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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 the 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 in need of assistive technology, by foregrounding the young participants’ digital abilities and facilitating them as 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 sixteen young participants. Empirically, the results contribute perspectives on this target group as producers (vs. users) with abilities (vs. disabilities). Methodologically, 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 toward digital inclusion by engaging a marginalized target group in digital production.

Keywords: Cognitive disability, Youth, Content production, Video tutorials, Participatory design

1 Introduction

Video tutorials are commonly used and produced by lay people to share knowledge and skills related to various interests. There are no limits on the uniqueness of topics and interests covered in online video tutorials, and that is perhaps one of the reasons tutorials have become a popular format for informal learning. In this paper, we report on research that uses 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 [3, 28]. We present how we have developed and explored video tutorials as a format for supporting digital production with 16 young people (age fourteen through twenty-eight) living with one or more cognitive disabilities. We have named this strategy — *‘participatory video tutorials’* — a strategy that supports the young people as active producers of their own digital content. The producer role comes with responsibilities, skill development, and social relations, and we argue that this support strategy can contribute to the empowerment of our target group.

Both this role and the presented method are enacted in sheltered environments (e.g., participating institutions) due to this study being a part of a pre-approved project. Therefore, the participatory video tutorial incorporates these environments by design, which means that there are inherent choices to be made about the structure of this approach regarding what to engage our participants with and how to keep them involved in the process. We go over this in Section 3. The presented research arrangement can answer certain questions (about the specific method it presents) and only give rise to other questions, such as what the results would look like if the participants and researchers had different relationships, and if the presented method were carried out at their homes instead of their schools, if their parents were involved instead of their teachers. As important and valuable as these questions are, they are outside the scope of this study due to the established agreements between the participating institutions. It is, however, important to note that as researchers, we come with a specific focus on our participants’ digital interests. This focus is meant to act as a methodological connective tissue between other researchers with interest in this field (e.g., Brereton, Frauenberger, Seale) as well as pedagogues and teachers from institutions that work with youth living with cognitive disabilities.

As discussed by Seale, supportive strategies for digital technology as a tool for empowerment of this target group are challenging [28]. Conflict of interest can easily occur when support of independence clashes with the role of professional or caretaker (family 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 suppress 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, which is defined as the power to act with others and by this develop knowledge and abilities to influence

personal and social spheres [15]. The developed strategy works with challenges of empowerment by suggesting structure and a process for cooperation with goals that support not only the young people’s personal development but also their competence in contributing to collective development (*ibid.*). The study complements dominant perspectives on this target group as disabled with a need of assistive technology by bringing a conceptual perspective on digital technology as a production tool, as well as by seeing the young participants as active producers of the digital content that plays a major role in their everyday social interactions [7, 12, 13, 26]. Methodologically, this paper contributes guidance to a participatory staging driven by the young people’s motivation to self-expression. In the following chapter, we first present background information on cognitive disabilities, related work on this target group’s uses of digital technology, and participation in digital production. Secondly, 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 sixteen participants. Thirdly, 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 engaging 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 including autism, a learning disorder, Down’s syndrome, and ADHD. Additionally, some of the participants are diagnosed with anxiety, and sensory impairment is common [20]. Thus, it is difficult to assign the participants specific diagnostic labels since most are challenged by comorbidity and because of diagnostic differences and consequently different individual competencies and potentials even for participants sharing the same diagnosis. Additionally, as for all human beings, possibilities for development for people living with cognitive disabilities are influenced by the dynamics of the individuals and social groups that they interact with [24]. The ecological focus of the World Health Organization [36] 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 [20]. On this background, we join HCI researchers arguing for a broad perspective when aiming to understand and engage this target group in HCI research [32].

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 [1, 9, 25, 27, 30, 33, 34], such as by participating in social activities mediated by online multiplayer games [27], online dating platforms [21], and by mobile applications more generally [33, 34] and a broad variety of consumer applications [3] that support reaching out and sharing 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 benefits from visual communication, known structure and repetition, and social interaction with a limited number of participants. Digital technology can support some of these needs [4, 10, 16], but challenges related to understanding social codes [9], like challenges related to inclusion in social groups also exist online [21, 28]. Research has identified a motivation among the target group to create and share online content to develop friendship [19, 29] but also a need to empower the participants to take responsibility and manage online interaction.

Professionals and carers often act as mediators when people with cognitive disabilities engage in digital production [29] and the limited research on empowering 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 group “in a passive role where they are recipients of technological expertise and protective guardianship” [28]. 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 [35]. 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 (“the norm”). With this perspective, it does not make sense to focus on the disability (“the defect”). What is important is the child’s uniqueness 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 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 digital technology [5]. People with cognitive disabilities tend to participate in design and research by proxy [6]. However, the limited related HCI research shows that this group is able to participate in design and research activities but requires flexible staging [22], careful interpretation [14], and respectful interaction emphasizing attention to mutual learning, self-expression, and self-determination for the participants [26]. In general, this research follows core principles from Participatory Design, treating people as competent practitioners and experts in their own experiences and practices [17] and contributes insights into how to stage participatory settings for marginalized users. In the following, we present how we have used this background in the development of participatory video tutorials.

3 Participatory Video Tutorials

This research was carried out in cooperation with four institutions for young people living with cognitive disabilities. All participants (sixteen in total, aged fourteen through twenty-eight 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 six through seventeen), (2) a high school for young adults with cognitive disabilities (ages eighteen through twenty-two), (3) a sheltered residence for young adults with cognitive disabilities (aged eighteen through twenty-eight), 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 twenty eight). The research is carried out in close cooperation with these institutions, where staff are confronted with the young people's increasing and extensive use of digital technology and searching support strategies for these activities. The two schools have set up computer areas and dedicated time for a staff member to stage activities such as to support the young participants in online gaming and production of specific content. The 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, fifteen can communicate in Danish, eight out of the fifteen can communicate in English, while a further six can partially understand English. English language skills make it easier to engage 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 such as YouTube). All participants live with Down’s syndrome, ADHD, autism, and/or intellectual disabilities, and several struggle with anxiety and other mental conditions. It is important to note that there is no such thing as a “pure” case of autism or any other neurological condition in this target group. Each individual constitutes a unique experiential case of a person who continuously learns how to live with their conditions in a world that changes its understanding of said conditions constantly [11]. What this means for the present study is that similar diagnoses are translated into a spectrum of experiences (*ibid.*). Inspired by [35] and participatory design research [31], 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, it has also been important 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. Using Vygotsky’s concept of the 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, and the participating schools often them to 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, meaning all participants have also had positive experiences with the tutorial format. To facilitate a process that is not only a personal but a collective development [15], 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. 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 to 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 Ethical and Methodological Study Design

From an ethical perspective, we can confirm that the research project has received ethical approval in accordance with national rules and the European GDPR legislation. It has been approved by the National Data Protection Agency, and rigorous ethical procedures are followed with support and administration by

the office for Grants and Contracts at Aalborg University (registration number: 2018-899/10-0192). All ethical requirements are handled according to national rules and regulations for ethical conduct, GDPR, and anonymity. Due to participants’ disabilities, this is extremely important and has high priority—we ensure that all measures and precautions have been taken. Methodologically, we have followed strict ethical codes while obtaining informed consent from our participants, the support staff that works with them, as well as their parents by: (1) taking time to explain to our participants the nature of the project, (2) continuously reminding them that they have to actively agree to be a part of the study and their identities will be kept anonymous, (3) reminding them that they can choose to leave at any time, (4) explaining that data gathered for the project will not be used for any other purposes and is subject to strict GDPR regulations, including deletion after a certain period. These key points were repeated throughout the project, in accordance with the findings from Cameron and Murphy [8].

3.2 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 production a three-to-five-minute video, consisting of three steps: (1) area of interest, in which the young people present an overview of their digital interests, (2) a demonstration of digital skills, in which they show how they pursue 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 “tutorial script”, using which they could reflect on prompts 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 an aid to better understand what types of digital skills the participants were interested in sharing and developing (Question 1.) and the 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 using their digital skills with friends at their school and similar institutions in their city via the 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 in 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 on 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 session. 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 and 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 faithfully as possible. Every participant was informed that the screen recorded content and that an impromptu 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, in which we imported footage of the recording session in DaVinci Resolve, a video editing program, and quickly visualized the script into a video timeline. Participants were invited to make corrections on the timeline to clearly reflect 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 finalization.

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 one to three iterations, and it ended when participants deemed the tutorial ready for publishing on the 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 participants there did not express a desire for a public premiere, instead opting to have their video tutorials shown at the first institution, where they had 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 were meant to support the social relations the participants have among themselves, as well as those with other students or residents in the participating institutions.

4 Results

The production sessions totaled 143 hours and fifty-two minutes of video footage, recorded by the researchers using three cameras and one smartphone. Researchers and participants co-edited the footage into thirteen video tutorials, totaling fifty-two minutes and five seconds and averaging four minutes per tutorial. There were three videos produced by a two-person group, and ten produced by one person. The agreed-upon structure of the tutorials (three to five minutes per video, three sections) was followed and carried out. As stated by staff members at one of the institutions, a main result of our strategy was 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 (e.g., struggling with symptoms of their diagnosed conditions) 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. To position ourselves in a way that allowed us to analyze this transition, we employed a participatory design approach, in which key aspects of the strategy (story line, video material, directing, co-editing) were delegated solely to the participants. What this means is that by design, our approach would not work without active engagement, and when such engagement occurred, we were in a co-directorial, co-editorial position to see exactly what made it work or not work and offer perspectives on why that might be the case.

In this section, we outline three key insights from our participatory video tutorial strategy, involving: (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 nevertheless proved sufficiently flexible, in that it was easy to adapt to each individual participant, either with props during filming or with video style during editing.

4.1 Setting the Stage for Professional Production

An important lesson learned from the production of the thirteen tutorials is that it is vital to set a stage for professional production. The participants all came to the filming sessions with expectations. An example is Malte (all participant names are pseudonyms), who had studied production techniques before we met and 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. 1). 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 to be shown instead of himself 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, a 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.

The two 4K cameras, 360-degree camera, dedicated software, two microphones and two artificial light sources filmed 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, who 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 and cameras, and in front of the video



Fig. 1 A video tutorial recording session with cameras, light, green screen, microphones and computers.

editing software. The professional setting transforms our efforts from ideas into a 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 for the purposes of 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. 2). 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 presented him with — the message he felt as most important was not clearly presented, according

to him. Carl decided that he should re-record the audio voice-over for the tips and tricks part of the video and fix the issue.



Fig. 2 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, in which they attempted to fix what was perceived as a sub-standard technical performance, as well as forcefully alter the agreed-upon script and use their own voice to reformulate specific tips and tricks. These participants show how they take ownership of the video and how they express the strong opinions they have about visuals and narrative. Ambitions that 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 put a great deal of thought into the content and style of the video they produced. This is also important, as staff and family can tend to think that the young people are simply 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. 3), and leave the production session relatively earlier than 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.), rendering their video less truly a product of their own. This type of reaction to the format is important, as it highlights the limits and outlines where it might break down if not adjusted even more to fit each individual’s needs. Researchers and support staff should



Fig. 3 Participant demonstrating how they attach a video file to an iMessage conversation.

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 (Local Area Network) 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 to participate 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 to their body, as well as a second GoPro camera mounted on a wall, filming a time-lapse (thus condensing around five to six hours of video footage into five to six 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 other equipment. Thus, 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. 4 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 as-

pects (the GoPro cameras strapped to one participant and mounted on walls to capture the entire event) and social conventions (gathering to watch others play in Fig. 4). Both events ultimately featured long gaming sessions (anywhere between 6 and 8 hours), and the video tutorials focused on identifying the important building blocks for such coveted activities (e.g., equipment, games, and friends). An interesting observation was that at one LAN party, the participants purposefully invited as many of their friends as possible, whereas the participants at the second LAN party were largely comprised of an already existing group of friends; they did send out an open invitation, but far fewer of their peers joined.

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 full recreating of the intro to the Netflix show *Stranger Things* in the 3D modeling program Blender (see Fig. 5).



Fig. 5 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. As digital producers, the participants’ roles were characterized by the need for a good setup — both 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 to the first type (“Coping with ambitions”) in that this group of participants had 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 found ways to overcome any issues that arose during filming and editing, in contrast with the first group, whose ambitions always seemed to outgrow their technical skills. The performative role thus requires less technical

support (they had 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). Additionally, the performativity extends beyond the production sessions, with one participant somewhat mentoring another in using a specific software (Roblox Studio), which was later used to attract the attention of the researchers.

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 only about personal development but also about collective development. The participatory tutorials were developed as a strategy to support this by not only 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 sharing with and use by others. This concept is simple, and the format was already familiar to and embraced by our participants. Our experience in this part of the strategy was positive but basic, as we merely created a private YouTube channel and did not research practices of engagement with it. We have not yet conducted research on methods of supporting the sharing and viewing of 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 were generally 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 were 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 emailed the researchers a few months after the premieres to request access to the channel so they could view and share their videos with others. Two other 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 (it post did not dramatically alter the participant’s 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 [2, 18, 23]. The processes succeeded in engaging all participants in the process and production of a tutorial, which was identified as a success by the participating institutions, since several of the participants had a history of withdrawing from activities or not finalizing them due to symptoms related to their 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, skill development, and demands for social cooperation, a key finding from this study is that the format has an elasticity that made it possible to meet the needs of 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 not only in producing and developing their own digital materials and skills, but also as a format for sharing their activities and interests and thus supporting their ability to reach out to peers in their own ways. This is an important point, which we want to highlight by referring back to the different approaches to a LAN party (4.2.3), which can be described as purposefully open versus somewhat exclusionary access to the events. Additionally, we see that while some participants interacted as little as possible (4.2.2), others made a point of supporting each other (4.2.4). All this constitutes a rich diversity of reactions to the format. 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 allowed the sixteen participants to become active co-producers of digital content they enjoy. 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 to share 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 and 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 thus contribute to digital empowerment and inclusion of this marginalized target group. We have summarized four takeaways from the research process, and we claim that the participatory video tutorials act as a support strategy when they address the principles of:

1. **Socio-technical Belonging.** The tutorials should belong in the socio-technical environment where they are being deployed. Most of our participants were already familiar with the idea of the format, having watched tutorials or made tutorials themselves. The format already had a place in their everyday lives.
2. **Technical Accessibility.** The tutorials should be technologically accessible. It is not necessary to have the same equipment as our research team (with three cameras, lights, microphones, etc.). A similar, if not the same, effect can be reproduced with more common or accessible technologies, such as a smartphone and free video editing software.
3. **Elasticity.** 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 three-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. **Material Reusability.** 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 of these takeaways 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 sharing activities have an important place in this process. The strategy’s ability to support the participants in producing digital content and use it to 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, other on their private TikTok accounts, still others more 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 proposed support strategy. While this study showed positive results with the participatory tutorial format, Seale [28] remind us in her research on the production of digital content for websites, that support strategies are not necessarily empowering if they are only temporary. Seale writes that “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.” ([28], 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, pursued 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. As the presented format is focused on engagement and uses participatory design, it inherently comes with a limitation of theoretical and methodological positioning. This positioning prevents us from providing stable definitions for the presented practices that could be used by support staff and other relevant stakeholders, for example. This limitation exists because in a participatory environment, said stakeholders must be directly engaged in all stages of the process, and our method was not set up to incorporate perspectives from staff and institutions, as we exclusively focused on the young people living with cognitive disabilities.

The support staff, however, has professional and personal proximity to our participants that is simultaneously a benefit and a potential challenge. On the one hand, caretakers have a good idea about what engages the young people and what calms them. On the other hand, support staff do not possess the socio-technical skills of gaining proficiency in video production and video management. It is important to stress that our focus on digital interests, and thus on specific video-related skills, narrows both our perspective and potential generalizability of our results. We recognize the danger of reporting on research that is too narrow and thus have strived to make it as useful as possible to all stakeholders. Additionally, we have plans for future research that would build on this foundation and offer insights to a broader audience of researchers, support practitioners, and administrative staff.

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 for 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 into 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 into the practice of 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 assistive technology by bringing attention to 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 for 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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