones (TV shows) | Emotions | The ability to change someone’s perspective when they watch something |
| **12** | Game Maker’s Toolkit (3D modeling software) | Design | Technical knowledge on game development |
| **13** | Resident Evil VII (Video games) | Emotions | Setting the mood; good storytelling and visuals. |
| **14** | Outlast 2 (Video games) | Realism | The realism of fear |
| **15** | Garage Band (Music generation software) | Music and enjoyment | Thomas got a ukulele |

A fairly balanced division between types of topics can be seen: four topics generally related to software, four - to television series and movies, five - to video games, and two to internet platforms. One of the major standouts in the discussions emerged from topic two, concerning *The Amazing World of Gumball*.

Figure 31. Thomas shares an episode of the TV show "*The Amazing World of Gumball*" via Zoom

Presenting the show, Thomas called it his "favorite series", because it combined "nostalgic, real pictures in the background" referring to the realistic animation of the grass, buildings, and sky, as seen in Figure 31, with cartoon characters. When he watches it, Thomas said that he "feels normal" and part of "a normal family". Later in the session, after discussing various types of software, TV shows and movies, Thomas appeared to connect some dots between the content he enjoys and the tools at his disposal, with regards to a main reason that drives him to develop his digital skills. He talked about a specific, almost indescribable feeling he gets when he enjoys content (e.g., TV show, movie, game) that holds special meaning for him. Thomas continued to refer to this difficult-to-verbalize sensation, saying:

> I want others to experience that, to get that [feeling – note, author] from a single scene, single picture. […] It is hard to share feelings. The only way to do it is to talk about it. I want to visually share them, if you can even do that. To create a scene where most people get the same feeling from, mystery, fear". (Transcriptions from field notes during the March 2021 session)

This line of discussion opened up questions about how Thomas thinks about self-expression and sharing his experiences so that others can "get the same feeling" from them. At one point during our conversation, Thomas shared that he was creating 3D models and YouTube videos, not only so others could experience what he felt, but

also because he had “no one to talk to about IT” in his immediate environment, apart from Andreas, his caretaker Harry, and to a lesser extent Jens and his father (transcription from field notes during the March 2021 session). Thomas’s desire to create for and share with others will be expanded further in Chapter 6, section 6.4.3.2. Staying with this online session, however, it is important to mention that sharing these feelings is not an easy and straightforward process. When talking about digital creation, specifically 3D modeling, Thomas says that:

> [T]here is always something that fails, there is always a syntax error, and at some point, I just can’t take anymore fails. You give up and do something easier that you do not fail at. If you push through the errors and finally do it, it is very rewarding. (Transcriptions from field notes during the March 2021 session)

Solving the technical error in Figure 28 and exchanging tips and tricks on finding audio, and more (Figure 29) are examples of shared experiences that make similar feelings of failure easier to deal with.

The March 2021 session lasted more than two hours and fifteen minutes, which was not enough to go through Thomas’ initial list. That is why days later he reached out via a chat platform called Discord, where he had expanded the list of topics (Figure 32) and shared it with me as a preparation for the next meeting taking place in May 2021.

```
Hey another thing here. If you want that list i wrote of
questions/things i want to show you can have it here. We can
always go over anything again if you want a better answer haha.
The plus is what we already talked about and the minus is new.

# Talking points

+ Metahuman ue4
+ Gumball universe
- My experience with core
+ Mit hjemland af Petko
+ Pinterest
+ GarageBand
- Little nightmares 2
- Story in video games
- Techno anthropology
+ Two minute papers
+ Outlast 2 (school floor layers of realism)
- What job do you want after you are done studying
+ Resident evil 7
+ Game maker's toolkit
- World building?
+ The wonders of green screen
+ Next time you come too aalborg
+      has been doing some video editing
+ Game of thrones
+ Music can inspire you (got, king falls)
+ Setting the mood like in king falls and and firewatch
+ Movie about alarm centralet i dansk
+ Gravity falls
+ Do you have time to play video games
+ 3d scanning
+ Firewatch
+ Pirates of the Caribbean
+ Davy jones
- Bear note app
- How Have have you been
- Tell me more about bulgaria
- Hunt showdown
- Rick and morty
- Show a little more gumball?
- I met an indian girl in here in denmark and she spoke danish
rather well
- The last of us 2
- Year walk
- Sea of thieves
- Have you ever been around Europe?
- Resident evil 8
```

Figure 32. Expanded discussion list by Thomas

The list in Figure 32 includes both new topics (marked with "-"), as well as March 2021 topics from Figure 30 and themes that emerged during the course of the session marked with "+". (e.g., "Next time you come to Aalborg", where Thomas and I talked about potential future meetings, and "The wonders of green screen", where we spent time watching and commenting YouTube tutorials on how to work with green screen). I am including this list to demonstrate how digital exploratory sessions can expand to cover many unplanned topics, thus allowing researchers and professionals another avenue to connect with a neurodivergent population. As tangential evidence to support my claim that following an exploratory digital perspective can open up new ways of connecting with the participants, I will point out that while the March 2021 session lasted for two hours and fourteen minutes, the May 2021 session took three hours and 12 minutes.

### 5.2.6. DAVINCI RESOLVE: BUILDING UP // JENS

The final online session from phase two of the fieldwork took place in early June 2021 between Jens and me. It came as a continuation of a short conversation Jens and I had in May 2021, when we spoke for 10 minutes prior to my session with Thomas, organizing the June 2021 meeting. At that point, I asked Jens how he was doing, he took a pause and said that he was "trying to survive" at school, as dealing with the COVID-19 restrictions and his own issues was not easy for him (transcriptions from May 2021 session). Seeing as lingering on this topic would be uncomfortable, we moved on to the activities for the day. In contrast with his September 2020 session, he had come prepared with digital footage and a plan. In a 2022 phone interview with Harry, I would find out that Jens was inspired by Thomas using the green screen room from 5.2.4, and had created a plan of his own.

In this final session, Jens developed his digital ambitions going back to the participatory video tutorial sessions (Chapter 4.6.3), and wanted to further build up his video compositing skills, this time using footage of himself instead of not zombies. Jens had emulated Thomas' approach and adapted it to his interest, showing how in-person collaboration can influence the pursuit of digital ambitions and aspirations.

Figure 33. Jens stands completely still while Thomas puts a remote control in his hand. Jens will start moving once Thomas is out of frame, and the end result will be cut in video

Jens' plan for the session was to have footage of himself inserted into a Danish television program where he would interact with a newscaster by using a remote control to freeze-frame and restart him.

To achieve that, Jens had enlisted Thomas for assistance. In Figure 33, Jens acts out a freeze frame, so Thomas can quickly place a remote control in his hand, which Jens will use to interact with the newscaster. Thomas will be removed in video post-production.

Figure 34. Jens is seen entering a frame from a Danish news program, holding a remote control

Yet again, this session did not have the goal of producing a finished, polished result in the form of a video file, but rather to push the limits of our technical abilities. The process of shared digital moulding is made visible in Figure 34. It shows the DaVinci Resolve video editing program running on my computer and the Zoom video conferencing program (green and red rectangle above the Danish newscaster) on the top of the screen, indicating that Jens has taken control over my mouse cursor, manipulating the video footage. That was necessary as while we were working in parallel, I had reached a place in the editing process that Jens wanted to directly interact with.

Finally, this session ended up being the longest one, lasting three hours and 21 minutes, and could easily have spilled into another meeting. However, due to scheduling issues, we were not able to pursue a second session, which leads me to the next section.

### 5.2.7. ENDING DATA COLLECTION

As evidenced by the increased duration of the online sessions in comparison with the in-person meetings (average time of the PVT sessions is 50 minutes, where average duration of the online sessions is more than double, at 140 minutes), data generation in a digital environment can grow substantially. That is a major reason why having a plan on how to end data collection is important. A potential weakness in my approach was that I did not have a plan on how to stop the collection of data, mainly due to the developing nature of the digital relationships between me and the participants.
The first phase of the fieldwork ended in January 2020 and the outbreak of the COVID-19 pandemic made the question of data collection irrelevant for a while. Renewing efforts in 2021 through the second phase of the fieldwork could have benefited from a structured approach to generating data and ending the sessions. However, I remained open for further contact with the participants and did not formally end the prospects of meeting again. A main result of this approach was that I remained in sporadic contact with participants over Discord, and kept Harry, their caretaker, informed on the general topics of discussion. I consider these conversations as supplementary data, which I later refer to in Chapter 8.

## 5.3. WHAT DOES THE FOCUS ON ONLINE SESSIONS POINT TOWARD?

As indicated earlier, the results of the fieldwork presented in Chapters 4 and 5 concern the same practice: the shared process of digital moulding. Specifically in the context of the current chapter, digital moulding refers to the interactions in an online space where the researchers and participants can simultaneously look at each other and their screens and can interact with each other's digital tools from a distance. The directness of the contact is different as the shared digital moulding process is inescapably front and center compared to physical sessions where someone else's presence can distract or otherwise have an effect on participants. Another feature of this chapter is that it deals with the data gathering transition from in-person to online-only environments. The digital environment repositioned how we interacted with our participants and what they felt they wanted to do. Additionally, the previously established rapport, build-up of ambitions, and desire to play, experiment, and learn all played a special role in the change in behavior. They also led to questions about what we could co-create together that would be different from the PVTs. Pursuing the answers to these questions highlighted the importance of sharing exploration and co-creation, as well as perceived failures and low points. It is critical in an online context that researchers and participants experience the same activities simultaneously, perceive them differently, and use that difference to propel future activities. Such pursuit helped contribute insights regarding how the participants used online spaces to reframe new social relations around ambitions that would otherwise be difficult to address. The questions of precisely what we did together, how we co-created and learned from each

other, and what social relations emerged from this process were explored in the online sessions:

- The social relations between the participants and researchers became more nuanced as they evolved in a thirdspace (see Chapter 6).

- The social relations between each participant and their counterparts changed after the introduction of new tools by the researchers. This insight supports the openness to new platforms showcased in Field Study 1, where we observed that the participants moved from one platform or tool to another fairly effortlessly. We saw this flexibility at play when their engagement was supported by the researchers.

- The social relations between the participants and non-participants highlighted a lonely picture: almost no one to "talk tech to," Jens's "not doing well," Thomas watching Gumball for "reality" and "family."

Digital activities have a different and often lower barrier to engagement compared to physical and offline activities as they rely on existing tools, which in our case were either owned by the participants or made readily available by the institutions. Without replacing them and without playing the role of a "crutch" that supports traditional, well-known, and well-received in-person sessions, the setup and number of options for digital activities can be far less taxing than setting up physical activities. Digital activities represent an area of participant engagement with neurodivergent youth that is far less explored, researched, and developed in comparison with traditional, in-person engagement. Doing more activities digitally could be beneficial in highlighting what needed to change and how in order to support and improve the offline lives of our participants. For example, digital explorations of interests can reveal less explored areas in need of support (e.g., by creating a virtual scene that offers a participant's feelings directly and visually to a willing viewer) and can be used by caretakers.

An important methodological note for professionals using digital activities in online sessions with neurodivergent participants concerns the following:

(1) **Lower barrier to entry.** In this, as well as the previous chapter, I demonstrated how we used existing tools (e.g., smartphones, game consoles, Chapter 4, section 4.5.3; Zoom; free and open-source software, Chapter 5, sections 5.2.2–6) in a manner that invited active participation from the neurodivergent students and residents.

(2) **The importance of sharing a struggle**. In the last two chapters, I provided examples of how simple technological struggles shared between the researchers and participants allowed the researchers and caretakers to more accurately pinpoint needs that were difficult for the participants to express

offline and to create spaces for the participants to react to those challenges on their own, should they want to. These included Jens and Carl's dissatisfaction due to difficulties in adequately visualizing and narrating their plans (Chapter 4, section 4.6.2), and Thomas's efforts to co-create a virtual environment and "feeling" that other people would be able to experience as well (Chapter 5, sections 5.2.4–5).

(3) **Utilizing virtual space.** Building on comparatively short in-person sessions (approximately 50 minutes for our activities) with online activities resulted in more than double the time on average spent in the virtual environment (approximately 140 minutes for online sessions). While virtual space on its own is unlikely to have caused the increased duration of the activities, diverse activities online can contribute to a desire for active engagement. It is important to explicitly state that we did not utilize virtual spaces as replacements or substitutes for engagement, nor did we use them as methodological crutches. These spaces were unique in the type of technological skills (section 5.2.3.), personal initiatives (sections 5.2.4–6), and reflections (sections 5.2.3 and 5.2.5) that they supported.

Ultimately, we found that the online sessions provided a different practical engagement and insights with regard to the desires, aspirations, and ambitions our participants might have had. In practice, the neurodivergent participants could be experts in this space as there was less stress due to the lack of physical contact on the one hand, and virtual spaces being much more familiar to both the researchers and participants than physical spaces on the other. The main takeaway from this observation is that online sessions were underutilized as far as our active participants were concerned. This was based on reactions from the participants, who said that they had almost no one to talk to about their digital skills, desires, and ambitions. Having access to technologies, which were social in practice (if not by design), only intensified the need for shared socio-technical experiences. Institutions and the professionals working there should not miss out on (or, worse, ignore) the effects that access, use, play, and development via creative technologies offer to neurodivergent youth. Based on my examination of creative technologies (e.g., devices that can run software for digital creation, like laptops with 3D modeling software or smartphones capable of creating, manipulating, and sharing visual materials) from a socio-technical perspective, I propose the term "ambitious technologies" as a way to encompass all the software and hardware I saw our participants work with that supported their active engagement in digital creation processes. In the case of this specific fieldwork, I define ambitious technologies as free-to-use or low-cost mainstream types of software (e.g., Blender, Roblox, TikTok, free-to-play games) and powerful enough, easily available hardware that has been adopted by large groups to create/express a creative vision (e.g., smartphones, tablets, laptops, desktop computers, and VR devices powerful enough to run the aforementioned software without frustrating their users with slow speeds). The conceptualization of ambitious technologies and their use in

digital interventions can be an opportunity for social relations and social participation to be strengthened for neurodivergent youth.

How exactly the technologies used by these young people and researchers can be better conceptualized in useful ways for professionals and researchers will be discussed in the following chapter, which deals with the question: what kinds of insights can we look toward when combining in-person and online sessions in a single digital intervention process?

# CHAPTER 6. ENGAGEMENT IN HYBRID CONTACT ZONES

This chapter refers to and builds on the ideas that are described in greater detail in a 2022 draft paper co-written with the DiGi project leader Professor Anne Marie Kanstrup from Aalborg University, Professor Margot Brereton from the Queensland University of Technology in Australia, and Associate Professor Jacob Gorm Davidsen from Aalborg University.

> "*The problem was simple: we did not understand each other. We were not communicating; we did not yet have a contact zone entangling each other.*"
> – Donna Haraway (2008, p. 215)

Throughout the fieldwork for this project, we could interact with the participants in a variety of ways, situations, and contexts. The more meetings we had, the less interested I was in how the participants were responding to formats that they had not actively created, and the more curious I became about the socio-technical configurations that allowed us to engage each other in a liminal sense (i.e., in scenarios beyond a somewhat clear methodological "script"). What stood on the other side of the participatory video tutorials (PVTs) and online sessions? Where would we find ourselves if we followed the interests and ambitions of our participants, not simply as researchers looking for data, but as learners who could offer co-producing assistance if and when needed by them? We never had a predetermined result in mind when setting the research goals. I never had an idea—either specific or vague—about the ultimate outcomes of the project as the goals evolved after each session. The more in-person and online-only sessions we had, the more important and interesting it became to ask: what practical engagements could become possible as our digital intervention approach consciously moved from a normative-epistemic register (where we set specific PVT frameworks but welcomed reconfigurations by our participants without making it easy, obvious, or even desirable for them to do so) to an epistemic-normative one (where the main focus was on open-ended, exploratory sessions that were co-constructed by our participants)? Even with all the good intentions at the beginning of the project on how open and supportive our approach would be toward the young participants who lived with cognitive and developmental disabilities that we could never experience or fully understand, in practice it was not obvious how to actually structure digital interventions that did not have a fundamental normative structure and ethos.

If we wanted to contribute knowledge on how digital interventions could support social relations among our target group, we needed to move away from the normative and into a more epistemic frame of engagement. The online-only sessions (Chapter 5) were one such attempt and worked in a more focused way with the participants' digital

aspirations, ambitions, desires, and needs. In that sense, I started exploring the potential of digital interventions as a supportive technique for what Wobbrock et al. (2011, 2017, 2018) called "ability-based design," where we entirely stopped considering the cognitive conditions we could only hope to acknowledge respectfully and productively and abandoned any hope of embodying or learning enough about them in time. It bears repeating that while in a Danish context the term "cognitive disabilities" (*kognitive handicap*) is still in use, researchers like Wobbrock et al. (2011) have argued that "one cannot have disabilities in the same way that one cannot have 'dis-height' or 'dis-money.'" Thus, it did not make sense to have the medical and cognitive diagnoses of our participants play an outsized role in the project. Instead, their digital and technological abilities were always more interesting. As described in Chapter 4, taking these abilities as a starting point allowed us to focus more on exploring their skills and pursuing their digital interests, which were not easily catered for in the physical settings at any of the participating institutions. In this chapter, I expand on how this exploration provided a more natural avenue for bumping into technical issues and thorny questions about self-worth and testing one's problem-solving skills. I also further explain how an expert–learner approach (where our participants were the experts, and we were learning how to exchange practical knowledge) can support strategies for addressing said issues.

These socio-technical configurations cannot be taken for granted. The entanglement of technical knowledge, ambitions, and social needs in a neurodivergent context and a research or caretaker's interest in developing and continuously enhancing support strategies and practices cannot be expected to unfold at all times and in all places. However, observing the activities described in Chapters 4 and 5 raised questions regarding the characteristics of environments that could be supportive of our participants' digital activities. Where do these environments exist? Under what socio-technical configurations do they become conducive to active engagement between researchers, pedagogues, and neurodivergent youth, all of whom may share a physical space but are forever separated by the inability to embody each other's worlds? A particular type of contact zone—a hybrid contact zone (HCZ)—can provide an answer to these questions. To that end, I use this chapter to explore what they are, how and why they helped illuminate my fieldwork and its practical implications, and what insights could be gained from them regarding the engagement and support of digital practices for our neurodivergent participants.

## 6.1. SITUATING CONTACT ZONES

The notion of a contact zone in human–computer interaction was discussed by Maja van der Velten (2010), who wrote that

> [the] concept of contact zone . . . explore[s] the space in which different knowledges meet and are performed . . . where knowledge systems [do] not

> meet as hegemonic wholes, but are relationally constituted, as such open for establishing new relations. (p. 11)

This generative perspective creates practical and conceptual space for the moulding of shared digital practices (both in physical and online environments) that can be situated and unfolded in a contact zone for the exchange of digital skills. Donna Haraway (2008) complicated the idea of contact zones by specifying that it "treats relations in terms of co-presence, interaction, interlocking understandings and practices, often within radically asymmetrical relations of power" (p. 216). While the power perspective is a somewhat intuitive idea to consider with respect to contact zones as they are necessarily a place of meeting for disparate and unequal participants, it is the terms "co-presence" and "interlocking understandings and practices" that stand out as clarifying characteristics of contact zones. These two descriptions alone paint a complex picture of a contact zone, where relationally emergent knowledge systems interact in flux and from unequal places of power.

Expanding further on the position of the contact zone, Haraway (2008) drew on her knowledge and interest in biology: "I remembered that contact zones called ecotones, with their edge effects, are where assemblages of biological species form outside their comfort zones. These interdigitating edges are the richest places to look for ecological, evolutionary, and historical diversity" (p. 217). Bringing into view the edge figure of a particular type of contact zone (in this case, an ecotone, which describes a *transition zone*; Hatvany, 2009) prevents us from looking at contact zones in a two-dimensional way. Instead, it allows us to consider them as fuller conceptual objects on whose periphery the mixing of assemblages happens. Further on in section 6.4.1, I will make the case for a particular type of transition area in an HCZ, namely, a digitone, where different technological and cultural practices mix to offer a wealth of interactions between participants (as experts and co-producers) and researchers (as learners and co-producers). To reach that point, however, I first need to situate the idea of a contact zone.

### 6.1.1. SITUATING FROM A SPECIFIC PLACE

The ideas regarding contact zones that I have presented so far may appear to be detached from any specific location. Haraway's (2008) mention of *ecotones* grounds them in a somewhat clearer space (that of transitional biological areas), and her prior work *Situated Knowledges* (1988) offers another useful consideration: a critical perspective on where these contact zones are positioned and what is visible from that arrangement. When discussing positioning and keeping Haraway's work in mind, it is helpful to refer to her classic coinage of the term the "*god trick*," which is a critique of a type of detached, almost disembodied scientist and designer, who sees "everything from nowhere," and a broader, deeper comment on how vision itself in science is "tied to militarism, capitalism, colonialism, and male supremacy – to distance the knowing subject from everybody and everything in the interests of

unfettered power" (p. 581). These considerations influenced the contact zones that I explore in this chapter as zones that were positioned clearly (1) in the classrooms and common rooms in the participating institutions and (2) in a shared virtual environment mediated by a video conferencing platform, which allowed for the shared and reciprocal control of the participants and researchers' technological tools. The contact zones I refer to also have a hybrid character (i.e., enmeshing physical and digital environments) and operate with and within diffused power relations (e.g., relinquishing control of the form and function of the online activities, as a researcher, in pursuit of offering support and not guidance). As such, I drew inspiration from Haraway's (2008) work to propose a specific configuration of an HCZ, which I elaborate on in detail later; one that is situated in the need to explore what happens when neurodivergent participants pursue their interests in digital technologies from positions of expertise (they are experts in what they do) and control (they could and did shape the format and content of the activities, as well as initiate the entire second phase of this project's fieldwork).

Another impactful contribution to the question of positioning and situated-ness comes from the exhaustive work by Teun Zuiderant-Jerak (2016) and his sociological interventions and investigations into "quality improvement and cost efficacy in Dutch hospitals" with the aim of intervening "in the management and doing of health care *in situ*" (Winthereik et al., 2016). The fieldwork presented in Chapters 4 and 5 was conceptualized as a digital intervention. As such, Zuiderant-Jerak's insights were quite helpful in positioning the intervention's role in a process of engagement (i.e., how to intervene in a specific situation). One way in which Zuiderant-Jerak defined a situated intervention was as "the result of a reconfiguration, not an intention set to bring in 'the new' or to 'fix' problems in the current health care system" (2016, p. 75). This understanding applied to our digital interventions on two important levels:

- Situating the digital interventions in the reconfiguration of the existing socio-technical practices engaged in by our participants. While we introduced specific digital tools, which were unfamiliar to our participants (e.g., video editing software), their purpose was anything but. Video editing was a well-understood practice by all the participants.

- The specific type of contact zone I propose in this chapter is not a space focused on facilitating ready-made solutions, but rather a space for exploration and play. The reconfiguration of existing knowledge and skills needed to happen in a manner preferred by our participants: not as a school lesson or dry research data-gathering activity, but as a creative outlet in which fun and play had their place.

No interventions or explorations can occur, however, without engagement between all the relevant parties. Here, I refer to Zuiderant-Jerak's (2016) focus on two different forms of engagement: the first "is about the engagement of social actors – patients,

nurses, doctors – in healthcare practices. The second is about sociology's engagement in attempting to change the world" (p. 76). The focus of this thesis is engagement with participants living with cognitive disabilities, caretakers, and support staff. Additionally, the thesis engages existing techno-anthropological approaches to digital health and health work with methodological approaches involving video recording, editing, analysis, and direct digital co-creation, as opposed to existing practices of distanced, somewhat detached digital mapping and data collection.

For Zuiderant-Jerak (2016), a ". . . situated intervention is [an] intervention situated in issues. When problems emerge, an in-between space opens up, one where different actors (say nurses and doctors) are brought into relation" (p. 76). I have been influenced by this way of thinking as it helps highlight a simple fact: the importance of digital practices for our participants was such that it opened an in-between space for actors like us, the researchers, to be brought into contact with the abilities and needs of the target group. However, I need to complicate the matter by foregrounding the fundamental communication challenges that almost entirely comprise the social relations our participants consider as their normal everyday lives. Society has deemed that they require almost constant professional support and will continue to do so in certain forms throughout their lives (i.e., with housing and municipal interactions and questions of labor, education, and broader socializing). As such, the mere sharing of issues becomes a problem: how is a teenager living with ASD, for example, supposed to express what they feel to be problems? Verbally? Only in their mother tongue? Only to official caretakers? Maybe in a written form? Or via some technological channels? And how do they modulate their concerns to be best understood by an unknown recipient?

A better attempt can be made to address these questions if the answers do not rely solely on one side, be that the target group or their caretakers. The in-between space, identified by Zuiderant-Jerak (2016), which influenced my conceptualization of a specific type of contact zone (see section 6.3), could benefit from a diverse set of communication approaches occurring at the periphery of the contact zone (e.g., setting up one-on-one online sessions and exploring individual use cases). This in-between space could also avoid calcifying communication in a rigid institutionalized structure (e.g., Magnus in a special school, pre-planned activities in a sheltered residence) by offering intuitive ways for researchers and caretakers to engage as learners, thus shifting the power dynamic.

In their review of *Situated Intervention*, Winthereik et al. (2016) pointed out that "for Zuiderant-Jerak, [an] intervention is a way of getting involved in issues (i.e., the quality of care*)*" (p. 76), which describes well how digital interventions coalesce into a specific contact zone and become involved in particular issues. An example from our study is the emergence of a PVT as a digital intervention that addressed the issues and needs written out by our participants and engaged them in video tutorial production, which thus allowed us to get involved with the issues.

## 6.2. FROM SESSIONS TO ZONES

After completing the two phases of fieldwork, I was able to start looking in a different way at what had occurred and how. The totality of the collected data demanded a more serious look at the work we had co-produced and how it had taken us to places in which we had discussed issues, ambitions, and desires and co-created unexpected things. This is why I began to consider the idea of zones as a concept that would allow me to see different aspects of the fieldwork and to re-evaluate our work. To start on this path, I used Mary Louise Pratt's (1992) book *Imperial Eyes: Travel Writing and Transculturation* as it offers a fundamental definition of the contact zone and guided my thinking:

> One coinage that recurs throughout the book is the term "contact zone," which I use to refer to the space of colonial encounters, the space in which peoples geographically and historically separated come into contact with each other and establish ongoing relations, usually involving conditions of coercion, radical inequality, and intractable conflict. I borrow the term "contact" here from its use in linguistics, where the term contact language refers to improvised languages that develop among speakers of different native languages who need to communicate with each other consistently, usually in context of trade. Such languages begin as pidgins, and are called creoles when they come to have native speakers of their own. Like the societies of the contact zone, such languages are commonly regarded as chaotic, barbarous, lacking in structure. (2008, p. 6)

Somewhat obviously, it would not make sense to follow Pratt's specific use of contact zones as spaces of colonial encounters in the context of this thesis as the binary opposition of proverbial colonizers (local society) and proverbial locals (the neurodivergent target group) has no antagonistic or exploitative elements in a Danish context, but rather the exact opposite: Danish society strives to value the dignity, autonomy, rights to self-expression and determination, and rights to assistance for the target group. There exists, simultaneously, a distinct history of tensions that define how neurodivergent people relate, find their way, and adapt to the broader, neurotypical society. As noted in Chapter 2, the Danish advocate for the rights of persons with intellectual disabilities Niels Erik Bank-Mikkelsen formulated the so-called "normalization principle" in the 1950s (Svendsen, 2006). The subsequent and long-lasting struggle by social groups to enact this principle speaks to the shifting position of neurodivergent populations in a 20th-century Danish social context. One specific characteristic of contact zones I would like to highlight here concerns the following quote by Pratt:

> In writing this book I have tried to avoid simply reproducing the dynamics of possession and innocence whose workings I analyze in texts. The term "transculturation" in the title sums up my efforts in this direction.

> Ethnographers have used this term to describe how subordinated or marginal groups select and invent from materials transmitted to them by a dominant or metropolitan culture. (2008, p. 5)

While decades-long policies and thought have developed with the explicit goal of supporting and assisting people from marginal groups, and specifically neurodivergent populations in Denmark, Pratt's use of *transculturation* is still relevant in the current thesis. It characterizes a particular type of contact zone, *the HCZ*, which directly addresses issues of dominant and marginal cultures (via questions of power) and positionality (were the participants in our study closer to a dominant cultural narrative or a marginal one?). Pratt elaborated a bit further: "While subjugated peoples cannot readily control what emanates from the dominant culture, they do determine to varying extents what they absorb into their own, and what they use it for. Transculturation is a phenomenon of the contact zone" (2008, p. 6). As I have shown in Chapters 4 and 5, not only did our participants determine what to absorb (actively or passively) from the local and global cultural codes (e.g., joining a global style of video creation for the social media platform TikTok in Chapter 4.6.1), but they were active in a transculturational sense by developing and broadcasting their own formats, narratives, and interests. Examples range from Thomas's tourist in a cyberpunk city (Chapter 5.2.4.), where Thomas decided on the format (3D modeling + video editing), and narrative (tourist—a type of explorer—wandering around an unfamiliar yet enticing cyberpunk city), as well as how and with whom to share his interests (in this case, enlisting help from both his caretaker and me). I contend that the data presented in Chapters 4 and 5 demonstrates how neurodivergent, socially vulnerable populations do not simply consume, but actively take the lead in producing transculturational experiences and engaging participants outside of their immediate social circle with them. In the next section, I expand on how an understanding of HCZs can be beneficial for support staff and researchers engaging with the target group.

## 6.3. HYBRID CONTACT ZONES

What makes the contact zones I presented earlier "hybrid" in the context of this thesis? The main reasoning behind this term refers predominantly to the collaboration between the differences in the experiences of the participants and the researchers, which were impossible to overcome. The mixture of these different worldviews through physical and digital environments describes the hybrid nature of the contact zones we inhabit.

### 6.3.1. DEFINITION

To further clarify the idea of HCZs, I provide the following definition: HCZs are socio-technical spaces that incentivize the interplay of social conventions and technological practices between disparate collaborators and act as translation zones where difficult-to-verbalize needs and ambitions can be explored via digital

technologies. Further, they mediate the interplay between said social conventions and technological practices through technical activities, which shape all the interactions and narratives within them, and where the inherent inequality between the participants is complicated by shared interests in each other's digital skills.

### 6.3.2. CONCEPTUAL FOUNDATIONS

When carefully considering both the in-person and online sessions described in Chapters 4 and 5, they appear to fit together conceptually. A caretaker from one special school described the participants in the online sessions as feeling a specific type of "*relief*." Henrik shared how the special school he works at has a green screen room, which is used by pedagogues and staff to record instructional videos and audio for all students. As seen in vignettes three (Chapter 5.2.3) and six (Chapter 5.2.6) from Chapter 5, the participants from this special school convinced Henrik to allow them to use the green screen room with the explicit purpose of spontaneously preparing video material for the online sessions. The availability of a green screen room in itself is interesting to note, as well as the funds and efforts that go into its use by pedagogues and staff. Such a structured space with specific uses and users in mind, however, does not prevent it from being used freely in an open-ended and playful manner as two participants were allowed to film each other for online sessions that they themselves had initiated.

This example brings to mind the work of Makhaeva et al. (2016), which provides a useful way of thinking about the role of freedom and structure in creatively collaborating with young neurodivergent participants. The main contribution of their 2016 article "Creating Creative Spaces for Co-Designing with Autistic Children" is the Handlungsspielraum concept. The authors defined it as:

> [a] conceptual space in which creative co-design activities take place. . . . "HSR" frames the dynamic balance between structure and creative freedom, aiming to find the appropriate balance for each participant, thus enabling them to experience their own creativity. It allows for a systematic adjustment of configurations to facilitate a creative process. (p. 53).

Figure 35. summarizes the format of the concept:

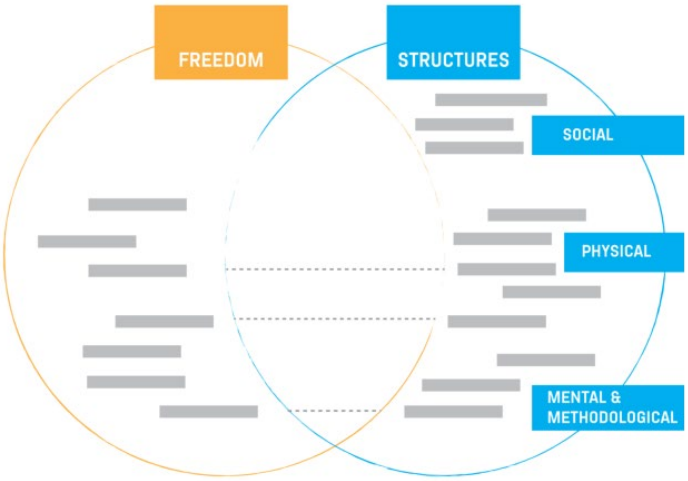



Figure 35. Visualization of the Handlungsspielraum concept from Makhaeva et al. (2016, p. 54)

In applying the Handlungsspielraum concept, a structured approach that includes social, physical, mental, and methodological elements is set up in a way that works as intended when the neurodivergent participants wish to express themselves in a free manner and explore their creativity. An HCZ facilitates a similar activity with one major difference: in this zone, engagement occurs when both the participants and researchers co-produce digital objects together, and when the researchers—at least for a period of time—embody the role of a learner to the participant's expert position, as I demonstrated in Chapter 4. Nevertheless, Makhaeva et al.'s Handlungsspielraum concept is still a useful practical tool for researchers and caretakers to plan, conduct and reflect on a creative process. As such, its understanding of freedom and structure reflect a key characteristic of the HCZ.

Another key aspect of the HCZ concerns play. Jens acted somewhat provocatively during our first two in-person sessions by taunting the researchers about their choice of technology and asking why they only had cameras with 4K resolution when higher resolution 16K cameras existed. He additionally made it clear that he was familiar with complicated video editing practices (e.g., extracting an object from a video file). However, as soon as Jens identified something interesting and potentially useful—in our case, the introduction to a video editing suite—his demeanor changed, and he displayed a much more agreeable part of his character (as per his caretaker and our limited time spent with him). At the same time, he demanded that (1) he be able to demonstrate what video editing skills he had acquired on his own (first online session), (2) he be able to collaborate with me while co-creating a composite video with zombies in an apocalyptic scenario (first online session), and (3) we extract him from

pre-recorded footage and insert him into a Danish news segment, where he could act out a funny sketch using the footage of the newscaster (second online session). Besides Jens, Magnus and Rune focused heavily on play during their sessions: Magnus's video was quite literally about a physical local area network (LAN) party where tens of his peers came together to play games, and he documented the process; Rune created gameplay videos with the sole purpose of editing game footage with memes and jokes that would be fun for him, his friends at the special school, his brother, and others. Additionally, Alfred and Martin also set up a LAN party at their sheltered residence, which we only attended for the first three to four hours but later found out had lasted throughout the night. Besides these somewhat obvious types of play, we also encountered an extremely engaging and unprovoked display of genuine joy and song by Jane, who demonstrated how she sent short video recordings to the people she loved via her smartphone.

All these examples serve to highlight the importance of Haraway's remarks that:

> People have to learn how to pay attention and to communicate meaningfully, or they are shut out of the new worlds that play proposes. Not so oddly, without the skills of play, adults . . . are developmentally arrested, deprived of key practices of ontological and semiotic invention. In the language of developmental biology, they become very bad at reciprocal induction. Their contact zones degenerate into impoverishing border wars. (2006, p. 232)

Haraway's insights into the fundamental importance of play for meaningful communication and ontological and semiotic invention are another aspect of the HCZ: it is a socio-technical space that is fully actualized when it is natural and easy for all the stakeholders to share a sense of play. In our specific case, that took the form of video tutorial manipulation and, later, the exploration of digital practices. However, HCZs can and should be adopted into the environments of professional caretakers and other researchers and have the potential for play infused into their unique environments, when appropriate.

### 6.3.3. ABILITIES IN THE ZONES

After highlighting the importance of freedom, structure, and play as fundamental characteristics of the HCZ, we need to ask: what abilities and skills of our neurodivergent participants could be adequately acknowledged and engaged within an HCZ? In Chapter 4, all 16 participants demonstrated how they successfully engaged with an unfamiliar research format by interweaving their personal interests and, to a degree, using them to strengthen an opportunity for the further exploration demonstrated in Chapter 5. Additionally, in Chapter 5 I presented a move from a normative-epistemic to an epistemic-normative format, where the focus of all the activities was on the exploratory, knowledge-generating leading role taken by our participants. As such, I was compelled to look into a specific type of system design that would be useful to support HCZs and to invite the transition from skill demonstration to skill exploration.

In discussing a theory for health promotion, Antonovsky (1996, as cited in Saplacan et al., 2020) talked about a "salutogenic perspective on the health and ease/dis-ease continuum." His work was founded on the idea that we should study what makes people healthy (i.e., "at ease") and not what gives them "dis-ease." As such, I have positioned the HCZ as a *salutogenic* zone (i.e., a space that focuses on health or practices and activities perceived to be beneficial and healthy and not one that is simply focused on engagement based on diagnoses). In simpler terms, an HCZ should be a space for generative activities, where researchers and caretakers can support neurodivergent participants by playing and experimenting with, failing, and testing their technological abilities.

As mentioned in Chapter 1, while linguistic, academic, ethical, and practical questions regarding the use of the terms "disability" and "ability" are a point of contention in the context of engaging neurodivergent target groups, providing a new definition for these two terms is not the focus of this thesis. Instead, the following question should be addressed: what happened to our participants' (dis)abilities in the HCZ?

Notwithstanding, it can be said that abilities—technical, cognitive, social, and so on—altered the participants' potential in different contexts. For example, Thomas's technical skills in creating and manipulating 3D objects in Blender and his social skills in teaching a researcher how to use sections of this program meant that he was able to establish meaningful social bonds with the researchers in both phases of the fieldwork in this research environment. These same skills had existed before the fieldwork sessions. However, their potential was expressed in a different way, where Thomas could share some expertise with a few classmates who shared some of his interests and partially share his interests with a caretaker. His abilities may not have revealed themselves in his interactions with the caretakers, support staff, and other participants in the special school environment in the same way as they did in the research environment.

This simple example is enough to discard any fixed definitions of "ability" or "disability" and allows me to make an argument regarding *situated ability*. Just like situated interventions (Zuiderant-Jerak, 2016) and situated knowledges (Donna Haraway, 2008), an HCZ is also a space for situated abilities. From a human–computer interaction perspective, Saplacan et al. (2020) described this term as "the human being's ability to comprehend, manage, or find meaning in an interaction with a system or technology" and further presents an ability continuum, which can be understood "in terms of a lesser- or greater scale, depending on how the individual, as a human being, experiences a situation where she interacts or uses a digital system or technology" (see Figure 36).

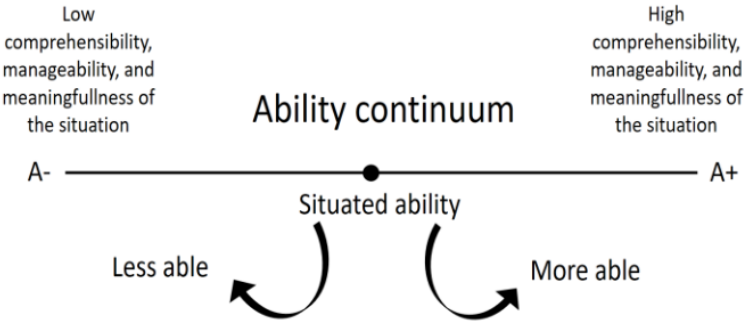



Figure 36. The ability continuum, as seen in Saplacan et al. (2020)

In other words, the higher the comprehension and the more meaning a participant indicates that they perceive, the more able they are in that particular situation, and vice versa for lower comprehension and meaningfulness. It was important to keep all interactions (in all the PVT sessions and online activities) situated in a particular context and to reflect on their entirety. What I mean by this is that Thomas's socio-technical abilities should be seen not merely as having been entangled with the type of interviews and activities he was a part of. Instead, they should be seen as emergent properties of a digital intervention format, in which (1) his practices were recognized as abilities and skills, (2) his practices were engaged with from the position of a learner, and (3) a shared responsibility was made clear in the activities, where Thomas, or any other participant, played a substantive leading role. In a nutshell, our participant's abilities mattered, they made a difference, and there were consequences from our shared choices. The difference these abilities made also depended on the environment (e.g., a PVT engagement may come with higher chance of social anxiety as it relies strongly on physical presence, which is something neurodivergent participants have issues with). However, situated abilities may pose difficulties for researchers or practitioners when they are unfolded in a virtual environment (e.g., online sessions). For example, Andreas and Thomas rarely, if ever, provided a detailed walk-through of their digital practices in Roblox Studio (i.e., logging onto the platform, setting up a shared virtual environment, preparing a very particular digital setup, and engaging in shared digital creation practices) as a sense of tacit understanding and knowledge took precedence over detailed verbalization and self-reflection. These types of practices indicate socio-technical abilities, which are embedded in a different kind of situation, one where researchers and caretakers learn more by co-creating from a learner's position instead of engaging in leading or managing roles.

### 6.3.4. HYBRID CONTACT ZONES AS A FORM OF THIRDSPACE

So far, I have introduced the concept of the HCZ, which was inspired by the works of Donna Haraway (2008) and Mary Louise Pratt (1992), and described the abilities I observed being displayed in the HCZs. It is thus clear that the HCZ concept is not entirely unique: it refers to a lived space with dynamic social relations between participants and researchers, which encompasses material (in-person sessions) and conceived (online sessions) spaces and yet is distinct from them. This particular description of an HCZ tracks very closely with the *thirdspace* theory introduced by Edward Soja in his 1996 book *Thirdspace: Journeys to Los Angeles and Other Real-and-Imagined Places*. Soja "purposefully reappropriate[d]" (1996, p. 53) French philosopher and sociologist Henri Lefebvre's (1991) *The Production of Space*. Soja presented different triads—physical, mental, social (Lefebvre, 1991, as cited in Soja, 1996, p. 62)—and outlined his idea of thirdspace. Briefly, Soja discussed Lefebvre's Firstspace, which he called "perceived space" and "can be seen within measurable and quantifiable constraints" (1996, p. 66). Secondspace is "conceived" space (p. 67) to be occupied by "designers, planners, urbanists and so on" and is the "custodian space not only of knowledge and signs but also of 'utopian thought and vision'" (Meskell-Brocken, 2020, p. 244 in: Ashley & Weedon, 2020). Finally, thirdspace is referred to as "that which is 'directly lived'" (Soja, 1996, p. 67) and, more importantly, constitutes:

> lived space as a strategic location from which to encompass, understand, and potentially transform all spaces simultaneously [...it] necessarily captures the contradictions and struggles to become the "space[s] of resistance to the dominant order arising precisely from their subordinate, peripheral or marginalized positioning." (Soja, 1996, as cited in Naraian et al., 2019, p. 211)

Additionally, Naraian et al. (2019) referred to Soja's work on thirdspaces when exploring the "varied meanings of disability" with a participant they had worked with. Their focus on disabilities can inform a particular way of conceptualizing the HCZ as a form of thirdspace. Specifically, an HCZ, as outlined in this thesis, should be seen as a form of thirdspace that decenters cognitive disabilities from their centrality in (what I call) management frameworks and into a more peripheral, personal characteristic that has less influence in hybrid and digital environments. By management frameworks, I mean personal and institutional modes of managing how our neurodivergent participants should live given their need to manage outbursts, bullying, and the processes of learning from a somewhat traditional, normative school perspective. As such, HCZs can be reappropriated by other researchers, pedagogues, and support staff into specific, situated ways of engaging the target group without letting their professional and technical skills get in the way of a shared experience. That sense of shared participation is a key benefit of any contact zone, and specifically the HCZ, which allows for physical, digital, and mixed interactions.

## 6.4. CONTACT IN THE ZONES

"*Play is the practice that makes us new, that makes us into something that is neither one nor two, that brings us into the open where purposes and functions are given a rest.*"
– Donna Haraway

The idea of an HCZ does not describe a normative space where only prescribed, pre-approved, and pre-determined relations can occur. The explorative focus in the online sessions helped define the HCZ as a conceptual space for a type of co-creative contact, where researchers learn (technical) skills from participants, which is distinctly different from the curriculum-first engagement in a special school, for example. The sheltered residences initiated their own type of contact. This contact, however, still lacked the type of taking-you-seriously-as-I-learn-from-you quality that our sessions allowed for. To clarify where exactly this contact occurs within an HCZ, I developed the idea of digitones.

### 6.4.1. DIGITONES

In her 2008 book *When Species Meet*, Donna Haraway was reminded of a specific type of contact zone, which she called an *ecotone*. It is related to the process of biological mixing, and she described ecotones as having "edge effects . . . where assemblages of biological species form outside their comfort zones. These interdigitating edges are the richest places to look for ecological, evolutionary, and historical diversity" (Haraway, 2008, p. 217). After participating and co-producing 13 PVTs, as well as being part of the online sessions with three participants, I could not help but notice the rich sociotechnical diversity of the situations, which ranged from trend consumption via algorithmically-curated social media news feeds (TikTok, Caroline and Hannah), through specific game ethics, which even included monetary exchange for support and fun (Destiny 2, Viggo), to generating virtual scenarios and pursuing a difficult-to-verbalize sense of realism via Blender (Blender and DaVinci Resolve, Thomas).

In this section, I make the case that these activities—and the entire fieldwork—took place within HCZs. I further specify the exact type of HCZ, which (inspired by Haraway) I call a *digitone*. A digitone is a type of HCZ where assemblages of digital practices and shared interests coalesce outside their comfort zones to come together into digital entanglements and interactions between (in this case, neurodivergent) participants as experts and co-producers and researchers as learners and co-producers. Here, I make a distinction between two types of digitones observed during the interactions with the participants, namely, normative-epistemic and epistemic-normative digitones.

### 6.4.2. NORMATIVE-EPISTEMIC AND EPISTEMIC-NORMATIVE DIGITONES

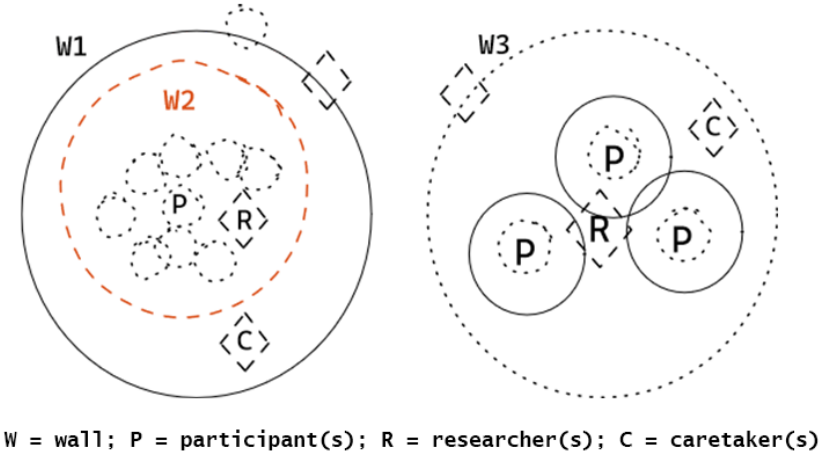



Figure 37. Model of a hybrid contact zone with two types of digitones: normative-epistemic (left) and epistemic-normative (right)

The left side of Figure 37 is a model of a normative-epistemic digitone. What makes it normative-epistemic is the necessity of structure and schedule, within which new epistemologies of digital practices can be pursued, allowed to emerge, and developed. Its closed outer wall (W1) represents the solid institutional framework of the participating special schools and sheltered residences. This framework is closed on purpose as it needs to operate within strict criteria (e.g., a medical diagnosis in order to allow a neurodivergent person to be signed up in a special school, and a municipal code regulating the purpose and activities of the institution). Another dimension of this somewhat solid wall are the actual physical environments with regulated access (who can go in and where they can go), as well as specific areas for study and play. Within this circle is a less rigid and more porous circle (W2), which signifies the open nature of activities within this digitone, specifically, the filming, co-production, and creation of the PVTs and their direct engagement with global digital cultures (e.g., TikTok dance trends, Destiny 2 gameplays). Within this smaller, more open circle are all the participants (P) in the PVTs. They are marked in incomplete lines to signal their active engagement with ideas and practices that do not originate in and are not mandated by the special schools or sheltered residence (e.g., exploring video editing, setting up LAN parties, creating 3D landscapes and objects in Minecraft). They are also moving in and out of the normative space and are thus present on its border. Alongside them as well as on the border of the institutions is a figure (R) representing the researchers. They are visualized as being in the middle of the creation process,

without pushing it in any specific direction, as well as on the border of the institutions to signal the import of unfamiliar ideas and (digital) tools. The caretakers (C) are also present should the participants need their assistance.

All the participating institutions operated on the logic of the need for structured, scheduled activities organized for the benefit of the neurodivergent teenagers and young adults studying and living there. This logic by necessity formed the normative framework around any type of activity undertaken by and with our participants. Using the results from the PVTs and online sessions, I have demonstrated how digital interventions can assist in the emergence of a multiplicity of epistemologies within this framework: knowledge regarding our participants' digital skills, their digital ambitions, their engagement as co-producers of digital content, and their abilities to explore and pursue personal needs via digital creation.

The right side of Figure 37 represents a model of an epistemic-normative digitone. What makes it epistemic-normative is the need for exploration and self-expression: an agenda-less stretching of existing skills until their limits are reached. Finding a path toward those limits and trying out ways to address them generates different kinds of epistemologies. Within this knowledge-making process exists a need for grounded, normative starting points: either the structured narrative of a story (e.g., with Thomas's cyberpunk city) or the predetermined output of digital tools (e.g., videos whose sharing and circulation come with their own host of issues and challenges). This digitone's outer wall (W3) refers to the open nature of an exploratory environment, in which the researchers join the neurodivergent participants in their familiar digital space (e.g., sharing an online session via Zoom, situated entirely in our participants' software of choice, such as Blender and Roblox Studio). More specifically, W3 represents a horizon of opportunities, which is more permeable to outside influences (e.g., our participants sought and found their own influences, like Ian Hubert's Blender tutorials on YouTube). Within W3 is a group of participants (P) and researchers (R). Again, the participants are open to influences and ideas and interact with each other directly and indirectly (e.g., Thomas joining Andreas's session and ending up playing a more substantial role in it than Andreas; Jens being influenced by Thomas's technological approach of putting himself inside a virtual environment and using him for technical assistance to prepare his digital materials). Their caretakers (C) are nearby, having helped with the digital setup but not engaging in the actual digital explorations.

I argue that both types of digitones were formed and occurred outside the comfort zones of the neurodivergent participants and the institutions with their existing formats of support. While some neurodivergent students and residents of the institutions either volunteered or agreed to participate in this project, the overwhelming majority of them did not. This speaks to the discomfort or simply just a lack of interest that did not incentivize most of the students and residents to step out of their comfort zones.

As far as the institutions are concerned, they have resources to provide support for a wide variety of the needs felt by their students and residents: from food and shelter, through education, social activities like movie nights, game events, field trips, and more. However, digital strategies for support, such as the digital interventions described in this project, are not yet recognized as important enough in a way that would codify their use. In the following sections, I provide examples of reflections from an epistemic-normative digitone, which took place over three online sessions with Thomas. These reflections serve as examples of the personal importance of the specific digital interventions and the questions they raised for our participant.

## 6.4.3. THOMAS' REFLECTIONS

### 6.4.3.1 Why did Thomas want to share what he shared?

*[M]y mind works differently, I suppose. . . . Sometimes I just can't understand the subject or switch from one point of view. And then, of course, I'm trying to change that. But I also see things differently and think differently, I suppose. . . . You want to share something—that's basic and that's just something you do that doesn't have to have a point to it—you just want to share anything you can. So that's the same as if I'm making something, a scene. I want to share it with others. There's no point to it, it's just. . . I just feel like I want to do it.*

– Thomas

Thomas appeared to be searching for a particular reason to share the results of his digital skills with others by referring to the way his mind works. Ultimately, he concluded that there was no need to justify it beyond the desire to share. In a sense, the possibility of sharing is what inspired Thomas to be involved in digital production. I argue that this reflection highlights an important part of co-creating an HCZ: recognizing the social and technical aspects of sharing can affirm a desire for social interaction for its own sake. Thomas and I co-created the HCZ by recognizing an innate desire for sharing and following it, even without having a specific goal in mind.

### 6.4.3.2 What motivated Thomas to pursue digital skills development?

*I think the biggest breakthrough was. . . I made a wedding ring. Because [my dad] was marrying his girlfriend and then. . . I made a wedding ring inside a little case to show to him. I couldn't buy it in real life, of course, but I just. . . I was happy about it. And then I made it in Blender. And the progress of making that—I learned stuff in Blender, and I learned… I don't remember, but I learned a lot of stuff. Wood texture, wood table with a box, and then you open the box and inside the box was a pillow with a ring on it.*

– Thomas

When asked how and why he started learning to work with 3D modeling software, Thomas shared the story of creating a wedding ring for his father since he did not have money to buy one. We refer to this reflection as an example of a motivation for entering an HCZ. We argue that a lack of money and access to free software, combined with a genuine desire to be supportive, resulted in Thomas creating the conditions for an HCZ even prior to this project. In this case, he did not engage with a disparate collaborator (neither his caretakers at the special school, nor finding a specific person to talk to online); however, he worked to entangle a social convention (i.e., giving wedding gifts) with a technological practice (i.e., learning how to use Blender), an extension of his motivation. We see this anecdote as a story about the motivation to master digital tools as they allowed Thomas to circumvent a physical restriction of crafting a wedding ring by creating it digitally instead. I argue that an HCZ can reveal existing personal motivations for digital production and push them further (e.g., co-creating the cyberpunk city, which took place after this reflection by Thomas).

#### 6.4.3.3 What was Thomas after?

> *And I mean, nowadays in the 21st century, yeah, it's getting easier and easier to share things visually, to create something new. . . . It's just part of the simple human brain. . . . You can almost think of a human brain as a black and white: there's stuff you want to do and stuff you don't want to, and the chemicals are getting released into your brain.* ***What brings you dopamine is just nature's way of saying: "you do that, that's good". And so, to get dopamine from a picture, would be, you know, incredible****. . . .* ***I want to create something that can bring dopamine and a cool, good feeling in somebody's brain, I suppose****.*
>
> – Thomas (emphasis by author)

I hypothesize that Thomas felt his interests and digital skills had been sufficiently recognized throughout the fieldwork, so he could freely reflect on what he wanted to do with them—bring a "good feeling in somebody's brain." Thomas contributed to the HCZ by highlighting what social conventions he wanted to be engaged in (sharing a pleasant feeling with others) and how (by creating "something"; e.g., the cyberpunk city presented earlier). The nuanced understanding of how brains work, and the role dopamine plays is interesting here as it can be read as a desire to deeply reach people through one's interests and experiences. We observed a specific understanding of human nature that informed Thomas's desires (e.g., *if I feel like that, then I can do x, y, z to make others feel the same way*), which can be seen as an outward projection of the self. The technological means of projecting were not seen as altering the self (Thomas did not talk about Blender changing him or how he felt) but were thought of as what could/would hopefully alter the other selves (the potential viewers or visitors of the cyberpunk city). In this sense, the technological means are a vessel imbued with what the self wants to share. This can be problematic because it may come with

expectations of actual change; it is reminiscent of the colonizing "contact zone" approach described by Pratt, in which one brings something to others without being as interested in their desires. However, in the HCZ case, Jake *was interested* in learning and exchanging with the researcher. We co-created the HCZ by considering how our efforts within it may impact those beyond it.

#### 6.4.3.4 What limited Thomas's ambitions?

*I always had a bad habit of giving up before I got anywhere because it was hard. The thing about modern brains is. . . you need more and more dopamine because it's easier to get it. You can go on Facebook, post a picture, and you get likes—you get dopamine. But if you need to train Unreal Engine, you don't get any dopamine for a while, and if you don't get a reward like that for trying, you give up. And that's hard to switch your brain to, to think about that. The human attention span has gotten shorter . . . over the last decades, I think. So that's a problem, which I openly admit [to], and I know about, but . . . you can't really just say: "Now I want dopamine and now I don't need it." It's all in the head.*

– Thomas

From an HCZ perspective, Thomas offered a nuanced idea of the nature of the limitations that constrained his digital skills development, specifically, his understanding of the effects of dopamine on one's brain and a profound helplessness to manipulate one's own reactions to their "natural" brain constitution. I argue that this reflection on limits provides an important insight into the co-construction of an HCZ: it was a space where Thomas acknowledged his limitations and, most importantly, shared that experience with the researchers. We co-created an HCZ by keeping a meta-reflective view on how technologies affected us and how we should use technologies (e.g., easier dopamine rush related to Facebook vs. delayed gratification related to work with Unreal Engine).

The two fieldwork phases organized around co-creating HCZs with Thomas outlined (1) the importance of recognizing the desire for sharing, (2) recognizing existing motivations for digital production, (3) considering what people outside the HCZ may want to be engaged with, and (4) keeping a critical view on how technologies affect people and how people should use technologies. With this background, the empirical results in Chapter 4. contributed guidelines on how to stage an HCZ:

- identify and build on existing interests for digital social engagement;
- ensure a central methodological space for a "learner" mode, where the researcher/designer and participant can focus their learning efforts on a shared external interest (e.g., digital production); and

- role parity, where the researcher/designer and participant's roles carry equal weight in the shared initiative.

# CHAPTER 7. DISCUSSION

*"Our systems need to be stirred up from time to time."*
– Harry, Head of Department at Kollegievejens Skole

Before I demonstrate how I have answered the main research question of the thesis formulated in Chapter 2, I will revisit the question of what this entire project was about and why readers of this thesis should agree that the research question matters at all.

As indicated earlier, the intersection of (digital) technology use and neurodivergent young people is an area of research where a diverse and engaged coalition of researchers is heavily invested. More specifically, researchers in the fields of human–computer interaction, critical disability studies, science and technology studies, communication studies, interaction design, design methods, ubiquitous computing, technology and inclusion, anthropology, and more are actively working to better understand, for example, how this target group uses digital technologies, what for, how technologies shape their social relationships, and what (un)intuitive limits can be detected with regard to the effects of digital technologies. Examples of researchers who are pursuing these questions include Margot Brereton, Christopher Frauenberger, Jane Seale, Meryl Alper, Kathryn E. Ringland, Laurianne Sitbon, Elinor Ochs, Filip Bircanin, Ali Adjorlu, and Diana Saplacan.

In this chapter, I will engage data and reflections in dialogue with the literature as well as insights from representatives of the institutions that participated in the project with the aim of outlining the lessons learned and limitations of the thesis. I will also reflect on the necessary future steps that can contribute to the academic and practical knowledge on how neurodivergent youth use digital technologies.

## 7.1. RECENT CALLS FOR RESEARCH

In Chapter 2, "Setting the Stage," I outlined several recent calls made by human–computer interaction and PD researchers for the need for practical and theoretical contributions regarding work with neurodivergent youth and digital technologies. More specifically, these calls identified:

- the need for better guidance on how designers and researchers can engage productively with conflict in a design process (Frauenberger et al., 2019b);

- the need to develop easier-to-implement methods and disentangle power relations when co-constructing experiences with the target group (Frauenberger et al., 2019a); and

- contributions to the supportive effects on educational practices by positive risk-taking (Seale et al., 2013).

I addressed the first call in Chapter 4 and the 2021 INTERACT paper "Digital Producers With Cognitive Disabilities: Participatory Video Tutorials as a Strategy for Supporting Digital Abilities and Aspirations." Specifically, I have shown how a participatory video tutorial (PVT) co-production process can be set up and implemented in a way that engages a diverse target group ranging from shy and quiet participants to skeptical, somewhat antagonistic ones. The warm reception from the different participants to the process indicates that they reacted positively to a single or multiple elements in the approach, and I invite other researchers to translate and adapt relevant parts of this experience to their own cases. To assist these efforts, my co-authors and I have provided a list of four principles for PVT production, which should be easy to adapt to other research configurations (these principles are *socio-technical belonging*, *technical accessibility*, *elasticity*, and *material reusability*). Further on, in Chapter 6, "Engagement in Hybrid Contact Zones," I provided the concept of hybrid contact zones (HCZ) and two specific instantiations thereof: a normative-epistemic digitone and an epistemic-normative digitone, which again can be adapted by researchers in different contexts. The key contribution with the HCZs is their identification as a type of contact zone (Haraway, 2008; Pratt, 1992) and form of thirdspace (Soja, 1996), which can lead to productive engagements with both positive and challenging digital ambitions.

I addressed the second call in Chapters 4–6 and a draft paper titled "Co-Creating Hybrid Contact Zones for Digital Production: A Participatory Case Study with a Young Person Living with Autism Spectrum Disorder." In Chapter 4, I provided examples of video tutorial co-production setups, which may look overly involved at first with their heavy reliance on filming equipment (e.g., multiple cameras, voice recorders, studio lights). However, I argue that the exact same PVT result can be achieved with existing video recording equipment (e.g., smartphones) and free-to-use software (e.g., for laptops and desktop computers, video recording programs like Open Broadcast Software Studio and video editing suites like DaVinci Resolve; for smartphones, built-in screen recording and video editing tools). In Chapters 4 and 5, I demonstrated how power relations can be managed when the role of the researcher/co-producer is first and foremost devoted to the position of a learner (i.e., one who learns from the existing skills and expertise of the participants). This is a crucial step that simultaneously boosts the confidence of the young people living with cognitive disabilities (who overwhelmingly experience issues of self-worth as they study and live in institutions that have outsized control over their lives) and situates the researchers and practitioners in a dual position of (1) knowledge gathering and (2) supporting data co-production with the participants. In Chapter 6, I used the concept of HCZ to clarify how researchers and neurodivergent participants can be repositioned to support the exploration of digital ambitions and social relations.

Finally, I addressed the third call in Chapters 4 and 5 and the 2021 INTERACT paper, as well as a 2022 draft paper on HCZ (Karadechev et al., 2022), by describing how two phases of the fieldwork were structured and implemented in support of positive risk-taking. Both the open and elastic structure of the PVTs and the open-ended online session format, which relied exclusively on the structural vision and technical skills of the participants, provided multiple and recurring examples of positive risk-taking. Examples include Jens's transformation from initial dissatisfaction with the PVT result (Karadechev et al., 2021, p. 10), where the researchers could not insert his digital avatar into the video tutorial well enough, to the months-long self-initiated preparation he engaged in to place himself inside video footage in an exploratory session. Another example is Thomas's shift from a well-rehearsed performance (Karadechev et al., 2021, p. 13) meant to minimize any chances of mistakes in front of others, to the digital scenario of a tourist in a cyberpunk city that he created entirely by himself. While the importance of the specific narrative and technological challenges should not be minimized, the defining characteristic of the positive risk-taking in these cases was represented by the amount of time that the participants volunteered to spend on these projects. Jens and Thomas's PVT sessions ended in January 2020; however, they remained actively engaged with their digital production efforts by themselves and with support from their caretakers from summer 2020 through fall 2021. In addition, Thomas and Andreas, with the knowledge of their caretaker, invested additional time discussing and sharing digital technology resources with me throughout 2020 and 2021 inside their preferred secure chat platform of choice, Discord, where they would occasionally ping me with interesting examples of game development, digital tools (e.g., tutorials for Blender), and so on. These additional efforts and extra time spent by the participants is indicative of the positive effects of the digital interventions in our particular case, which made our positive risk-taking desirable.

## 7.2. HOW DID I ANSWER THE RESEARCH QUESTION, AND WHY DOES IT MATTER?

Following the brief overview of how the three main calls for action from researchers have been addressed through fieldwork and theoretical contributions, I will now move on to the main research question of the thesis and interrogate it through some examples from the data. The question, as outlined at the end of Chapter 2, reads as follows:

*How can a digital intervention approach be co-developed and used as a research design technique to support digital co-production and social engagement through active participation, digital skills development, aspirations, and knowledge exchange between neurodivergent youth and researchers collaborating as co-producers and co-creators?*

While in a conversation with Harry, a former teacher and the head of department at one of the special schools that participated in the project, he made the following points:

> The Danish school system does not think that being a netizen is important. . . . Some young people with anxiety thrived through the [COVID-19] lockdown because they did not have to socialize in ways that made them struggle with going to school. . . . They socialize in their own way. (phone interview, June 4, 2022)

This opinion suggests a profound mismatch between the governing logic that is responsible for the care and day-to-day integration into neurotypical society for our participants on the one hand, and the current, relevant socio-technical needs of the neurodivergent participants on the other. I deliberately refer to this notion of mismatch here because it is precisely that perceived gap that the research question of this thesis attempted to address.

Danish institutional support for neurodivergent youth has historical roots in the 1950s and is well developed in terms of specialized schools and sheltered residences with a focus on individual support, strengthening social relations, and assisting with day-to-day issues of life, school, and work. Nevertheless, there are still aspects of the neurodivergent experience that can benefit from more insights. Harry's reflections do not have to be taken at face value, of course. They seemed to be corroborated by Thomas and Jens, who said that they had "no one to talk to about IT" (Chapter 5, section 5.2.5) and that they were "trying to survive" at school (Chapter 5, section 5.2.6), which does add weight to the argument that their digital ambitions and desires were not yet being recognized or engaged with in a way that worked for them. It bears repeating that Thomas and Jens were the only two participants who directly voiced these feelings. While that may sound like an insignificant sample to some researchers, it really should not be taken as such. Andreas, another participant, was so determined to develop and share his digital skills that he reached out to Danish YouTubers and arranged for them to do a video review of a video game he had developed (Krossing, 2020), and Marius had been creating video mashups for his fellow students to enjoy for a while. These examples are not meant to suggest that special schools and sheltered residences must be involved in every single digital activity undertaken by their students and residents as that may prove counterproductive. What they are meant to suggest is that the lack or inability to engage neurodivergent youth with digital skills in a structured, school/residence-sanctioned manner indicates a lack of understanding on the part of these institutions—a knowledge gap that this project wants to contribute to. Additionally, these instances of digital production should indicate that while only a few participants were visibly pursuing their socio-technical ambitions, there is no reason to assume that they were the only ones.

To that end, I offer a more direct answer to the research question: I have proposed a digital intervention approach to be used as a research design technique as a way to address the identified institutional knowledge gap. As previously discussed, our version of digital intervention was a combination of physical sessions with a focus on digital production (i.e., PVTs) and online sessions with a focus on digital skills exploration. Through this process, the participants became co-producers of video tutorials and were involved in the improvement of the approach itself (e.g., the suggestion for LAN parties came from two groups of participants independently of each other, not from the researchers trying out a different approach). Three of the participants decided that they would invest time—a notoriously difficult ask of them—into digital skills development once they felt like they were being taken seriously. Their investment of more than two and a half times per session on average (around 140 minutes online compared to around 50 in-person; Karadechev et al. 2022, p. 8) indicates that an element of the digital intervention approach resonated with them at those particular points in time. I take these facts as indicators that the intervention sessions were successful in stimulating *active participation*, *digital skills development*, *knowledge exchange*, and *ambitions* in all 16 participants. Additionally, requests from Thomas, Andreas, Lars, and Carl to have a version of their PVTs without a DiGi project logo for personal use on their private social media channels suggests that they were engaged enough to want to take more steps in the direction of sharing their content, engaging people outside their immediate class circle, and potentially more (e.g., communicating their results via their social media channels on YouTube, TikTok, etc.).

Ultimately, a combination of the four PVT principles (Chapter 4), exploratory ethos (Chapter 5), and HCZ concept (Chapter 6) resulted in a positive response from our participants, and I propose that this combination be adapted and translated into other activities at Danish and international institutions that work with this target group.

The main lessons learned regarding participation in research on digital technologies with neurodivergent youth were as follows:

- Active participation can be supported via digital interventions using technologies that are familiar to the target group (e.g., social media, game development and 3D modeling software).

- Active participation can be supported via digital interventions that build on the target group's existing knowledge with suggestions for related technologies (e.g., complementing existing ambitions for video editing with alternative video editing suites).

- Researchers and professionals who adopt a learner position and open space for neurodivergent participants to act as tutors/teachers of their existing

digital skills and ambitions in a shared format (e.g., video tutorials, online exploration) can further help bring the voices of these participants into focus.

- Exploratory roles (e.g., tutor, learner) can support an open-ended knowledge exchange and highlight the need for the inclusion of the specific characteristics of a shared hybrid environment to facilitate collaboration (e.g., HCZ).

## 7.3. REVISITING CARE AND KNOWLEDGE

Bellacasa (2017) wrote about care being inscribed in more than human things. In this thesis, the combination of PVTs and online sessions, with all the associated activities, represents the "more" than human things. Inscribing care was a priority throughout the process—from conception (e.g., attempting to ensure that our participants were in a position to express themselves) through to implementation (e.g., the kinds of technologies we used and how), exploration (e.g., how we built on shared experiences with the guiding voices being those of the participants), and reflection (e.g., via interviews on what these activities meant for the participants). These activities should not be seen as the full extension of care, or even the most appropriate manifestation of care that could be shared between researchers and participants. They do, however, represent a care-first approach that attempted to actively engage the participants who volunteered to be part of this study. Practically, this was done with due consideration of their autonomy (e.g., approaching questions about their personal preferences, needs, and ambitions with specific care regarding how they interfaced with their technologies of choice), their privacy (e.g., displaying care regarding all the participants' preferences with respect to sharing or obscuring personal details, such as names, when co-producing the PVTs, by ensuring they were only accessible via a private YouTube channel), and more. Care, as Bellacasa (2017) conceptualized it, is engaged in the personal relationships between researchers, participants, and technologies.

Polanyi's (2009) understanding of tacit knowledge was instrumental in shaping my expectations when engaging in all the fieldwork activities. Specifically, the notion that we—researchers as well as participants—were unable to explain how we knew certain things was instrumental in our leaning on video usage as much as possible. The visualization of personal visions, ideas, and ambitions and the act of tangibly exploring what could be co-produced digitally was the direct result of Polanyi's "we know more than we can tell" quote. While attempting to put ideas and aspirations on a screen certainly did not allow us to bypass our inability to tell everything we knew, it did offer an avenue for engaging, familiar, and achievable activity for our participants to simply play with.

## 7.4. WHY CO-DEVELOP DIGITAL INTERVENTIONS?

In Chapter 2, I defined a digital intervention as "a practical, engaging, and appropriate way" (Chapter 2, section 2.1.3) to make use of digital technologies when engaging with neurodivergent young people. Additionally, I mentioned that a digital intervention can simultaneously be "the tool (e.g., a digital work flow inquiry), the environment (e.g., a video call), and the theme (e.g., video tutorials) of an intervention process" (Chapter 2, section 2.1.3). In this section, I turn my attention to existing and future reasons that supporting the need to co-develop digital interventions with neurodivergent participants.

First, as mentioned in section 7.1, research interest and identified institutional knowledge gaps exist in the co-development of digital interventions. Second, there are also questions regarding digital interventions focused on digital ambitions and aspirations. As reported by Weber (previously Andreasen) and Kanstrup (2022), this particular target group develops coping strategies in order to better participate in online culture. However, coping strategies are also needed in the physical world, which is not built to accommodate neurodivergent youth. To that end, it is important to note the inherent suspicion and reservations toward the world that existed in our participants, as well as how easy it was for them to be hurt in it via an unintended word or an unfamiliar social situation, could easily have had deeply negative effects on them. Our participants' sense of adventurousness therefore suffered. They had fewer reasons to try and be social and fewer reasons to risk getting hurt. This was why co-developing digital interventions with them could be beneficial. Using concepts like the HCZs and practical approaches like video co-production and exploration were intended to facilitate exploration on personal, social, and technological levels. These concepts and approaches can handle real yet lower stakes risks for collaboration, personal ambitions, and aspirations, where it is less of a problem to fail. That is why it is important to continuously rethink and recalibrate the perceptions and uses of technologies by this target group and why co-developing digital interventions can be beneficial.

Thinking about ways to understand what technology does and means for young people who live with cognitive disabilities in a digital production process, Davidsen et al. (2021) wrote about a digital fabrication process, which was co-created with a pedagogue from a special school for neurodivergent youth. The authors reported on a discrepancy between the principles of digital fabrication and pedagogical practices at a teaching institution (described in Figure 38). Specifically, they found that students should be engaged with *real problems* (virkelige problemer), yet at the same time, institutional practices put more emphasis on *personal interests* (personlige interesser). A pedagogue or professional in a special school must therefore engage in a translation process and find or create ways to transfer the digital fabrication concept into a specific context with the target group. Davidsen et al. proposed that pedagogues, practitioners, and professionals working in special institutions see the process of

digital fabrication as a continuum between general principles and the needs of the participants.

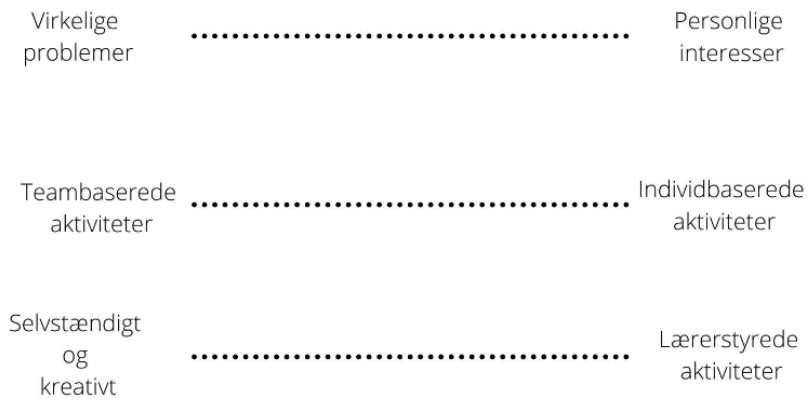



Figure 38. *Kontinuum* from Davidsen et al. (2021, p. 14)

The authors outlined three general principles and three types of interests and activities that should be considered by practitioners working with neurodivergent youth, as per Figure 38:

- The continuum on top spans between *real problems* (virkelige problemer) and *personal interests* (personlige interesser).
- The continuum in the middle is between *team-based activities* (teambaserede aktiviteter) and *individually based activities* (individbaserede activititeter).
- The continuum on the bottom spans between *independent and creative activities* (selvstændigt kreativt arbejde) and *teacher-led activities* (lærerstyrede aktiviteter).

I propose that by adopting an HCZ approach, relevant stakeholders and participants from the target group can both move more freely on this continuum. For example, as described in Chapter 4, the researchers performed different roles (e.g., conducted interviews, setup and maintained the existing technologies) and relied on the participants to demonstrate and expand on their digital skills and ambitions and to later provide feedback and be engaged in the PVT co-production process. Looking at these activities through the middle continuum from Davidsen et al.'s paper reveals movement from a team-first focus (e.g., how could we practically set up a physical space and engage the participants, how could the participants share what they wanted more effortlessly) to individually based activities (e.g., only the participant could demonstrate their skills, only one researcher was engaged in video editing).

Another reason for co-developing digital interventions has to do with building on the current understandings of technology use by neurodivergent participants. Relevant examples of technology use by this target group can be used by professionals, institutions, and researchers to update existing approaches, and conceptualize newer ones. Practitioners have reflected on technology as being like a sandbox; it can allow for social engagement by the target group that is inaccessible elsewhere (e.g., via game development, participation in social media trends, 3D modeling). As more social activities become available online, the importance of a broader and at the same time deeper understanding of the role of technology for socially vulnerable populations increases. Instead of simply honoring institutional missions (e.g., supporting existing curricula-based approaches), in this study, I engaged in an individual-first exploration of the meaning and importance of digital skills and pursued this through customizable, individual-first, physical and online-only digital intervention sessions.

Further, the PVTs and online sessions presented an implicit challenge to the normative activities that are part of any institutional curricula. The challenge was contained within the exploratory aspects of the activities (e.g., how would the neurodivergent participants act as co-producers, what would they focus on, would they—and how would they—choose to further develop their focus). The challenge was, arguably, where the skills development and knowledge generation could happen, but it came with risks. Would the participants engage with the proposed formats at all? If they did, would that engagement be superficial? One way of addressing these questions was by turning the expert–student aspect on its head, putting the experts in the position of learners, and establishing a research environment where they had to explore digital practices together with the participants. During the activities described in Chapter 4, and especially in Chapter 5, I underplayed my role as a researcher, and potentially as an expert in the eyes of our participants by relying exclusively on their digital skills and never actually solving any problems on their behalf. Rather, we engaged in a co-operative process of exploration. I did not offer specific guidance unless specifically requested. Instead, it was the participants who had to guide me, and this played an important part in addressing how they may have felt or seen themselves as "disabled," "handicapped," or simply different people. Being an adult who works with teenagers comes with a specific baggage (i.e., they are usually guided by adults and told what to do throughout the day). Stepping aside from this controlling role into an exploratory, co-producing, co-creative environment is also a characteristic of a professional, active engagement, which made it possible for an insight to emerge: looking at the potential of neurodivergent producers is much easier when we, as researchers and practitioners, do not let our own skills get in the way of exploratory digital practices by consistently exercising control over the process and outcomes.

In terms of how our participants actually reacted, a point needs to be made. According to Harry, both Thomas and Jens found it very difficult to meet people, "especially if something is at stake" (phone call, June 4, 2022). Accordingly, they were more willing to take risks online as they could blend fairly easily in digital communities. As per

Harry, these digital communities are the places where the participants can go to "practice receiving and giving critique," which is a major social hurdle for them. In addition to that Harry says that most students in his institution "[…] are not adventurous when it comes to the real world. They are not as interested in the natural world. They are cautious, because they know the real world can give you scars and it can hurt you and you can be treated badly by people" (phone call, June 4, 2022). I propose that by co-developing digital intervention sessions, we co-created an environment where critiques and acknowledgments were given in ways that stimulated active participation and saw some students coming back for more activities and explore, as they likely do not associate digital environments with the scars mentioned by Harry.

In sum, the answer to the question posed at the beginning of this section *(Why co-develop digital interventions?)* is as follows:

- This process relies on direct and active co-operation and engagement with the members of the target group, who are in the non-traditional position of being co-producers.

- The process is aligned with the target group's existing practices (digital creation), which can be used to both illuminate as well as support their further development and the exploration of these skills.

- Calls exist for the further development of digital intervention practices by researchers in relevant academic fields (e.g., Frauenberger, Alper, Seale, Brereton).

- This approach to research and participant engagement is underutilized by practitioners and researchers.

## 7.5. RELIEF AND VOICE

Stress, anxiety, and fear were never far away from the daily experiences of our participants. To that end, the digital interventions we offered also related to questions about the effects they may have had on our participants with regard to their emotional states. In a phone interview, Harry, the head of department at a participating special school, shared that Andreas, Jens, and Thomas, the three participants who had engaged in both the PVTs (Chapter 4) as well as the online sessions (Chapter 5), felt "relief in two senses" (phone interview, June 4, 2022). Specifically, they were relieved because (1) the sessions were received as constructive situations in which an adult took them seriously, which Harry contrasted to what they felt like when they were "going to school," and (2) the participants allegedly felt a kind of relief "when you get something out of your system" during and after the sessions. This reflection on relief raises questions about environments in which neurodivergent participants have

to deal with different kinds of stress, anxiety, and fear, such as schools and workplaces. In contrast to those environments, the digital interventions were structured as arenas for self-expression, collaboration, and co-dependence based on existing digital skills. As indicated through the examples in Chapter 5 and the reflections from Harry, this approach had positive effects on the participants who experienced a sense of relief through their participation and co-production, which was a form of enacted autonomy.

The participating institutions are not meant to be places where neurodivergent students and residents feel stress and anxiety, and they are not sources or conduits of such emotions. However, stress, anxiety, and discomfort were part of the back story of many of our participants, and as such existed in their daily routines at the institutions. As Harry shared, Thomas's anxiety had been growing throughout his stay at two schools he had previously attended. Accordingly, for example, if he were to be approached with a mathematics book, he would almost certainly not go back to school for a few days while he dealt with the stress of engaging in a traditional class environment. According to Harry, the process of dealing with these issues had improved; however, any progress in that regard would take a significant amount of time.

When Andreas, Jens, and Thomas talked to pedagogues and their teachers about how they used technologies (e.g., digital interests like game development, game play, coding, 3D visualizations), they would often receive responses that may have felt dismissive. As per Harry, some teachers' reactions to technological topics carry the following meaning: "oh, so you like to play on the computer; oh, that's sweet but kind of a waste of time" (phone call, June 4, 2022). Similar reactions and attitudes most certainly do not reflect an inherent negative or dismissive attitude toward neurodivergent youth by the teachers and pedagogues. Rather, they likely reflect the existence of a specific socio-technical distance. Most teachers do not have and are not trained in the technical skills necessary to support the wishes and ambitions of their students. This can prove problematic as the digital arena is a space for different and vital affordances for the target group (e.g., direct participation in global trends, digital skills development through tutorials from professionals). Here, the important question of recognition comes up, specifically regarding the inherent power dynamics in a special school or a sheltered residential environment. Canadian philosopher Charles Taylor discussed the importance of recognition in his 1994 essay "The Politics of Recognition," where he wrote that:

> . . . our identity is partly shaped by recognition or its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves. Nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being. (p. 25)

While no evidence or suggestions exist that Danish social and pedagogic traditions are deliberately oppressive or imprisoning (on the contrary, the social and political movements from the 1960s and 1970s onward have consistently supported an inclusive approach toward the target group), it does not follow that every single approach succeeds in recognizing neurodivergent youth as best as possible. Put simply, not taking someone's skills and abilities seriously due to a lack of training or technical expertise can be the result of a lack of recognition and a failure of imagining what is possible. Thus, the horizon of possibilities for neurodivergent young people can easily be constrained by a system-centric view, which may value study curricula and fail to technologically educate teachers, instead of by existing skills and abilities of the target group that can engage with possible new (socio-technical) configurations. The political charge of Taylor's (1994) thinking on recognition can be useful in highlighting the improvements special schools and sheltered residences can make to better engage with their students and residents and recommit to supporting individual needs.

Harry reflected further on some of the challenges faced by the target group by focusing on the perceived expectations of how one should behave online and how these expectations easily contribute to a growing sense of anxiety among neurodivergent youth. As Harry said:

> You are only valued if you are an extrovert, and if you have introvert tendencies, you will have a hard time being part of the clique in the gymnasium, [which] puts stress on teenagers, when they go through the upper classes in *folkeskolen* [high school] and gymnasium. You have to present yourself in ways that do not feel normal. . . . Society is not meant for that kind of personality. (phone call, June 4, 2022)

First, it is important to note that these considerations are not exclusive to neurodivergent youth, which is the point. Such expectations are also felt by neurotypical youth and adults who are online. While neurotypical people react within a framework of a neurotypically dominant society, neurodivergent individuals—in our case, young people—have comparatively fewer avenues for reaction toward a system logic that (1) may not even recognize they have abilities and skills worth sharing, (2) would generally not be prepared adequately to engage with said abilities and skills, and (3) may not have incentives to develop appropriate ways to engage with neurodivergent young people.

While attempting to solve these issues is beyond the scope of this thesis, it does contain insights that may be useful to individual professionals and institutions that are engaged in supporting feelings of relief and self-expression in the target group. My proposal for engaging with issues of recognition, anxiety, and fear concerns the use of video, specifically, the co-production and exploration of visual self-expression, thus bypassing potential issues with verbal speech and supporting and developing

existing practices that are reliant on video (e.g., social media use, skills development via online video tutorials). This process proved to be effective when focused on knowledge exchange, for example, when Jens and Thomas taught me how to use Blender and forced me to learn video compositing (i.e., combining two video sources into a single video), while I in turn shared my experience with video editing and color correction in DaVinci Resolve with them from the position of an enthusiast. While neither Andreas, Jens, Thomas, nor I were professional users of the different technologies at hand, the shared enthusiasm to explore, learn, and develop skills facilitated serious engagement while preserving an element of fun, where, for example, we could work together to extract Jens from pre-recorded video footage and insert his image into another video stream so that he seemed to be interacting with it (Chapter 5, section 5.2.6). This is one type of example of how video can be used to support personal relief (i.e., exploring personal interests without consideration for study curricula or not having their digital skills recognized appropriately by the support staff they rely on in their daily activities) and invite the voicing of preferences, opinions, and general self-expression (e.g., coming up with specific digital scenarios, reflecting on questions of reality, positioning, and agency, as seen in Chapter 5, section 5.2.5).

I propose that these examples, while limited in number, provide an in-depth look into reactions to active engagement with video. They suggest that such an approach may be in line with existing digital skills and ambitions for neurodivergent youth in Denmark—and likely elsewhere. Such methodological approaches do not appear to be too advanced or beyond the grasp of the target group; on the contrary, some of the participants in our study even brought additional knowledge to the sessions (e.g., how 3D modeling works), from which the researchers could benefit.

To that end, an active and rich digital intervention approach can be re-appropriated by researchers in relevant fields, teachers, pedagogues, and administrators working with neurodivergent youth into their own day-to-day practices, for example, by adopting context-specific versions of the co-producer roles and PVT/online sessions.

## 7.6. ON THE MATTER OF CONTROL

Thomas wanted to be able to create a digital representation, a virtual environment, within which people could feel exactly what he felt. This—the question of feeling—is an important one as neither neurotypical nor neurodivergent people have it easy when they want to share *how* they feel. Given his high-functioning autism, Thomas had more avenues for expressing his perspectives than people whose control over their bodies was much less than his. For example, he was able to engage in fine-tuned, precise actions in Blender and recreate the environments that he wanted to share with others (e.g., an introduction to a Netflix TV show, a digital landscape, a cyberpunk city). This was not the case with all the participants in the project (some lacked the

physical control and others the mental focus to execute such tasks) and was likely not the case with all the students in Thomas's special school.

What this entire project rests upon is shared practices, mediated by digital technologies, that support a sense of shared responsibilities, of the enactment of a sense of control through which the participants were actually using their digital skills to communicate, visualize, or just express deeply felt feelings. Examples included being popular on TikTok, sharing encouraging and happy moments with people they loved, and enjoying gaming together in a virtual and physical environment.

The goal of the project was never aimed at researchers or practitioners and how we could better understand what neurodivergent participants are feeling. It was aimed at co-constructing an environment where digital skills and experiments could be explored together, where a failure to meet expectations could be incorporated into another round of exploration, where existing hardware and software could be reconfigured as a *thirdspace*—an HCZ—that is easy to replicate and be adapted to specific conditions by researchers, pedagogues, caretakers, and neurodivergent people in their own environments.

While not every social group of neurodivergent participants will have the cultural and technological know-how to be engaged in video production (e.g., for social media or technical skills development) or online exploration (e.g., to create virtual cities), the desire for self-expression and making a unique experience of a lived condition available to others, especially through technical means, will likely remain. I interpreted the example of Thomas learning Houdini and Blender to create a digital wedding ring for his father as his powerlessness in the face of a genuine need for social relations. Thomas could not *not* learn how to make that wedding ring because of his specific connection with his father. The specific tools—Houdini, Blender—are representations of technologies that can accommodate a diverse set of engagements, which means that Thomas could try, fail, and learn over and over again at his own pace and without the support of a dedicated school class or activity. I related this accommodation to a specific sense of control that Thomas could experience and build upon, one, where he was able to achieve visual results on his own and use them in service of his relationship with his father.

I contend that the four PVT principles (Chapter 4) and the concept of HCZs (Chapter 6) can be used as building blocks for future pedagogic practices and/or research and can help kick-start discussions not just about *how* we engage neurodivergent youth through digital technologies, but where and in what kinds of environments. After months-long fieldwork sessions, both in-person and online, I can report that, for this particular project, while the in-person phase was instrumental in establishing the necessary rapport and introducing the researchers to the neurodivergent students and residents, it was the online sessions that offered more time and space for sharing and exploring digital practices, self-reflection, and personal ambitions.

Ultimately, this study aimed to contribute to the literature on research that can help support the sense and practice of personal control that is otherwise structurally, socially, administratively, politically, and economically limited for socially vulnerable populations. Currently, technological domains for digital expression, creation, and participation do not appear to have been adopted in-depth by the institutions that play a major role in regulating and supporting the daily lives of our participants. As such, technological domains still offer spaces where *neurodivergent* youth can share experiences with *neurotypical* youth—they can play the same games, follow the same social media trends, use the same digital tools for creation, go to the same sources of news and entertainment, connect with loved ones on the same platforms, directly engage in the same kinds of humor (e.g., creating game play compilations for others to laugh at), and critically, do all that together. Not using sanitized versions of the internet, hardware, or software tools that are specifically designed for neurodivergent users represents one less barrier to the sharing of ultimately unknowable experiences between neurodivergent youth and their caretakers, pedagogues, researchers, and more, yet such sharing can be achieved with the help of freely available digital technologies.

# CHAPTER 8. CONCLUSION

In Chapters 4–6, I wrote about how neurodivergent young people can be engaged as co-producers of digital content, which results in a process of shared digital moulding. Throughout this thesis, I relied on theoretical sources and two-phase fieldwork to outline a specific conceptualization of a digital intervention approach, which was developed closely with neurodivergent young people who studied and lived in three special institutions in Denmark. This digital intervention approach was grounded in the lived, familiar, everyday digital practices that our target group engaged in and was made up of two parts: participatory video tutorials (PVTs; Chapter 4) and online sessions (Chapter 5). I demonstrated how the four principles for PVTs outlined in Chapter 4 can support digital video production efforts with neurodivergent youth. However, these principles are not exclusive to digital video and could be adapted by researchers and professionals in their existing practices. This would specifically mean that academics and caretakers would be able:

- to recognize the importance of actual practices and technologies (*socio-technical belonging*);
- to use tools that are familiar to participants and/or introduce new tools that are desired and will thus be better absorbed (*technical accessibility*);
- to either use existing methods or (co)develop new ones that would encourage exploration and active participation (*methodological elasticity*); and
- to commit to embedding these practices over the long term, thereby potentially altering and improving existing institutional attitudes in favor of practical support based on well-received approaches that could enrich the daily lives of participants (*material reusability*).
- Further, in Chapter 5 I offered examples of online-only digital activities that support exploratory engagements with neurodivergent youth. Researchers and professionals could benefit from these examples by adapting the re-contextualization of prior content (e.g., trying out the Roblox Studio tutorial in section 5.2.2), exploring various forms of compositing (e.g., from video and 3D compositing in sections 5.2.3, 5.2.4 and 5.2.6), and more.

Such examples show how a traditionally silent population, dependent on personal and institutional support, can be approached via less explored roles of co-producers, creators, and experts – importantly, - in formats which are not native to many professionals (specifically in the participating institutions), or researchers. The opportunity for sharing a process of knowledge building, as well as sharing potential embarrassment or disappointment when the exploration goes in unexpected

directions, is quite important. As Harry notes in a phone interview in Chapter 7.4., this target group knows that "the real world can give you scars" (phone call, 4 June, 2022). While the digital interventions I have reported on are not meant in any way to substitute or diminish the role of in-person, physical interactions, they can be contextualized in ways that stimulate neurodivergent youth to pursue more avenues for self-expression, which can include offline ones.

Thomas can serve as an interesting example in this regard, as months after co-producing the participatory video tutorial and engaging in 3D production, he shared that he was getting more involved in other hobbies with his father, e.g., blacksmithing, woodcutting, and wood construction. I draw no direct connection between our digital interventions and these hobbies, yet it would not make sense to omit mentioning that Thomas – unprovoked – bragged about getting increasingly involved in them.

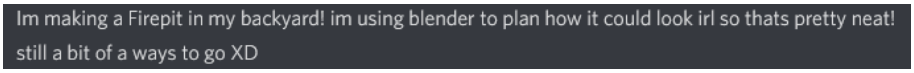



Figure 39. Thomas shares his experience of wood construction in an online chat application called Discord. Thomas's caretaker was always aware of the communication that took place on this chat platform

Figure 40. shows what Thomas's 3D model created in Blender looked like.

Figure 40. Thomas' firepit plan in Blender

Figure 41, which was shared by Thomas, demonstrates the physical progress made by him in putting together a tent and firepit.

Figure 41. Thomas' firepit construction in his backyard

I refer to this example for another reason, namely, to address the abundance of data, which I discuss in the following section.

## 8.1. LIMITATIONS

This PhD project had a number of practical, ethical, and theoretical limitations. For one, the sheer volume of audiovisual material that was produced in the two phases of fieldwork presented a challenge in and of itself. A total of 266.5 hours of audio and video were produced and recorded (approximately 235 hours during the in-person sessions and 31 hours during the online-only sessions). This included footage from voice recorders, two cameras, a 360-degree camera, and a smartphone camera, as well as screen recordings of desktop computers, laptops, tablets, and smartphones. In a traditional video ethnography study, for example, each type of video would be analyzed on its own. Incorporating the sheer diversity of materials, however, presented a challenge to how I could and would approach this data. For example, in focusing on the camera footage from the PVT sessions, I could have analyzed the participants' behavior, physical ticks, body language, interactions with the technology, and more. I attempted to address this limitation by taking inspiration from Derry et al. (2010) who discussed different types of approaches to video data:

> "The aim is to make the complex understandable. This is accomplished through a process of selectively organizing a research presentation (a story) into "digestible" chunks and then contextualizing them within a narrative thread that not only makes

> consumers of the research (viewers as well as readers) feel they were present but may also include participants as partners in telling the stories." (p. 12)

While I consider the many layers of data—video, audio, images, and text—to be an extremely rich repository, I certainly recognize that too much data can be difficult to process and weave into a coherent narrative. This concerned not only the footage of the participants, but also the footage co-created by the participants and me, which introduced another layer of complication.

Regarding the data co-produced with the participants (e.g., the PVTs), I was considerably influenced by Jakob Høgel's (2011) work on hunting for plot and weaving baskets of data. In his article, he wrote:

> "According to Eisenstein, artistic syntax depends on two human principles: Hunting (plot) and basket weaving (interweaving forms) (Antoine-Dunne & Quigley 2003:71) [...] It is about seeing qualities that may not stand out in a single clip but can become visible when put in a certain sequence, like the patterns in a basket. Editing is not building up to a plot climax, but an arduous process of prying out links and contrasts by trying many possible combinations of clips." (2011, p. 8)

This process of hunting and weaving and seeing qualities in video was fairly straightforward to enact during the PVT co-creation process, where the participants and I needed to make numerous choices regarding which seconds and minutes of footage should be used given the hours of available footage. The same process was, however, less helpful in determining which data should be highlighted in my written PhD thesis. In the case of this project, that was primarily due to the multitude of stories that came together that never really fused into a singular narrative (e.g., as discussed in section 4.6.3, some of the participants would show and tell their stories, while others would frustratingly try to cope with ambitions too grand to practically enact). Rather, the narrative in this thesis was supposed to show a tapestry of examples of digital interventions and open up questions and conversations instead of reducing disparate personal narratives to less nuanced descriptions.

While these limitations have been and still are difficult to deal with, they are highly useful in pointing out avenues for future work that could be explored in other projects.

## 8.2. INSIGHTS

Regardless, as well as because, of the known and unknown limitations that shaped this project, many insights and new knowledge were gained, which I would like to address in a succinct manner.

- *Shared digital moulding is important.* Employing digital co-production related to existing interests in an exploratory manner (via tutorial creation or exploratory online sessions) in a digitone/HCZ was a well-received form of support for digital skills development, digital ambitions, and the pursuit of aspirations.

- *PVTs and online-only sessions can be used as a type of customization approach for engagement.* I have demonstrated how neurodivergent youth were engaged using PVTs and online-only sessions. However, for this approach to matter and to be put to good use, it cannot be limited to the participants alone. It has to be applied to the institutions as well. Teachers and pedagogues should have the ability to customize their classes and approaches to include digital intervention practices on a regular basis. This could be undertaken using roles, expanding the thematic focus of existing classes and activities, and more.

- *Participation relates to the moments of thematic contact*. The question of participation with regard to socially vulnerable groups in general, and neurodivergent youth in particular, can appear complicated. What I propose in this thesis is to address the question of *how do we get in touch with* (Bellacasa, 2017) what is important for the target group? Giving workshops (Rice et al., 2018) and providing technologies so that participants can create devices (Frauenberger et al., 2016) provide ways to address that question. I propose that *learning with* and learning *as a co-producer* offers another powerful approach to explore new aspects of participation from a socially vulnerable position.

- *The processes of creation, recording, editing, manipulation, and remixing of video can allow for the quick and authentic explorations of personal interests.* Video editing is important because it is an area of ambition and aspiration that has wide coverage (from TikTok to Blender), and as such can engage diverse groups of participants.

- *We do not hear enough from neurodivergent youth.* While we co-created video tutorials and explored digital worlds with the participants in this project, there are still a few avenues where their practices and creations could be engaged by outside stakeholders. The exception of Anders reaching out to a Danish YouTuber to review his game highlights how isolated this group's voices can be. Digital interventions should echo such voices and not leave them confined to the institutional borders that they study at or live in.

## 8.3. MULTIMEDIA STORYTELLING

In a 2018 paper, Rice et al. discussed a methodological format they had developed called multimedia storytelling. This format is enacted as a workshop and

> can be conceived as a process of auto-poesis (self-creation/self-becoming; Braidotti 2008) in an expansive community space that allows us, as storytellers, to explore the liminalities, marginalities, and privileges as well as uncertainties and change-bilities of our bodily selves and lives. (pp. 4–5).

They also proposed that engaging multimedia storytelling with digital technologies ". . . marks a posthumanist shift away from 'man' as the measure of all things toward more expansive conceptions of humanity, including of subjectivity as a 'construct that emerges in concert with technology'" (McNeill, 2016, p. 66). I referred to the work of Carla Rice and her colleagues (2018) as I see similarities between their storytelling format and the implications of the PVTs and online sessions within the digitones I have presented throughout the thesis. While the need for a contiguous narrative here is less pronounced than in Rice et al.'s work, there is a shared understanding that using digital technologies and a variety of platforms and tools can be

> understood as visualizing and collectivizing biomythography in the ways that they offer users a repertoire of image, myth and history from which to co-create self-stories and give politicized communities access to new spaces for intersectional self-invention and narration (Baer, 2015). (Rice et al., 2018, p. 4)

This sense of biomythography and self-invention and narration appeared to be visible in the online explorations by Thomas and Jens when they played themselves and characters (e.g., a tourist in a cyberpunk city) and used video compositing to create stories of who they were and what they could do (e.g., Jens entering footage of a Danish newscast and controlling the presenter). I propose that the digital interventions in this thesis, as seen through a multimedia storytelling perspective, can be viewed from a feminist perspective and augment our participants' "personal stories with history, myth, and image, moving beyond dualisms of private and public, story and history, text and image, researcher and participant, and past and future to surface/create/tell who we become in relation through our research" (Rice et al., 2018, p. 5). Moving beyond such dualisms would be less difficult to attempt while working with neurodivergent youth when done in an exploratory manner, as shown in Chapters 4 and 5 and conceptualized in Chapter 6.

While Rice et al. (2018) developed and used multimedia storytelling through various types of workshops oriented "towards research reflexivity, . . . exploring social phenomena . . . and . . . open to the . . . public and broader research community (p. 6), I initiated a different kind of digital intervention approach, which was also built on interaction and engagement with multimedia. Specifically, the two types of digital interventions—PVTs and online-only sessions—were focused on exploratory engagement via digital production.

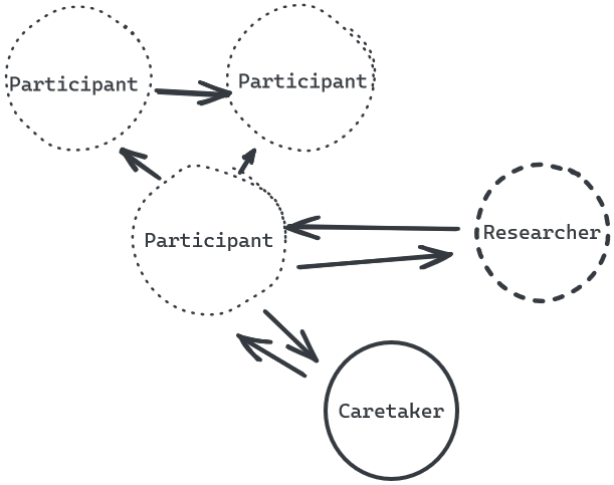



Figure 42. Visualization of a circular flow of information, where participants, researchers, and caretakers exchange and diffuse information and knowledge

An important difference between the methods presented by Rice et al. (2018) and the efforts in my project is that on the one hand, Rice et al. reported on storytelling workshops, which included "group-tailored tutorials on the fundamentals of photography/videography, video editing, and creative writing" (p. 6) where the researchers and professionals taught the participants. On the other hand, both the PVT and online-only sessions in this thesis were co-learning environments in which the flow of information and knowledge was more circular than linear (visualized in Figure 42). Specifically, in the first online session, Thomas and Andreas guided me on how to practically use Roblox Studio, and starting in the first PVT session and throughout the second and third online sessions, Thomas taught me how to use various Blender functions. Figure 42 represents the knowledge exchange between the researcher and participant and how the participant then diffuses that knowledge to fellow students or residents as well as their caretaker. Taking this into consideration with the multimedia storytelling approach by Rice et al., my contribution may be beneficial to academics from the feminist studies and disability studies traditions for which Rice et al. wrote, as it provides examples of different engagement practices with neurodivergent youth.

## 8.4. A PARADOX OF ENGAGEMENT?

Throughout this project, we worked with neurodivergent young participants who were studying and living in special institutions in Denmark. All the participants were thus used to interacting with figures of authority (e.g., caretakers, pedagogues, teachers), and as an outside researcher, I represented one such figure. Nevertheless, the short time I spent with the participants changed the type of authority I might initially have been perceived as having. Davidson et al. (2021) talked about viewing digital

production and technologies as offering a particular sandbox, which could be better utilized in these institutions. However, this possibility could grow into a structural paradox, which I wish to outline here.

The participants in this study enjoy using digital technologies for many reasons. Harry, the head of department at one of the special schools, identified one such reason when he said that the participants' digital ambitions and aspirations were taken seriously in a way they approved of but did not experience to any significant extent in their respective institutions (phone interview, June 4, 2022). Our participants, as well as their fellow students and residents, relied on the caretakers, professionals, pedagogues, and policymakers for the functioning of the institutions. In other words, they relied on familiar structures and activities and a supportive environment. According to Harry, it is in a "teacher's nature" to assist in that regard by leading exercises, structuring activities, and being in control. That reaction is one of the reasons teachers are needed: they can enact an order that is beneficial to neurodivergent youth. As per Harry, teachers "want to support behavior that would help our [participants] to engage better in society" (phone interview, June 4, 2022). Therein lies a potential paradox of engagement, however. When it comes to the use of digital technologies in institutions, teachers' support can easily get "in the way" of the students or residents. The very same institutional structure they rely on and the people who enact it may not be best suited for enabling engagement via digital technologies.

To make the point more bluntly: institutions where neurodivergent youth study and live absorbed traditional technologies (e.g., no hot stoves left unattended, no sharp knives laying around) long ago. That is to say that the daily lives of our target group are generally very safe, which is good. However, these same institutions have not yet had the time, interest, or need to absorb digital technologies in the same way. The paradox I am alluding to here refers to a precautionary principle with regard to the engagement of neurodivergent youth via digital interventions: the positive responses both the researchers and institutional staff witnessed in the course of this study may have been the result of an approach that is antithetical to the current institutional approach. Where teachers may generally want to teach, protect, and guide neurodivergent youth, they might not see the immediate benefit of exchanging digital skills and knowledge on the same topics that their students find interesting. The research outlined in this thesis (methodologically in Chapters 3–5 and theory-wise in Chapters 2 and 6) shows that the exploratory digital interventions allowed the neurodivergent young participants to be engaged in a way that elicited positive responses and resulted in their sharing of those experiences with a researcher and actively building on them. I am not making the case that such an exploratory approach is fundamentally incompatible with an institutional structure. I am, however, drawing attention to the fact that our participants reacted positively to being engaged this way. The paradox of engagement, which I formulated out of precaution and authenticity (Børsen, 2021, pp. 178–179), concerns scenarios in which teachers, pedagogues, and caretakers potentially engage this target group in digital environments by relying on

their experience with traditional technology (i.e., where structuring, leading, and arranging activities play a major role), yet in so doing, neglect to benefit from a different digital-first approach. Throughout this thesis, I have demonstrated that digital technology engagement can be:

- *more practical* to the target group as our participants gained knowledge and expertise in digital tools, which are needed in a 21st century society (e.g., the students who gained an interest in learning how to use a video editing program in Chapters 4 and 5);

- *more enjoyable* as our participants took on less familiar and less explored roles, such as those of co-producer, world builder, and social media content creator (as seen in the making of the PVTs in Chapter 4);

- *more interesting* as our participants had the opportunity to follow and train an exploratory instinct, which can be dangerous in a purely physical environment (see experiment with world building in Chapters 4 [virtual landscapes in Roblox Studio] and 5 [tourist in a cyberpunk city]);

- *more natural* as the engagement relied on access to existing technologies, which were chosen by our participants and were in active daily use (e.g., smartphones, digital platforms).

As such, I am not condemning the existing institutional framework of actively preventing neurodiverse youth from experiencing and engaging in interesting and positive experiences. Instead, I am making the case for exploring and further developing the potential of digital interventions in participant engagement, the support of digital ambitions, and social needs. The horizon of possibilities for neurodivergent youth may otherwise be constrained by a system-centric view (where grades and policies regulate what is to be done and how) instead of possibilities and actual abilities (where the low-hanging fruit of "let's try to accomplish something new" is not seen as vital). The exploratory attitudes shared between the researchers and participants throughout the fieldwork for this thesis proved to have a positive effect. They created spaces for digital exploration by building on the existing digital practices engaged in by our participants and further expanded those with relevant information available online. The relevance here was not dictated by a policy, but was rather determined in the dialogue between the participants and researchers, as well as the pedagogues.

This exploratory approach appears to be in contrast with the system-centric view, where curricula-based studies, grades, and structures are the foundational way for interaction. What, then, might it mean for an institution to adopt exploratory approaches with a focus on digital interventions? There have been attempts at residential sites and special schools to create, for example, makerspaces and digital fabrication environments, as reported by Harry (phone interview, June 4, 2022). In his

experience, however, such efforts were very much regulated and difficult to sustain. For this reason, I propose the digital interventions presented in this thesis as alternative ways of engagement.

## 8.5. FUTURE STEPS

To begin addressing the question of the future steps this project could take, I first need to reflect on the changes I experienced during this project and how they have affected what I see as possible and necessary. I therefore pose the following questions:

- How have I changed during this project?
- What have I learned about the purpose of research with neurodivergent youth via digital interventions?

In 2019, at the start of field study 2 and before reading any articles, journal papers, or books, watching relevant videos, or spending countless hours in discussion with academic staff in Denmark, Bulgaria, and Australia as well as with other friends and colleagues, it struck me as peculiar to talk about youth living with cognitive disabilities in a digital context. If my supervisor had to use my computer, I thought, they would surely feel like they were limping digitally, with all the hundreds of customizations I have made to my system. I was sure I would feel the same if I had their computers as well. In a sense, I thought, we are all disabled when it comes to digital technologies as, by definition, there cannot be one right way to use them. It is all a process of adjustment. After two and a half years of working on this project and spending time (although admittedly not as much as I would have wanted) with 16 neurodivergent young people, my thinking on these questions has changed.

The DiGi projects' embrace of Vygotsky's (1993) defectology, combined with the unexpected in-person and online sessions with our participants, made me realize the following: Focusing on specific digital configurations to engage neurodivergent participants offers an inexhaustible source of knowledge and information, and researchers and professionals can—and likely will—engage endlessly with them. The more important and interesting questions for me, however, turned out to be those concerning the emergence of co-constituting human–technology relationships, for example, the fact that Thomas was incapable of not learning how to use Houdini and Blender to create a digital wedding ring for his father, and the fact that Josephine could not not create a sort of private, message-based audio and video channel for the people she loved by sending them dancing and singing videos while being minimally verbal. While at the start of field study 2, I would have thought that there was more to the intentional, somewhat rational, and person-centric desire that people have to customize their technology to how they like and use it, I now think otherwise. Based on what I experienced with our participants, I am more interested in future iterations

of this project aimed at exploring how socially vulnerable populations gravitate toward certain technologies due to them being the only existing (or only known) means of self-expression, self-exploration, and social communication.

Thus, my thinking on the second question—about the purpose of digital research with our target group—has shifted. While in phase one of my fieldwork I proposed a normative video tutorial structure, the purpose of which was to be filled out and customized by our participants, at the end of this project, I had turned toward more "off the script" experiences. Specifically, these are where processes of shared digital moulding and shared joys and anxieties with socially vulnerable populations can be a stepping stone to new shared socio-technical relationships between researchers, target groups, technologies, and stakeholders; where research could aim to uncover spaces for curiosity (e.g., Thomas wanting to create a virtual environment where others would be able to feel what he feels) and what-ifs instead of prescriptive research. That is why it is my hope that, through its descriptions and stories, this project will raise more questions than it answers.

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# APPENDIX

In the course of my PhD, I have attended research seminars and presented at an international conference. The appendix includes a paper called “Digital Producers with Cognitive Disabilities: Participatory Video Tutorials as a Strategy for Supporting Digital Abilities and Aspirations”. The paper has been published in and presented at the INTERACT 2021 conference in Bari, Italy, 30 August – 03 September 2021. It presents a digital intervention strategy that supports digital empowerment of young people living with cognitive disabilities, their reactions to it, and four principles for digital engagement offered to researchers and professionals.

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# Digital producers with cognitive disabilities: participatory video tutorials as a strategy for supporting digital abilities and aspirations

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**Abstract.** This paper presents 'participatory video tutorials' – a strategy developed to support digital empowerment of young people living with cognitive disabilities. The support strategy complements and expands dominant perspectives on the target group, which is often seen as disabled and with need of assistive technology, by foregrounding the young participants' digital abilities and facilitating that they can be active producers of digital content, which already plays a major role in their everyday social interactions. We present the background and framework for participatory video tutorials and the results from staging digital production with 16 young participants. Empirically, the results contribute perspectives on this target group as producers (vs. users) with abilities (vs. disabilities). Method-wise, the results outline four principles (socio-technical belonging; technical accessibility; elasticity; and material reusability) that can assist HCI researchers, professionals, and caretakers in their efforts to support the target group in digital production. These principles are guidelines for a participatory staging, driven by the young people's motivation for self-expression. The study and the results contribute an example and a strategy for how to work with digital inclusion by engaging a marginalized target group in digital production.

**Keywords:** Cognitive disability, youth, content production, tutorials, participatory design

## 1 Introduction

Video tutorials are commonly used and produced by lay people to share knowledge and skills on various interests. There are no limits on the uniqueness of topics and interests dealt with in online video tutorials and that is perhaps one of the reasons for tutorials to become a popular format for informal learning. In this paper we report from research using a video tutorial format to engage and support young people living with cognitive disabilities in sharing and advancing their digital abilities. The motivation for this research is grounded in empirical studies identifying an increasing use of digital technology in the everyday life of people living with cognitive disabilities and a subsequent call for strategies to support this target group in their

digital abilities and aspirations (Andreasen & Kanstrup 2019; Seale 2007). We present how we have developed and explored video tutorials as a format for supporting digital production with 16 young people (age 14-28) living with one or more cognitive disabilities. We have coined this strategy 'participatory video tutorials' – a strategy that supports the young people to be active producers of their own digital content. The producer role comes with responsibilities, skills development and social relations and we argue that this support strategy can contribute to the empowerment of this target group.

As discussed by Seale, supportive strategies for digital technology as a tool for empowerment of this target group are challenging (Seale 2007). Conflict of interest can easily occur when support of independence clashes with the role of professional or caretaker (families and friends). For example, in situations where those aiming to support people with cognitive disabilities fear backlash from the digital production activities, intentions of support can bring oppression on the young people's ability to speak up. Support of digital production is a difficult balance with risks of being counterproductive to ambitions of empowerment defined as the power to act with others and by this develop knowledge and abilities to influence personal and social spheres (Freie 2006). The developed strategy works with challenges of empowerment by suggesting structure and a process for cooperation with goals that are not just supporting the young peoples' personal development, but also competence to contribute to collective development (Ibid.). The study complements dominant perspectives on this target group as disabled with a need of assistive technology as it brings a conceptual perspective on digital technology as a production tool and the young participants as active producers of digital content that plays a major role in their everyday social interactions. Method-wise, the paper contributes guidance to a participatory staging driven by the young people's motivation to self-expression. In the following we first present background information on cognitive disabilities, related work on this target groups' uses of digital technology and participation in digital production. Second, we present the participatory video tutorial format and the principles of the developed 'participatory video tutorials' and how we staged this approach in four settings with 16 participants. Third, we present the results, including an analysis of the participants' ways of engaging in the digital production and the developed tutorial format. We discuss these results in relation to the concepts of empowerment and digital technology use for people with cognitive disabilities and conclude with guidelines for using participatory tutorials as support strategies for care workers. Additionally, we make suggestions for future research on approaches to engage people with cognitive disabilities in research on the design and use of digital technology. The study contributes insights to Human-Computer Interaction (HCI) research on how to engage a marginalized target group in design and use of interactive technologies and bring reflections on strategies for digital inclusion.

# 2 Background

## 2.1 Cognitive disabilities

Cognitive disabilities can be presented through a broad variety of clinical diagnoses that affect cognitive abilities. In the study presented in this paper all participants live with a neurodevelopmental disorder and have one or more diagnoses like autism, learning disorder, Down's syndrome, and ADHD. Additionally, some of the participants are diagnosed with anxiety, and sensory impairment is common (Schalock et al. 2010). Thus, it is difficult to present the participants with a specific diagnostic label since most are challenged by comorbidity and because of diagnostic differences and consequently different individual competencies and potentials even for participants sharing diagnoses. Additionally, like for all human beings, possibilities for development for people living with cognitive disabilities are influenced by dynamics of the individuals and social groups that they interact with (Ochs and Solomon 2010). An ecological focus from the World Health Organization 2001 is often presented as an important theoretical model for understanding this target group, emphasizing a broad variety of factors influencing individual functioning, including health, context, participation, adaptive behavior, support, and intellectual abilities (Scharock et al. 2010). On this background we join HCI researchers arguing for a broad perspective when aiming to understand and engage this target group in HCI research (Sitbon et al. 2018).

## 2.2 Cognitive disability and digital technology – a call for participatory support strategies

Research on the use of digital technology among young people living with cognitive disability is limited, but some studies show how internet technologies offer opportunities for this target group to develop and maintain social relations (Alcorn et al. 2011; Pincheviski and Peters 2015; Ringland et al. 2016; Seymour & Lupton 2004; Söderström 2009 and 2011; Caton and Chapman 2016) for example by participating in social activities mediated by e.g. online multiplayer games (Ringland et al. 2016), online dating platforms (Löfgren-Mårtenson 2008), and in general by mobile applications (Söderström 2009 and 2011) and a broad variety of consumer applications (Andreasen and Kanstrup 2019) that support abilities to reach out and share experiences through digital technology. However, research has also shown that digital participation is complex and requires support for a target group living with one or several cognitive diagnoses. The target group often profits from visual communication, known structure and repetition, and social interaction with a limited number of participants. Digital technology can support some of these needs, but challenges related to understanding social codes (Caton & Chapman 2016) just like challenges related to inclusion in social groups exist online (Seale 2007; Löfgreen-Mårtenson 2008). Research has identified a motivation among the target group for creating and sharing online content to develop friendship (Seale & Pockney 2002;

Hegarty 1998) but also a need to empower the participants to be able to take responsibility and manage online interaction.

Professionals and carers often act as mediators when people with cognitive disabilities engage in digital production (Seale and Pockney 2002) and the limited research on how to empower this target group in online activities has emphasized the complexity related to this type of support. An empirical study from 2007 of how adults with learning disabilities were supported in online publishing activities concluded that support strategies often have the potential to place this target group 'in a passive role where they are recipients of technological expertise and protective guardianship'. (Seale 2007) Hence, there is a call for solutions that encourage carers of people with cognitive disabilities 'not to underestimate their ability to cope with the risks of Internet use and to recognize the 'resilience' that might be created through interdependent collaboration with support workers' (Ibid.).

We build on the above related research in our development of support strategies for digital production, specifically by anchoring our research in Vygotsky's theory on 'defectology' and his concept of Zone of Proximal Development (Vygotsky 1978). According to Vygotsky, a child with a disability is no less developed than a child without a disability, but develops in different ways than most children, i.e., the norm. With this perspective, it does not make sense to focus on the disability, i.e., what Vygotsky terms as the defect. What is important is to focus on the unique since the disabled child represents a qualitatively different development. Further, as captured in the concept of the Zone of Proximal Development the child is able to perform other activities when guided by a more capable peer. An important aspect of Vygotsky's theorizing is thus to focus on the environment in which the child is learning and the support from more capable peers. This perspective has formed the theoretical background for developing participatory video tutorials and grounded our attention on the participants' abilities and aspirations. We term this a participatory approach as it is related to HCI research calling for development of approaches that can support opportunities for people with cognitive disabilities to participate and express experiences and desires with digital technology (Bircanin et al. 2015). People with cognitive disabilities tend to participate in design and research by proxy (Brereton et al. 2015). However, the limited related HCI research shows that this target group is able to participate in design and research activities but requires flexible staging (Makhaeva et al. 2016), careful interpretation (Frauenberger et al. 2019), and respectful interaction emphasizing attention to mutual learning, self-expression, and self-determination for the participants (Rajapakse et al. 2019). In general, this research follows core principles from Participatory Design treating people as competent practitioners and experts in their own experiences and practices (Greenbaum 1991) and contributes insights on how to stage participatory settings for marginalized users. In the following we present how we have worked on this background in the development of participatory video tutorials.

# 3 Participatory Video Tutorials

The research is carried out in cooperation with four institutions for young people living with cognitive disabilities. All participants (16 in total, aged 14 through 28 years old) study at or live in the institutions, located in a city in Northern Denmark: (1) a school for children with cognitive disabilities (ages 6-17), (2) a high school for young adults with cognitive disabilities (ages 18-22), (3) a sheltered residence for young adults with cognitive disabilities (aged 18-28), and (4) a sheltered residence for adults with cognitive disabilities (from age 28 - three of the participants in our study moved during this research from the sheltered youth residence as they turned 28). The research is carried out in close cooperation with these institutions where staff are confronted with the young people's increasing and comprehensive use of digital technology and in search of support strategies for these activities. The two schools have set-up computer areas and dedicated time for a staff member to stage activities in this area, for example to support the young participants in online gaming and production of specific content. The sheltered residences have tried to initiate conversations with their young residents about digital behavior. All four institutions are interested in exploring ways to engage the young people and develop support strategies that can facilitate their digital abilities and aspirations. The decision to explore opportunities for this through the tutorial format was taken in cooperation with the institutions where a project team of management, teachers and pedagogues have participated in ongoing research and development of digital activities.

All participants are Danish and excluding one minimally verbal person, 15 can communicate in Danish, 8 out of the 15 can communicate in and 6 can partially understand English. English language skills make it easier to interact with the interface of some of the programs used for digital creation (this is especially helpful for participants who watch English-language tutorials on platforms like YouTube). All participants live with either Down's syndrome, ADHD, autism, and/or intellectual disabilities, and several of the participants struggled with anxiety and other mental conditions. Inspired by Vygotsky (1978) and participatory design research (#Simonsen & Robertson), the point of departure for developing the participatory video tutorial format as a support strategy has been to acknowledge the diversity of the young participants and to enter their world (vs. developing a fixed format). Consequently, the point of departure has been to openly ask the participants what they feel skilled in doing via digital tools, and how and why they want to present their abilities to friends and fellow peers. With Vygotsky's concept of Zone of Proximal Development, we engaged with each participant on their specific terms and needs, acknowledging that the needs and requirements can change during the production process. The participatory video tutorials format allowed us to work on developing a unique tutorial structure, grounded in each participant's specific digital abilities and aspirations. Overall, we adhere to principles of reciprocity and commensurability, where both participants and researchers have shared responsibilities in the common goal to co-create a video tutorial together.

Tutorials as an audio-visual format are well known to the participants. The participating schools often use tutorials and work with information that relate to the young people's specific topics of interests. The sheltered residences have had positive experiences producing their own short tutorials about everyday tasks (how to use the dishwasher etc.), which the residents can access via QR codes. Thus, the participants all have existing positive experiences with the tutorial format. To facilitate a process that is not just personal but also a collective development (#Freie) we created an unlisted YouTube channel where all participants can upload their own material. Importantly, they can also see material co-produced by friends in their own or other institutions. Producing for a YouTube channel comes with specific commitment to making the process focused, professional and engaging in a recognizable way for our participants. We named the YouTube channel '#ProjectName TV'. To stage a professional atmosphere around the production, we created a logo and printed it on a large poster, which was set-up in rooms at the institutions dedicated for production. The ambition was to underscore the action-oriented approach of the tutorial production and to support the participants in tapping into a co-producer mode.

### 3.1 Participatory video tutorial production sessions

To engage the participants with the tutorial format, a production process was developed with three sessions: pre-production, production, and review, elaborated in the following. The process requires coordination with the institutions that prepare the participants for the activity which is especially important for this target group.

**Pre-production:** At a one-hour meeting volunteering participants from all institutions were presented with the video tutorial idea and structure, which includes a 3-to-5-minute video, consisting of three steps: (1) area of interest, where the young people present an overview of their digital interests, (2) a demonstration of digital skills, where they show how they achieve their interests, and (3) tips and tricks for solving issues that viewers should consider. The participants were asked about their digital interests and what they would like to make a video about. To help structure their responses, they were given a sheet of paper called 'tutorial script' where they could reflect on questions like "*I would like to make a video tutorial about..."* and "*Who would you like to watch your video tutorial?".* The researchers and participants discussed these questions, but answers were not required immediately. After this meeting, the young participants shared their thoughts about the production of tutorials with support staff at the institutions. This worked as preparation for both the young producers but also for the researchers as a help to better understand what types of digital skills the participants were interested in sharing and developing (question 1.) as well as providing an indication for what social groups or audiences they saw as important (question 2.). An important part of the preparation was preparing the participants for their role as producers. Hence, the upcoming production sessions were predicated on the idea that the participants are digital producers who have volunteered to demonstrate digital ideas and abilities and share their interests via their digital skills with friends at their school and similar institutions in their city via the #ProjectName YouTube channel. It was clearly communicated that the researchers played a

secondary role as co-producers, who supported the participants' in their production with recording equipment and with editing the material.

**Production** of the tutorials: This part of the study was carried out during two-hour sessions with each participant. The production rooms set-up at the institutions were equipped with video cameras (one stationary, one mobile, one 360-degree) and audio recording devices (dictaphone and wired microphones for the participants). Screen capture software was crucial for the sessions, as it allowed the recorded footage of the participants' activities to be edited later. For desktops and laptops, we used Open Broadcaster Software (OBS), and for recordings of mobile phones and tablets we used the integrated screen recording functions of iOS and Android. Once the recordings began, one of the researchers engaged in a semi-structured dialog based on the tutorial script that the participants had prepared before the recording sessions. During the recording, the interviewer detailed the script via conversations with the participants as they explained what they were doing and why this was important for the tutorial they were producing. This script used the three-step structure of the tutorial (1. area of interest, 2. demonstration, 3. tips & tricks) and added notions of visual style (e.g., background music, text, fonts, colors), ensuring that the participants' ideas of content and style are represented as best as possible. Every participant was informed that the screen recorded content and on-the-spot-made script would be used for draft videos, which they should review in follow up sessions. Immediately after filming, we initiated short and rough video editing sessions as we imported footage of the recording session in DaVinci Resolve, a video editing program, and quickly visualized the script into a video timeline (see example in Fig. 1).

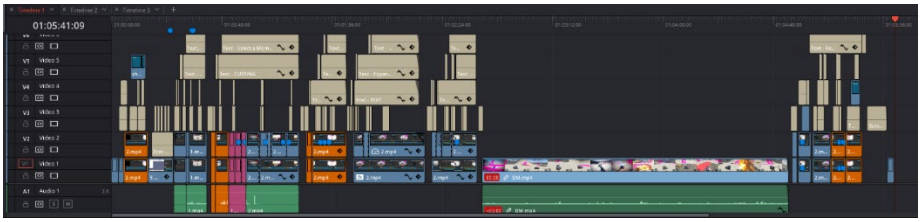


**Fig. 1.** Example of a script turned into a video timeline: there are 8 distinct sections to this specific video tutorial, demarcated horizontally by different colors and spaces between the elements on top.

Participants were invited to make corrections on the timeline, so it best reflects the structure they had in mind for their video. Aside from these in-person sessions, video editing took place after the production sessions ended. Researchers edited the original video files outside the institutions and created draft tutorial versions with the explicit intent that they should be reviewed by each participant before finalizing them.

**Review**. After the production session, a researcher created draft versions of the tutorials, based on the materials and conversations from the production sessions. In a one-hour follow-up session the researchers played this draft video to each participant individually and asked them for feedback. Participants were encouraged to say what they liked and disliked and point to it on the screen. They were also invited to individually engage with the video editing process by taking control of the editing software and making changes on their own. For some, this involved changing font colors, while others would engage in a narrative exercise, moving video sections around on the timeline and changing the structure and meaning of the video. The review process consisted of 1-3 iterations, and it ended when participants found the tutorial ready for publishing on the #ProjectName TV YouTube channel.

**Sharing** the tutorials. All tutorials were published on an unlisted YouTube channel (meaning only people with a specific link could access it) and shared with support staff from all institutions. A premiere was set-up at two schools and one sheltered residence. Two videos were made at the second sheltered residence, but the young people there did not express a desire for a public premiere, and instead opted to have their video tutorials shown at the first sheltered institutions, where they have lived previously and knew most of the current residents. During the video premieres, fellow students and residents were invited to see the tutorials. At this session, each producer was presented, we watched the tutorial and in some cases the audience asked questions. The premieres were staged as a festive activity with a red carpet laid out for the participants, applause, and popcorn. The physical and digital acts of sharing the finished videos is meant to support social relations the participants have between themselves, as well as social relations with other students or residents in any of the participating institutions.

# 4 Results

All production sessions total 143 hrs. and 52 min. of video footage, recorded by the researchers using three cameras and one smartphone. Researchers and participants co-edited the footage into 13 video tutorials, totaling 52:05 min., and averaging 04 min. per tutorial. There are three videos produced by a 2-person group, and 10 videos produced by one person. The agreed upon structure of the tutorials (3 to 5 min. per video, 3 sections) was followed through and carried out. As stated by staff members at one of the institutions, a main result of our strategy is that the process succeeded in engaging the participants to follow all the production steps and to produce a video. This is especially important as several of the participants had a history of withdrawing from activities or not finalizing them due to diagnoses and difficulties with coping with demands for focus, conversation and delivering, all of which were a requirement in our format. By supporting their engagement with video production, we established a space where our participants transition from consumers to producers of digital content.

In this section, we outline three key insights from our participatory video tutorial strategy: (1) staging a professional setting, (2) embracing multiple production

strategies, and (3) sharing digital production. These three insights are based on analysis of video recordings from the production which have been coded into themes identified as related to the young participants' engagement with the tutorial format. All participant names are anonymized following informed consent with a support person present. The identified three insights come together to offer a framework which is rigid in its constitutive parts (what the video tutorials are made of, and how they are carried out) as well as its output (the videos themselves). The framework proved flexible enough in that it was easy to adapt to each individual participant, either with props during filming or video style during editing.

### 4.1 Setting the stage for professional production

An important lesson learned from the production of the 13 tutorials is that it is vital to set a stage for professional production. The participants all came with expectations to the filming sessions. An example is Malte who had studied production techniques before we met, and who came in with the idea to do something with "a green screen" and "video". When he entered the production room for the first time, Malte expressed reservations towards the two 4K cameras we brought to the production room, dismissively asking "are they only 4K? Where are the 16K cameras?" and then asked, "What about the green screen?". Malte wanted to make a tutorial that presents techniques for creating a drawbridge in Minecraft. He requested an overlaying image of himself on top of the Minecraft footage, which could be added by manipulating video with the help of the previously requested green screen. School staff provided a green sheet which was set up on a whiteboard and that seemed to satisfy Malte's needs regarding the production room (cf. Fig. 2). Starting the production, it turned out that Malte did not want his own face to be part of the video. Consequently, the green screen was not a production need but important for staging a professional setting. Malte decided that he wanted to create a digital avatar which could be used instead of him inside the video tutorial. This start of the production demonstrates two things: first, Malte's individual knowledge of video production, and second – most importantly – the expectations and aspirations of our participants. Creating a tutorial may not technically require 16K or 4K cameras, but it does require staging that feels professional to the participants, as well as a specific goal, a clear framework, a well-suited stage with dedicated time, quiet room, as well as participants who know their roles, are dedicated to the cause, and can adapt to the demands of the moment. The entire activity seemed to diminish in value if the production setting did not reflect a serious commitment to respectfully and adequately representing the interests of the participants.

**Fig. 2.** A video tutorial recording session with cameras, light, greenscreen, microphones and computers.

The two 4K cameras, 360-degree camera, dedicated software, 2 microphones and 2 artificial light sources film our participant physically and his Minecraft skills digitally. We figuratively and quite literally put him in the spotlight to physically underscore the video production mode we were engaged in. As we work within a participatory design framework, where the research is not directed *at* our participants but conducted *with* them, we highlight the role of the equipment as something that solidifies a fundamental methodological point: Malte is the expert of his activities, he decides what information is important and what needs to be shared. He is a co-producer of a participatory video tutorial format, and we find out what the tutorial will be about together, while we film and edit next to the green sheet, cameras, and in front of the video editing software. The professional setting transforms our efforts from ideas into specific tutorial script and video.

### 4.2 Embracing multiple production strategies

The role of a digital producer comes with making choices about form and function and requires the participants to pay a different kind of attention to the task at hand. When they engage with the format and present something they care about, they are prompted to pay attention to *what is important* about their area of interest. This task is inextricably linked with the practical issue of figuring out *how to visualize their area of interest* for others and for themselves. Both questions require levels of reflexivity and decision-making that turn this video tutorial format into a viable tool for support staff and researchers to better understand what kind of digital production support is needed by youth living with cognitive disabilities and why.

The choices our participants make are inherent to the role of a producer of any content. What makes them important as a result for this paper is the analytical potential they carry for researchers and support staff who strive to better understand different digital production strategies developed by the target group. We have identified four

approaches that describe how our participants engage with the participatory video tutorial format.

**4.2.1. Coping with ambitions.** The first approach deals with ambitions that exceed the participants' current technical abilities. For example, Malte created a digital environment and an avatar in Minecraft. His ambitions for the visual look of the avatar in the tutorial required transparency in the image, which the researchers could not support to a satisfying degree for Malte (the result can be seen in Fig. 3). Frustration was visible when Malte tried to but could not accomplish the task and would not give up on the idea, later returning for a third session with an avatar he had made and was satisfied with. Another participant, Carl, found himself in a similar situation when he saw the draft version of his video tutorial. In a video about setting up and playing a 3D game set in space, Carl felt displeased with the draft narrative we have presented him with – the message he felt as most important was not clearly presented, according to him. So, Carl decided that he should re-record audio voice-over for the tips & tricks part of the video and fix the issue.

**Fig. 3.** (**Coping with ambitions**) Digital avatar and environment prepared by a participant. Removing the unequal shading around the avatar was a big technical issue.

These examples serve to highlight how young people with cognitive disabilities struggle to re-formulate their ideas and make sure they are faithfully represented in the final video version. There is a clear desire for digital production, but an unclear way of realizing that desire. The participatory video tutorial format elicited a hands-on approach from some of our participants, where they attempted to fix what was perceived as a sub-standard technical performance as well as have them forcefully alter the agreed-upon script and use their own voice to reformulate specific tips & tricks. These participants show how they take ownership of the video and how they go about the strong opinions they have about visuals and narrative. Ambitions, which may not be easy to accomplish right away have seemingly not deterred Malte and Carl, but rather inspired them to improve their skills as digital producers. All participants have put a lot of thought into the content and style of the video they have produced. This is also important as staff and family can tend to think that the young people are just relaxing or playing with digital content, when in fact they are very serious about (in these cases) producing Minecraft environments, 3D games, etc.

**4.2.2. Show and tell.** In contrast with the previous production strategy, several participants exerted almost no production control over the form and content of their video tutorials. They would share how they execute certain tasks, e.g., Josephine's communication via iMessage (Fig. 4), and leave the production session relatively faster compared to others. These participants seemed disinterested in the production process but interested in sharing their digital insights and seeing their content in a finished video form. Their relation to the participatory video tutorial format is much more direct, in the sense that they acted only on the explicitly verbalized tasks (e.g., sharing a digital skill, choosing fonts, etc.), therefore making the format and the video their own to a lesser degree compared to others. This type of reaction to the format is important as it highlights its limits and outlines where it might break down if not adjusted even more to fit each individual's needs.


**Fig. 4.** (**Show and tell**) Participant demonstrating how they attach a video file to an iMessage conversation.

Researchers and support staff should use this type of reaction to also incorporate the format's limitations in their planned activities.

**4.2.3. Connecting physical and digital experiences**. The third type of reaction to the participatory video tutorial format were two independently requested LAN parties at a school and a sheltered center. Participants interpreted the opportunity to create a video as a chance to record a live activity. They expressed a great desire to set up and film a physical activity and shared aspirations about participating in LAN parties. Researchers and support staff facilitated a LAN party, and a producer documented the entire event. The producer recorded the activity with a GoPro camera strapped on them, as well as a second GoPro camera mounted on a wall, filming a time-lapse (thus condensing around 5-6 hours of video footage into 5-6 seconds). At both institutions, participants were either helping with or taking the lead in setting up cables, laptops, desktop computers, physical areas for virtual reality games, and so on. Hence, the video was very much a documentary showing how to set-up a LAN party, the joy of gaming with others and cleaning up.


**Fig. 5.** (**Connecting physical and digital experiences**) Initiator of a LAN Party (red hat) plays a game with friends.

At both institutions, the LAN parties had powerful effects, combining physical, festive events with digital activities to support digital production among the target group. This was largely achieved through a merger of technical aspects (the GoPro camera strapped to one participant and mounted on walls to capture the entire event) and social conventions (gathering to watch others play in Fig. 5). Both events ultimately featured long gaming sessions (anywhere between 6 and 8 hours) and the video tutorials focused on what are the important building blocks for such coveted activities (e.g., equipment, games, and friends).

**4.2.4. Performative role.** The final reaction to the tutorial format is visible in four examples, where the young people displayed an almost effortless control over their preferred medium of work: the process of preparing for, shooting, editing, and publishing a video on TikTok, video import, editing and exporting in the open-source ShotCut video editing software, creating landscapes in Roblox Studio, and a full recreation of the intro to Netflix's show *Stranger Things* in the 3D modeling program Blender (see Fig. 6).

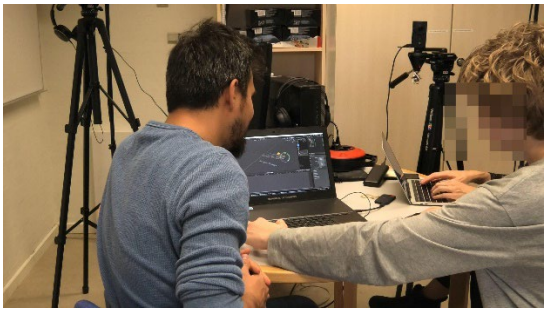

**Fig. 6.** (**Performative role**) Participant demonstrating how he transforms letters in Blender.

The video tutorial format was applicable to the interests of these participants as they are all visual, with a narrative and somewhat clear structure and goals. The main task

these participants focused on as digital producers was to perform what they know well and make clarifying corrections at the review sessions when the researchers' draft videos were not clear enough in visualizing their ideas in the tutorial. As digital producers, the participants' roles were characterized by the need for a good setup - physical (room, adequate equipment) and digital (video editing software to edit their presentations), - and the time and space to present what they have made. This engagement with the tutorial format is somewhat similar with the first type (*Coping with ambitions*) in that this group of participants has a clear idea of what they want to create, and they execute on it. The main difference is that this group is generally pleased with their result and finds a way to overcome any issues that may arise during filming and editing, in contrast with the first group, whose ambitions always seem to outgrow their technical skills. The performative role thus requires less technical support (they have already mastered their tools) and more socio-technical presence, where a caretaker or support staffer would learn with this group how their tools (Blender, TikTok, Roblox Studio, etc.) can be used in new and exciting ways (e.g., to gain more followers on TikTok or to create new worlds in Roblox that can be used for game design).

### 4.3 Sharing digital production

In section 3.1. we described sharing the tutorials as a key part of the participatory video tutorial structure. As emphasized in our theoretical framework, empowerment is not just about personal development but indeed a collective development. The participatory tutorials were developed as a strategy to support this by not just focusing on the individual's digital skills and aspirations, but also sharing these and connecting to others via the YouTube platform. The inherent purpose of the tutorial format is to be shared and used by others. This concept is not only simple, but the format was already familiar to and embraced by our participants. Our experience in this part of the strategy is positive, but basic as we have merely created a private YouTube channel and did not research practices of engagement with it. We have not yet conducted future research on methods of supporting the sharing and viewing self-produced materials. We have facilitated three premieres, presenting the produced tutorials to an invited audience. While this might seem simple, it was a step that was highlighted by the staff as a success. Several of the participants are not keen on sharing with others. Watching the participants present their tutorial as proud producers was a positive conclusion to the process. A teacher at one of the institutions argued that having a result to show and share is important in most activities and this activity resulted in products they are proud of.

Several of the participants appreciated the production process so much that they reached out to the researchers after the premieres to be able to continue their activities as digital producers. Two participants emailed the researchers a few months after the premieres to request access to the channel so they can view and share their videos with others. Two participants, Andreas and Thomas specifically requested an altered version of their video tutorials with no mention of their affiliation to the research

project. They wanted to republish the videos as their own on their personal social media channels. Emilie, another participant, shared the TikTok video we co-produced on the social platform immediately after the filming session and we monitored engagement with the post for a few weeks (the post did not dramatically alter the participants' follower count). Another participant, Jens, produced a tutorial about German foot soldiers and reached out to the researchers during the draft video editing phase with a coat-of-arms he had made for his personal YouTube channel. Jens wanted the coat-of-arms to be in the video so he could also use it on his personal social media accounts. These are some of the main examples of participants, unprovoked in any direct way, requesting specific actions that would make it easier for them to share their video tutorials with others and continue their activities as digital producers. The participatory video tutorial format was engaging enough to support and stimulate the participants' need for sharing self-produced materials with others.

# 5 Discussion

The participatory video tutorial strategy presented in this paper was developed in cooperation with the young participants and the staff at four institutions in North Denmark. The processes succeeded in engaging all participants in the process and production of a tutorial which, by the participating institutions, was identified as a success since several of the participants had a history of withdrawing from activities or not finalizing them due to diagnoses and difficulties with coping with demands for focus, conversation and delivering. Though the participatory video tutorial format is demanding as the producer role comes with responsibilities, skills development and demands for social cooperation, sharing a key finding from this study is that the format has an elasticity that made it possible to meet the target group with all its diversity. Surprisingly, the digital arrangement proved to be more fluid and easier to manipulate than the physical arrangement, which required much more thought and care to set up. The tutorial format proved to be able to support the participants in not just producing and developing their own digital materials and skills, but also as a format for sharing their activities and interests and by this support their ability to reach out to peers. The analysis also showed that the four-step process of engaging young people with cognitive disabilities as producers of digital content relies on their familiarity with the software applications and digital platforms, as well as their desire to create something and make it available for others to watch. A synthesis of these results identified four important principles for supporting this target group in digital production elaborated in the following section.

## 5.1 Principles for participatory video tutorials

We have shown how our strategy has allowed the 16 participants to become active co-producers of digital content they like. We found that being a co-producer comes with a set of characteristics: (1) responsibility (to play their role as co-producers in a professional environment), (2) skill development (to have the reflexivity for sharing

existing abilities and developing their abilities through a tutorial process of sharing) and (3) social interactions (establishing a working relationship regarding digital production with the researchers, support staff, and sharing the finished material). On this basis we argue that participatory video tutorials can be used as a support strategy for the digital production needs and ambitions of young people living with cognitive disabilities and by this contribute to digital empowerment and inclusion of this marginalized target group. We have summarized four principles out of the research process, and we claim that the participatory video tutorials act as a support strategy when they:

1. Already belong in the socio-technical environment where they are to be deployed. As was the case with our participants, most of them were already familiar with the idea of the format, have watched tutorials or have been making tutorials themselves. The format already had a place in their everyday lives.
2. Are technologically accessible. There is no requirement to have the same equipment as our research team (with 3 cameras, lights, microphones, etc.). Similar if not the same effect can be reproduced with existing technologies, e.g., a smartphone and free video editing software.
3. Are elastic. To faithfully represent and clearly visualize unique self-expression by different individuals, the format must be methodologically elastic. This means that its structure (e.g., the 3-step tutorial framework) should be equally understandable to participants who act only when they are explicitly asked to as well as to more outgoing participants who want to pursue very specific ideas and outcomes.
4. Produce reusable material. To ensure that the positive change brought about by the format is permanent, its constitutive parts – the video files, the filming environment – must be easily reusable in different contexts. For example, our co-produced videos were collected in a private YouTube channel that can be used for creative and educational purposes by the participating institutions.

The core contribution from these principles is that they refocus the participants as people with abilities (vs. disabilities) and producers (vs. users) of digital content through the production responsibilities of the format. Another important finding is that participatory video tutorials are not just a product of this study, but a process, and that sharing activities has an important place in this process. The strategy's ability to support the participants in producing digital content and by this reach out via digital platforms is an important finding that calls for future research in sharing practices among youth living with cognitive disabilities and how they perceive their own work when it is available on the open internet. The analysis of the production process revealed that each participant displayed different ways of sharing their video tutorials

- some wanted to share them on their public YouTube channels, some on their private TikTok accounts, and some wanted to share privately. This diversity in the outcome of every tutorial session showed that this kind of production entails different ways of producing and sharing content and highlighted the elasticity of the strategy.

### 5.2 Challenges for participatory video tutorials as support strategies

As presented initially and in related work, developing support strategies for people living with cognitive disabilities is complex. At the end of this process a key question remains about the future effect of the developed and suggested support strategy. While this study showed positive results with the participatory tutorial format, Seale (2007) remind us in her research of the production of digital content for websites, that support strategies are not necessarily empowering if they are only temporary. Seale writes: "there appears to be little point in parents, carers and support workers adopting strategies that help adults with learning difficulties to use home pages as tools to advocate for permanent change if those strategies in themselves are only temporary." (Seale, 2007, p. 184). In this case the four types of engagement and the unprovoked requests for materials, which the participants wanted to share and work on after the production process, indicate that our participants have long-term interests in digital production. However, these interests must be addressed seriously, followed up in cooperation with the staff at the institutions and developed into permanent practices if benefits from the processes of digital production are to be sustained and developed further.

The support staff has professional and personal proximity to our participants that is simultaneously helpful as well as a potential challenge. On the one hand, caretakers have a good idea about what engages the young people and what gets them to calm down. On the other hand, support staff does not possess the socio-technical skills of gaining proficiency in video production and video management. Section 4.2. presents us with a complex set of reactions towards the tutorial sessions and reveals four styles of engagement from the target group. To support digital creation and sharing practices, support staff should first recognize the nuanced effects they have on the young people. One way to do this can be to use the produced video tutorials as learning material in their scheduled sessions and learn from them. Second, support staff should dedicate time to exploring digital skill development and digital skill sharing alongside the young people living with cognitive disabilities; not teaching them to do something but learning with them. This can be done by refocusing existing pedagogical approaches that require computer time as content creation sessions, applicable to levels the young people are comfortable with. Finally, the caretakers can also support the young people by continuously integrating parts of the video tutorials in the daily lives of the participants, thus ensuring a sort of permanent commitment to digital skill support. Further development of the participatory video tutorial format as a support strategy requires research on how best to integrate this format in the practice at the institutions.

# 6 Conclusions

The participatory video tutorials presented in this paper proved to be able to engage our participants as digital producers studying at or living in their respective institutions. All participants engaged actively in the four steps of the production process: pre-production, production, review, and sharing. The analysis of this process showed that there are multiple ways of engaging with this format and that the elasticity inherent in it is an important principle for the support strategy. The strategy developed and explored participatory principles grounded in the socio-technical environment of the participants, their ability to access and work with the technology, a methodological elasticity that allowed for structural rigidity (when outlining video structure) and processual adaptability (when customizing the format for each individual participant), and finally a product that can be shared and re-purposed by participants and their support staff.

As such the study has contributed new perspectives and empirical examples on a target group that is often regarded as disabled and in need of assistant technology by bringing attention on these young people as producers (vs. users) with abilities (vs. disabilities) and by this contributing insight to HCI research on how to engage a marginalized target group in design and use of interactive technologies. A point of future research, identified during this project, concerns the online sharing practices of young people living with cognitive disabilities, as well as their attitudes towards ownership, reuse and repurposing of digital content. Finally, this paper highlights the issue of retention and use of existing materials - if the young people's digital productions are not inscribed in the daily practices of the participating institutions in any recognizable way, there is a high risk of losing all the benefits brought about by the production process; benefits that are equally acknowledged by researchers, support staff, and the young co-producers of digital content.

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