Facilitating for Capabilities
Empowering People with Intellectual Disabilities
Using Proxies to Facilitate Participation

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Master thesis in Design, Use, and Interaction
at the Department of Informatics

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Abstract

This thesis presents findings on how to facilitate a design process with people with Intellectual Disabilities (ID), utilizing already existing practices, and proxies’ knowledge in facilitating the inclusion of people with ID into design-making. With the overarching goal of exploring possibilities for design with people with ID—effectively seeking to share power by utilizing a Participatory Design (PD) framework—I present a long-term PD process that initially investigates how an ethnographically inspired immersion into the context might benefit a later facilitation for the inclusion of people with Intellectual Disabilities and their proxies into design-making.

In the initial inquiry stages of design, I conducted a long-term ethnographically inspired immersion into an activity center for adults with ID, which led to two implications for a future design process. The making stages should facilitate for care workers to facilitate their own participation, and, it should build the process on already established forms of mutual learning and practice.

In combination with techniques for generating design ideas, these implications led to initial stages of a long-term PD process where two main implications surged. When designing with people with ID and their proxies, the PD process should enable appropriate proxies to facilitate the inclusion of the people with ID into design-making activities. Moreover, the inclusion of people with ID, by the proxies, lets people with ID transcend from informants to acknowledged and legitimate participants, sharing in the decision-making power of any design-making stage.

While this thesis mainly seeks to contribute to design with people with ID—some of the underlying values and ways of approaching design with people with vulnerable agency, hopefully, make it applicable to a broader audience.

Keywords: Participatory Design, Ethnography, Intellectual Disability, Immersion, Proxy-design, Cognitive Disabilities
Acknowledgment

It is with some melancholy that I write this acknowledgment as this thesis has been a personal and long one. I have the world to thank for the people that contributed to enabling this exciting journey.

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Åsmund Dæhlen

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Chapter 1

Introduction

This thesis describes a Participatory Design (PD) process conducted at an activity center in Norway, offering daytime services for adults with Intellectual and, or physical disabilities.

Since 2010 I have worked with people with Intellectual Disabilities (ID) in two different housing communities, working with people of all ages and capabilities. People with ID face wildly different challenges, some need robust support throughout life, others, through time can develop and learn how to live more independently. However, no matter what, as care workers we are always there to support these people. Trying to describe why I enjoy working with people with ID is nigh impossible, but after having to quit my job to write this thesis, what I discovered I appreciated was the community which the users and care workers constituted. The ‘guys’ have left me with countless memories. Therefore, I want to employ my background as both an interaction designer and care worker to contribute to developing the possible space for people with ID’s integration into society.

Throughout history people with ID have suffered discrimination and abuse, however, in years following the Second world war, there has been a radical shift, giving focus to peoples inherent values and possibilities for equal opportunities (Ministry of Children and Equality, 2016). Gradually Norway has sought towards a society offering equal possibilities focusing on integrating people with ID into all layers of society. Through de-institutionalizing in 1991-1995 (Ministry of Children and Equality, 2012) and subsequent work, detailing the success and giving directions for the future (Brevik & Høyland, 2007). Concerning people with ID in general, there is a debate on the best living situations, economic factors, size of communities, and more (NAKU, 2019).
Introduction

Nevertheless, as we have moved towards a society where digital technology becomes deeply ingrained into our personal lives, I think we need to face how we are to integrate technology into the lives of others, especially those with less agency to make decisions on their own.

1.1 Motivation

“When we are no longer able to change a situation [...] we are challenged to change ourselves.”

(Viktor E. Frankl, 2011, p. 91)

The way I see it, technology shapes our reality—it changes how we think and how we act upon the world. In different frames of mind this concept of technology’s intentionality can be recognized in: ‘signs and tools’ (Vygotsky, 1980); ‘knowledge in the world and knowledge in the head’ (Norman, 2013); ‘present-at-hand and ready-to-hand’ (Heidegger, 1993); ‘pragmatic, action-oriented and hermeneutic, experience-oriented’ (Verbeek, 2006); ‘politics of artifacts’ (Winner, 1980); and many more. Verbeek (2006) specifically questions how engineers materialize morality—manifesting morals in physical artifacts—and discuss how technology, end-user, and designer in combination create a mediation of the world for the end-user. Here I present two ways that technology mediates human understanding and behavior in: hermeneutics and scripts (Verbeek, 2006). Both can be explained using artifacts, familiar to any car user: speedbumps are artifacts, scripted to direct our moral choices actively; a passive speed limiter shows you how fast you are driving, and expands our universe of discourse giving us more information without directly pointing out a specific answer.

Consider this theoretical scenario: in 2005 older adults, prone to “wander” is equipped with alarms, letting them push a button setting off an alarm letting care workers track them and help them home. Here the intentionality of the technology is fully resting in the hands of the bearer. However, what happens as tracking technology is used more and society on a broader scale starts to accept that companies like Google and Facebook track our movement. Is that our values start to change, and boundaries pushed. What if someone realizes the convenience of
what the tracking technology can do: alert caretakers before the user steps out the door? All of a sudden, the power to direct how the world is present has changed hands and rests entirely on people who develop or control the technology.

Moreover, this is motivation: I want to find ways to design with people with Intellectual Disabilities using human-centric approaches, that seeks to be emancipatory, letting intentions rest with the end-user. I believe that Participatory Design, and the approach taken in this thesis, is a step in a direction where we, as designers, can think critically about the decisions we make and the values we inscribe into the things we make.

1.2 Research question

Based on the outlined motivation, the research question of this thesis is:

How can we facilitate design with people with different intellectual capabilities using Participatory Design?

1.3 Objective

To answer the research question, the main objectives of this thesis are:

1. To explore how ethnographic immersion into the context can bridge potentials for facilitating design with people with ID.

2. Explore how a PD process might be fitted to the contextual needs of an activity center

This thesis position itself within the field of Participatory Design, specifically proxy-design, and more generally any who seek to design with people with ID.

1.4 Thesis structure
Introduction

The empirical research conducted in this study is split into phase 1 and phase 2. Each phase concludes on some learning outcomes which is then discussed.

Chapter 2: Background and empirical context present an overview of the empirical context and how I established a relationship with the activity center. I then present the people and give a general insight into the context.

Chapter 3: Theory: Understanding participation presents the theoretical foundation with which I discuss the resulting outcomes from Phase 1 and 2. It shortly outlines some theory behind Participatory Design and then specifically targets related work on the concept of participation.

Chapter 4: Phase 1: Investigating possibilities for participation is divided into three parts: First, it shortly outlines ethnography and presents ethnographically inspired methods. Second, presents analysis and results. Third, it presents the findings which culminate in some implications for future work. The research from Phase 1 has also been published (Dæhlen and Joshi, 2019, see Appendix 6).

Chapter 5: Phase 2: Facilitating participation is divided into three parts: First, it builds on the implications of Phase 1 and concepts from related work to build a set of methods. Second, it presents some results. Third, present some main findings.

Chapter 6: Main findings and discussion First present an overview of the main findings and process then utilize the learning outcomes presented and discuss these in relation to related work from chapter 3.

Chapter 7: Contributions and salient questions presents some possible beneficiaries, how they might apply the knowledge generated and lastly present some salient questions that might direct future work.

Chapter 8: Conclusion Summarizes the thesis’ most prominent learning outcomes and implications.

The initial inquiry of this study resulted in a paper by Dæhlen and Joshi (2019) (see Appendix 6).
1.5 Ethical considerations

When recording data throughout this thesis, I have been careful as not to reveal any personal information or information that otherwise can identify the context of the activity center. The context contains much information displayed on the walls and around the center that can make it easy to identify. One of the tools I used to gather data was a polaroid camera, which let me capture more personal photographs while still maintaining the privacy of the users. By doing this I could physically censor the polaroid film using stickers capture a digital photo (Polaroid 1), and then give the photograph to the people pictured.

Throughout the thesis, I use capabilities to describe the cognitive, and sometimes physical, ability to direct oneself towards something. This is heavily inspired by Joshi, (2017), who focuses on the designing for the changing bodily capabilities of older adults. The use of capabilities in this thesis helps to express the approach to designing with the affordances that each person holds, rather than designing for any disability they might have.

1.6 User and end-user

Throughout this thesis, I use different words for participants. In the Norwegian Patient and User Rights Act (Ministry of Health and Care Services, 1999), a user is “defined as a person who requests or receives services covered by the Health
and Care Service Act which is not health care.” (translated by author). In more demotic terms a user is someone who wants to or receives help from a facility or service (Bahus, 2018), and throughout the thesis describes a specific person or several persons with ID. When talking about traditional design-users, or more general users of any design I specifically use end-user.
Chapter 2

Empirical Context

The empirical context of this research is an activity center offering daytime services for adults with intellectual and physical disabilities. The center accommodates circa 40 adults with intellectual and physical disabilities, has around 15 employees, and is ran by a local partition of Oslo Municipality. The layout of the activity center and the activities that are offered are specifically personalized to support each users’ capabilities, both physically and cognitively to contribute and enhance the users’ well-being and happiness.

2.1 Establishing a relationship

Relationship with the activity center was first established in March of 2018 where I contacted several institutions working with people with ID, and after a chain of emails, developed a volunteer-based working relationship with this center based on the mutual values, shared with the manager of the activity center. Throughout the process, the manager of the activity center has been a crucial piece in both exploring and enabling the possible interactions to come.

Contact was first established by email, where I presented my thesis of how I want to approach design when working with people with ID. Knowledge of the activity center came from prior work with some of the users of the center. Later we set up a meeting where we agreed to arrange for long-term collaboration where I worked on a volunteer basis receiving formal training. While I was scheduled to work every Monday, they never relied on my presence when arranging work-weeks and I was considered an addition to the existing work-force, able to assist in the daily functioning.

2.2 People
Empirical Context

The users of the activity centers’ capabilities range from mild to profound intellectual disability with a substantial spread in physical capabilities. While the specific cognitive and physical capabilities of individuals are of no particular interest to detail in this study, I think it is important that we have a common understanding of what it means to face a life within these borders as many are not familiar with the subjects at hand.

The World Health Organization—Article ICD-10, chapter V section F70-F79—categorize people of intellectual disabilities within the framework of mild to profound mental disabilities, grading their IQ range and mental age (Table 1). What is specifically worth noting is that mental age and IQ does not account for their life-long learning. Their lives are by far worldlier than what their characterization indicates, and their embodied and otherwise obtained knowledge and experiences are as rich as their lived lives.

One goal of using the WHO-classification is that I will be able to relate any persons very general set of capabilities to the audience of this paper, without alluding to specific health issues or otherwise personal capabilities.

In relation to capabilities and as an attempt to describe in very broad terms—but by far not applicable to all—an individual with mild capabilities is someone who can maintain good social relationships and contribute to society with some support. Those of moderate capacity will need varying degrees of support in life and work. Individuals of severely reduced capacity are likely in need of continuous support while people with profoundly reduced capacity have deep limitations in self-care and communications (ICD-10, Chapter V, F70-F73, 2016). This means that some of the users at the activity center require one-on-one assistance and complete attention to their well-being while others work more independently or even without direct assistance.

I do not presume to know the capabilities of the users, and I have not investigated their capabilities beyond what I have perceived in the inquiries. The descriptions and classifications in this thesis are how I classify their capabilities after working in the context within my understanding of ICD-10, Chapter V, F70-73. The
capabilities of the users of the activity center range from mild to profound, all adults from ~20 to ~70 years old.

Table 1: World Health Organizations ICD-10, Chapter V, F70-F79.

<table>
<thead>
<tr>
<th>Intellectual Disability</th>
<th>IQ range</th>
<th>Mental age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>50 - 69</td>
<td>9 - &lt; 12</td>
</tr>
<tr>
<td>Moderate</td>
<td>35 - 49</td>
<td>6 - &lt; 9</td>
</tr>
<tr>
<td>Severe</td>
<td>20 - 34</td>
<td>3 - &lt; 6</td>
</tr>
<tr>
<td>Profound</td>
<td>&lt; 20</td>
<td>&lt; 3</td>
</tr>
</tbody>
</table>

2.2.1 Care workers

The care workers background ranges from non-related or lacking higher education to educated social therapists—people with a higher degree in ergo therapy or otherwise specializes in ID.

2.3 Getting a feel of the activity center

The activity center is in a weathered house of what used to be the local grocery store, located in a big 70s neighborhood in a partition of Oslo municipality. The center is co-managed alongside a brother center, whom I visit in later stages of the process but is left out of the initial phases. The building is covered with large windows giving a good view of the local neighborhood and giving plenty of options for outside light to shine in. The cantina, where some of the users cater homemade lunch for the care workers and users, is located by the cornerstone giving a good view of the outside garden, parking space, and garage exit. I have spent most of my time in the larger living room spaces where often humbler activities are conducted. The walls of the larger living room space are covered in photographic collages of the users and employees, art and other various signs. As you enter there is a social space to the right with chairs and sofas where everyone gathers before lunch and in later hours of the day to drink coffee and chatter. The parallel corner hosts a large table with chairs where the group I have worked
Empirical Context

closest with has their morning meetings, planning their days and conversing about what was. Next to the table, there is a large fish tank, sewing equipment, and a massaging chair. The center hosts several rooms with different equipment, individualized specifically for some users, and other more general activities and equipment. On the cornerstone overlooking the city, there is a shop, where anyone can come and buy the things made at the center.

Figure 1: Social spaces at the center
Figure 2: Shop overlooking the neighborhood
Chapter 3

Theory: Understanding Participation

This chapter first introduces some concepts from Participatory Design, then introduce a view on how the analytic processes can occur in PD and lastly present some related work when designing with people with ID using PD.

3.1 Introducing Participatory Design

The roots of Participatory Design lie in the social, political, and civil rights movements in the 1960s and 70s when collectives, centered on shared values and beliefs, started to demand an ever-increasing control in what happened throughout society (Simonsen and Robertson, 2012). This, in combination with the introduction of computers—which changed the work-scape; automating and extending the possibilities for work—was the catalyst for the workplace democracy movement that sparked interest in how to involve workers in the decision making of design (Simonsen and Robertson, 2012).

“At the heart of this tradition is an unshakable commitment to ensuring that those who will use information technologies play a critical role in their design. (Simonsen and Robertson, 2012, p. 2)

To summarize the heart of the tradition Bratteteig, Bødker, Dittrich, Holst Mogensen, and Simonsen (2012) use the phrase having a say, which implies that the users have a direct impact on the critical decision-making in design. In both democracy and PD, for a voice to be heard, power needs to be delegated, in referring to Bødker, Kensing, and Simonsen (2004), Robertson and Simonsen (2012) calls the users in participatory design ‘genuine participants’, and “refer to
The word *participation* indicates that there is an act of taking part in something. However, as presented earlier participation in Participatory Design is more than just taking part; it is about enabling the participants to take an active role in shaping the outcome. It is about the designers sharing their power to make design choices between all participants in the process and thus, the mindset of letting people having a say lets the designers address power and strive for more genuine participation in the critical decision-making processes of design.

It is well known that “*Language functions in maintaining and changing power relations in contemporary society*[..]” (Fairclough, 2001), and it is no different when designers communicate with non-designers (Bratteteig et al., 2012, p. 134). Another facet of the power of language is that to respect someone; we need to understand them, and not just what they say they do, but what we, the researchers, observe them do. In PD we call the search for this mutual understanding *mutual learning*. In this paper, and as an important asset to PD (Bratteteig et al., 2012), I have emphasized ethnographical inquiries as a means of getting access to space where not only we can learn each other’s language, but also explore and observe in situ.

I will not go into detail on phenomenology or any relating theory, but I feel like I must create a backdrop to my understanding of artifacts and our understanding of the world because of the utmost role it plays in this context and to PD in general. In different modern philosophical literature relating to human understanding, we often talk about tools and signs as mediators of our understanding (Vygotsky, 1980). For Vygotsky, the tool is an artifact that we use outwardly to affect the world, while a sign is a tool we use inwardly to help us understand the world. This concepts of human understanding through these inward and outward tools can be seen in works of socio-culturalists and phenomenologists alike (Heidegger, 1993; Merleau-Ponty, 2005; Verbeek, 2005; Vygotsky, 1980). In different means, this explains why language is power as language is both a tool and a sign, without language—either by use of the body or voice—we are limited in our ability to both think and act. In PD we seek to integrate the end-users into a world of
language which they do not speak and for people with or without intellectual and, or physical disabilities this means a restriction in their ability to participate, but especially for those with ID as their capabilities does not afford what design usually require. Therefore, mutual learning is so incredibly important for both the researcher to understand people with ID, their context and the care workers and vice versa.

The last principle covered here, often called co-realization, co-creation (or construction), is best described by Bratteteig et al. (2012):

“The third basic perspective is involvement in design, or co-realization. Because of the fact that it is difficult for users to imagine technical possibilities, Participatory Design emphasizes different ways of visualizing possible solutions, with prototyping as the most important technique. [..] “A tangible artefact makes it easier to imagine the consequences of a design suggestion than would an abstract description. Users can utilize their professional competence and experience in the evaluation of a design suggestion, both as an artifact in their work and as a possibility for doing their work differently”. (Bratteteig et al., 2012, p. 133)

Thus, what I talk about when I talk about participation are the core values of PD: having a say, mutual learning, and co-realization. It is important to emphasize that they are by no means mutually exclusive and are very much dependent and intertwined.

3.2 Analysis in Participatory Design

Before moving on to defining a set of frames for what participation might be, I cover how analysis might be understood in a PD process. Analysis in PD is one of continual growth and understanding, where analysis and reflection go hand in hand. Bratteteig et al. (2012), outlines analysis in PD-processes well:

“It is often difficult to tell the difference between analysis and design in Participatory Design: [..] Furthermore, analysis and design are
more intertwined when design is carried out stepwise, when analysis and design are integrated into each step: we understand the situation, we make a design suggestion, and we analyze and evaluate—understand the new situation—and then make this a basis for a new design suggestion. Demonstrations and prototypes can also be used as tools for analysis, for exploring the use context (Schön and Wiggins 1992).” (Bratteteig, Bødker, Dittrich, Holst Mogensen, & Simonsen, 2012, p. 134).

Moreover, they continue with why the process of continual analysis and decision-making is so important in a PD process:

“A closer connection between analysis and design makes it possible for all participants to engage in the moves between understanding and exploring new possibilities: the understanding develops during the design process, and all participants should be able to take part in this development. In this way, users ‘who do not know what they want before they see it’ can see various possibilities open up and hence develop a sense and opinion of what they really want.” (Bratteteig et al., 2012, p. 134)

Bratteteig et al. (2012) point out that prototypes can be used as “techniques for analysis—understanding the use context and the technical possibilities better—and for design—trying out ideas for new technical solutions.” Throughout Phase 2 the ideas created has been a vehicle for both analyzing the technical possibilities, specifically related to the capabilities of the users, and how we can further the process of design. Both the resulting discussion and products of the different techniques utilized in Phase 2 have been driving forces for discussing and planning how to conduct future activities with the care workers.

3.3 Related work: Understanding participation

As stated earlier in referring Simonsen & Robertson (2012) "participation is the core of participatory design" (p. 5), and the core of the field lies in the
investigations of what ‘genuine’ participation is and how we can support it. To support genuine participation means to address questions such as:

“what does participation mean in terms of actual power to make decisions; who needs to participate and how can this be managed and supported; how can the design process itself be designed so people can participate in it; and what kinds of design tools and methods do we need?” (Simonsen & Robertson, 2012, p. 5).

I emphasize Holone and Herstad (2013) when they say that there is still a discussion on what participation is after four decades. In this thesis, I strive for a particular focus on emancipation through the sharing of power. Bratteteig and Wagner (2014), on the sharing of power in PD, conclude that participation occurs when: “Users can contribute to creating choices, selecting a choice, concretizing choices, and seeing/evaluating a choice. Users do not need to participate in all these (parts of) design moves to contribute to a participatory design result.” (p. 32). Holone and Herstad (2013) specifically cite PD studies working with often marginalized groups of people like children with ID (Frauenberger, Good, & Keay-Bright, 2011) as well as older citizens. Another value led PD process is Joshi (2017), who research how to design enabling technology for older adults, based on capabilities rather than disabilities.

This chapter is grouped into three main issues. First, on informing both researchers and participants understanding and imagination of possibilities. Second, tools and techniques that extend the possibilities for participation. Third, how we can ensure participation in the face of cognitive, physical and organizational challenges. One important thing to note is that these are not mutually exclusive, they intertwine on multiple levels, and the different means and methods of each often overlap. Ending this chapter, I present a table with some graphic illustrations that is continually updated to support the building of knowledge throughout the thesis.

3.3.1 Informing stakeholders
Genuine participation requires that the researchers and participants understand, and imagination of possibilities are informed through, e.g., discussions, interviews, contextual observations, other ethnographical inquiries and the later phases of making. To gauge participation is often more than just methods; it is how we apply them, one example of this is long-term participation.

Redhead and Brereton (2012), found that short-term methods were ineffective when trying to engage and understand local community practices and that in order to get the insight they needed an approach that let them draw on already existing routines and practices. One of their main finds was that long-term commitment let people from different contexts get insight into their prototype (p. 3). Overall Redhead and Brereton (2012) fostered a formula of a sustainable form of communication where the community members could participate in a more reliable manner, and on their own terms, not depending on working around other commitments like family life. Holone and Herstad (2013) say that all projects that seek co-creation need time to get to a “starting line” to find a mutual language and understanding, but when involving children with disabilities the time to get to the starting line increases. This becomes even more important when only people already invested in the lives of the users understand their highly individualized forms of communicating, which is the case when working with ID.

To further the argument of long term-commitment as a means of seeking genuine participation, Joshi and Bratteteig, (2016) talk about a successful mutual learning process as one that:

“[..] enables all participants to widen their imaginative capacity and build on each other’s ideas [..] They need to spend time together: over time, their imagination about design possibilities, about needs and wishes for technology solutions change as they learn more.” (p. 3).

In conducting PD with older adults at a care-center, Joshi and Bratteteig (2016) extended the ability to participate by conducting several smaller activities, often multiple times, to make sure the older adults could participate despite having bad days. A result of this was—along the same lines of Redhead and Brereton (2012)—that the mutual learning process is not something that ends with
contextual inquiries but continues together with co-realization as design ideas spurred discussions and inspired to explore more possibilities further. In our own study (Dæhlen and Joshi, 2019), after conducting a long-term ethnographically inspired study, we emphasize the importance of understanding existing means of mutual learning to engage the participants in later stages of design.

Almost any iterative design cycle suggest four stages of design: inquiry, building requirements, prototyping and testing—which is then iterated upon. Bratteteig et al. (2012) suggest a more detailed approach in PD, where several of the phases are iterated upon within one iteration, as the arrows in Figure 3 (Bratteteig et al., 2012).

![Figure 3: Participatory Design cycle from Bratteteig et al., (2012)](image)

### 3.3.2 Tools and techniques

To achieve co-realization and for non-designers to become active decision-makers they need tools and techniques that extend their capabilities beyond what is normally achievable. I understand tools and techniques as defined by Bødker, Kensing, and Simonsen (2004) where tools are “suggestions for graphics, figures, and models to support the processing and presentation of knowledge contributed by a technique” (p. 21). Bratteteig, Bødker, Dittrich, Holst Mogensen and
Simonsen (2012) explain that the relationship between tools and techniques, and methods, differ from the traditional way of viewing a method like a cookbook recipe that can be followed step-by-step. This is because in PD methods need to offer general guidelines “that must be carefully selected, adapted and appropriated to the specific project and situation at hand” (p. 118). Thus, a method is the sum of the participatory perspective, guidelines, techniques, and tools used and they describe the technique as what explains how to conduct a specific activity, while the tools are the objects that support the technique.

Another contribution to understanding what a method incorporates in PD is Brandt, Binder, and Sanders (2012) saying that any PD practice needs to combine the elements of making, telling and enacting because, when we tell stories about what we make or enact scenarios of use, we elicit our ideas to the world creating possible spaces for thoughts and ideas to grow. “the number of possible tools, techniques and applications for making, telling and enacting is limitless. The challenge is to determine which tools and techniques are most effective [..]” (Brandt et al., 2012, p. 175).

When looking at PD-papers they all uniquely use and combine elements of telling, making and enacting: Hussain, Sanders, and Steinert (2012) used a variation of card sorting to help elicit stories and explore possibilities; Galliers et al. (2012) created workshops where users enacted current scenarios of use, then later involved storytelling; Kanstrup, Bertelsen, and Madsen, (2014) propose a method based on walking to enabled a sense of enactment and chance to talk and Nicholas, Hagen, Rahilly, and Swainston (2012) use games and personas, engaging children in making and enacting.

Adding to the specific context of designing for people with ID, whether it is related to health issues, cognition or physical capabilities, researchers report on a need to use already established practices to support the PD process (see Grönvall and Kyng, 2012; Joshi and Bratteteig, 2015; Ballegaard, Hansen, and Kyng, 2008). Other related works, supporting the notion that design practices should be built on already established practices are Yakhlef and Essén, (2013), who, through a phenomenological lens views the body as a tool for innovation.
Examples of some specific techniques are sensitization, picture collaging and drawing for co-design from Visser, Stappers, van der Lugt, and Sanders, (2005). Sanders (2000) states that the purpose of these kinds of tools and techniques is to “give people so they can express themselves visually and verbally.” These tools and techniques seek to bridge a language gap between designers and non-designers where the physical objects create a visual language that lets the participants express and explore how things might work in the future (Sanders, 2000; Sanders & Stappers, 2014). Sanders and Stappers say (2014), in expressing the changing role of making, that during the very earliest exploratory phases of design “the focus is on using making activities for making sense of the future” (p. 6) and later “[..] the prototype is a vehicle for observation, reflection, interpretation, discussion, and expression” (p. 6). Brandt et al. (2012) express the essence of these generative techniques in the framework of telling, making and enacting where each of the three is equally important in generating design. In the case of a low-resolution prototype the artifact itself may be ambiguous, but combined with the collaborative act of telling a story or enacting a possible use scenario innovation can occur (Sanders, Brandt, & Binder, 2010).

Visser et al. (2005), point out that sensitization packages is parallel to Gaver, Dunne and Pacenti’s (1999) cultural probes and often use the same tools but differs in purpose: Gaver et al. (1999) uses the probes for gaining insight into the context as inspirational data to stimulate designer’s imagination, while the generative toolkits of Visser et al. (2005) seek “a more deliberate and steered process of facilitation, participation, reflection, delving for deeper layers in the past, making understanding explicit, discussing these, and bridging visions, ideas and concepts [scenarios] for the future.” (Sanders and Stappers, 2014, p. 8). The two views differ in whether you view the end-user as subject or partner (Sanders and Stappers, 2008).

To summarize, when we talk about participation in relation to the tools and the techniques we use, they enhance the possibilities for having a say by extending the possibilities of both co-realization and creation of spaces where mutual learning can occur. However, they need to be tailored to the context and its people.
Brandt et al. (2012) presents a framework of understanding tools and techniques as ways of telling, making and enacting, and lends us a possibility to operationalize and examine participation.

### 3.3.3 Challenges to participation

In this section, I present challenges participatory designers face when attempting to give people the possibility to impact decision making facing cognitive, physical or organizational challenges. This means being given different options to participate in the face of different capabilities or otherwise organizational limitations. This section is divided into smaller sub-sections each detailing different challenges and possibilities. Can we recount participation by proxy as ‘genuine’ participation? Are there options to design by proxy when strong cognitive limitations are present and how can we actively work to engage all stakeholders?

#### Participation by proxy

There is an apparent limited research on design with people with ID specifically but, there is a broader field of research into people living with cognitive or sensory impairments and their inclusion into the design process.

Francis, Balbo, and Firth, (2009) suggest that “direct involvement of people with cognitive disorders, such as autism, is problematic due to their highly individual communication, cognitive and behavioral difficulties.” (p. 133). They also point to benefits of long-term commitment as a means to get to know the individual differences. Their end suggestion is to overcome these problems by empowering the family and care-takers to act as proxies, where designers can function as facilitators.

Boyd-Graber et al. (2006), who used speech-language pathologists to fill the role of proxies, found that the proxies gave useful insight into user requirements but were poor placeholders for testing paper-based prototypes. Galliers et al. (2012) used long-term commitment as a means of building a foundation to communicate with people with aphasia where communication, comprehension of language and
difficulties with abstraction was tackled by hands-on physical activities and
discussions grounded in 20 workshops, over ten months, and thereby
circumvented using proxies. Putnam & Chong, (2008), relied mostly on proxies
to gather information, using online surveys, on software and technology use of
people with Autism Spectrum Disorder. Others have raised questions on whether
stakeholders like family and caregivers, can be reliable sources of participation
because they tend to over or underestimate abilities of the end-user (Hendriks,
Huybrechts, Wilkinson, & Slegers, 2014). Hendriks et al. (2014) end with saying
that they will not presume there are design methods to be applied, but rather that
methods need to emerge and transformed by knowledge about the individualized
needs of users and context. While aphasia and dementia are not intellectual
disabilities, these studies demonstrate that through exploring different means of
communication we can further expand how to facilitate for participation for
people with cognitive differences—even though there is an apparent disconnect
between what design require and the capabilities of the participants.

As we have seen in the backgrounds chapter, people diagnosed as ID have proxies
in different parts of life. Taking a look at studies on designing with people with
ID, they all use some design-by-proxy (e.g., Brereton, Sitbon, Abdullah,
Vanderberg, & Koplick, 2015; Dawe, 2007; Havgar, 2016 (master thesis)). Dawe
(2007) used family and caregivers as proxies for people with ID in co-designing
a PDA-smartphone where she engaged users in the exploratory as well as testing
phases. She hypothesizes that the exploratory probes were successful because
“technology probes support knowing-in-action and reflection-in-action; and the
probe has affordances that connect emotionally with the participants with
cognitive disabilities” (p. 2181). Not unlike Galliers et al. (2012) the user in
Dawes (2007) study could communicate through physical interaction with
technology designed to probe for information. To read more on embodied
interaction and how we can utilize it to explore possibilities for participation see
Joshi (2017). Relating the concept of embodiment to Brandt et al. (2012) we can
see that the concept of enactment, of using technology in context, can be utilized
as a technique to engage participation of people with cognitive disabilities by
creating other means of communication through enacting. This brings us to the
next section and how we can work with the capabilities at hand when designing with people with cognitive or physical disabilities.

**Participation by presence**

In their systematic review of designing with developmentally diverse children, Börjesson, Barendregt, Eriksson, and Torgersson (2015) find that:

> “Children having Down Syndrome or intellectual disabilities are relatively seldom included in the design and when they are they have a rather passive role. They are usually observed in a natural setting during the requirements phase, when using prototypes in the design phase, and when working with the final product during the evaluation phase.”
> *(Börjesson, Barendregt, Eriksson, & Torgersson, 2015, p. 82)*

This section outlines literature on how the participation of the end-user can affect the design process when designing for people with cognitive and physical impairments as well as how organizational limitations might affect the ability to participate.

Bigby, Frawley, and Ramcharan (2014) raise the question whether the inclusion of people with ID into research is feasible at all and in their peer review found that:

> “Evidence needs to be gathered about the value added to research endeavors by the participation of people with intellectual disability through the different inclusive approaches discussed in this study. The value of inclusive research should not be assumed or overrated. (p. 8).

Bigby et al. (2014) also raise questions whether people with intellectual impairments leveling profound to severe are willing or able to be involved. Lastly, they call for greater conceptual clarity on inclusive research so that inclusive research is not a rhetorical statement.

In their paper, Rogers and Marsden (2013) present a familiar issue of addressing people with disabilities in the third person and brings up an example where
someone asks a carer on whether or not the user ‘takes sugar’ in her tea. Brereton et al. (2015) continues this notion and says that “Even those who cannot answer the ‘Do You Take Sugar?’-question might be able to answer if addressed in a different way.” (p. 5). Brereton et al. (2015) contribute—in a similar fashion to Galliers et al. (2012) and Dawe (2007)—that prototypes can be an important aspect in finding mechanisms that can empower people with cognitive and sensory impairments (CSI). They also found that their prototypes changed the social interaction between proxies and people with CSI because it lets people with impaired ability to understand abstractions have hands-on experiences and “show, share and interact” (Brereton et al., 2015, p. 17).

“With enacting we refer to activities where one or more people imagine and act out possible futures by trying things out (by use of the body) in settings that either resemble or are where future activities are likely to take place” (Brandt et al., 2012, p. 164).

However, as Brandt et al. (2012) says, “enacting needs staging.” There are multiple ways of setting the stage for enactment. Halse, Brandt, Clark, and Binder, (2010) present studies where, among others, the stage is set by evocative cards and participant-sketching. Foverskov and Binder (2011) used wooden dolls to enact possible scenarios when exploring the use of more tangible use of social media for older adults. Iacucci, Kuutti, and Ranta (2000) used game-like scenarios with toys and an active game-master(domopro) that facilitated the unfolding of the role play. This brings us to the topic of how we can adapt our PD-process to the context of physical and organizational limitations.

Hendriks et al. (2014) found that dementia users had to break their participation because they felt weak. They also experienced that the participants joined the PD activities to do the researchers or loved ones a favor and not with intrinsic motivation. As an adaption to some of these issues, Joshi and Bratteteig (2015), in working with elderly, initially found it hard to recruit the users of the care-center to commit to long term participation and ended up with a more adaptable approach of recruiting for individual activities on the day they were conducted. When seeking long term commitment, they had several examples where
“participants refused to sign because ‘I might not even be alive then. This is not for me!’” (p. 21) and:

“their determination to keep their promise and being uncertain about their health condition: they were reluctant to promise something that depended on them having “a good day” but agreed to participate if they could give the final answer in the morning on the day of the activity.” (p. 22)

Converging on some learning outcomes Joshi and Bratteteig (2016), present five points: First, “Recruiting for a particular activity proved to be easier than recruiting for a long-term commitment.” (p. 21). Second, they found that the timing of the sessions was important and “we had to look for open windows and opportunities for engagement in-between [..]” (p. 22), these shorter sessions in turned enabled participation from more people and exposed their themes to more people, more often. Third, they facilitated for continuity—when facing sporadic and inconsistent participation—by utilizing different social contexts and spaces to make sure they were visible, both literally and as a way of encouraging discussion among the residents. Fourth, they argue that older adults “are as different as anyone else—maybe even more.” (p. 23), and thus, to make sure older adults were represented used an open strategy of inviting different stakeholders and instructed the older adults to represent themselves strictly. Fifth and last, they made sure there was an immediacy to the participation—making sure “the threshold and seriousness of participating [..]”-would be easy. The division into smaller activities made this threshold easier. They also made sure to show interest, and help with real-world problems of the older adults, solving simple problems. In a similar fashion Galliers et al. (2012) ensured participation facing physical challenges by making sure the participants had easy access to the context and held workshops in rooms more available.

3.4 Participation: the founding principle

The methodology for this thesis is PD and its overarching principles of democratization and emancipation. In this thesis, I argue that PD is not a system
of methods but rather a frame-of-mind, a ‘sign’ with which I chose to approach the situation as it does not direct what methods to do, but rather how to think about and approach certain situations. For now, Table 2 presents an overview of the related works in the three means of genuine participation, the most related principles and, a summary of techniques. The table will continually be updated through each coming design phase, assisting in structuring of knowledge, how it is used and how it affects the process using simple illustrative arrows.

Table 2: Overview of the process and knowledge generated

<table>
<thead>
<tr>
<th>Means of genuine participation</th>
<th>PD principles</th>
<th>Summary of techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Informing the researcher and the participants own understanding and imagination of possibilities.</td>
<td>Having a say; mutual learning</td>
<td>Long-term commitments, Contextual inquiry, ethnography</td>
</tr>
<tr>
<td>(2) Tools and techniques to extend a space for understanding and making</td>
<td>Having a say; mutual learning; co-construction</td>
<td>Telling, making and enacting (Brandt et al., 2012). Generative tools and techniques (Visser et al., 2005)</td>
</tr>
<tr>
<td>(3) Participation by proxy and, or presence to tackle challenges of genuine participation when facing cognitive, physical and organizational challenges</td>
<td>Having a say;</td>
<td>Long-term commitment, adaptability, proxy-design, facilitating your own participation</td>
</tr>
</tbody>
</table>

Theory
Chapter 4

**Phase 1: Investigating possibilities for participation**

This chapter details the first phase of this project. First, because of the inherent difference between ethnography and PD and the attention PD researchers has given this discourse, I outline a view of ethnography in PD. Second, I cover the methods used. Third, I present the analysis. Fourth, I present some intermediary results and last, detail the main findings and ending on some implications, directing the future design process in *Phase 2*.

The research conducted in this phase resulted in a paper by Dæhlen and Joshi (2019) which is a basis for summarizing the analysis and presentation of findings.

**4.1 Part 1: Ethnography and methods**

While PD represents my methodological view, I want to utilize traditional ethnographic methods, because in this situation they best serve the context and its people, when focusing on democratization and emancipation, seeking to give the participants a say, but mostly create possibilities for mutual learning. This chapter first outline ethnography then discusses its alignment and dichotomies to PD. I ground my approach to ethnography in a short theoretical chapter because I leaned on not just descriptions of methods, but the reflexivity ethnographers teach. Ethnography is used as a method to gain access to *reflective practitioners* because to make sense of the seemingly chaotic nature of any workplace, and create spaces for conducting design—we need to access those who master the chaos (Schön, 2017).
4.1.1 Ethnography

Ethnography as defined by sociologist Hammersley and Atkinson (2007), which there seems to be a broad consensus upon (O’Reilly, 2012):

“Ethnography usually involves the ethnographer participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal and formal interviews, collecting documents and artefacts - in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry.” (Hammersley and Atkinson, 2007, p. 3)

PD researchers Blomberg and Karasti (2012) center ethnographical principles on: “[...] studying phenomena in their everyday setting, taking a holistic view, providing a descriptive understanding, and taking a member’s perspective.” (p. 88). These principles can be recognized in Hammersley and Atkinson (2007) when they elaborate by listing five points on what ethnographic inquiry often features (here shortened considerably): Research takes place in the field. Data often comes from “participant observation and/or relatively informal conversations” (p. 3). Collection of data is relatively unstructured: First, the process is often not preplanned and does not follow a fixed ‘research design.’ Second, the categories for analyzing data is not built into the data collection but in latter sessions of analysis. In-depth study of smaller cases with commonalities. The data analysis is in nature interpretative and qualitative. It produces subjective descriptions, explanations and theories.

Alignments and Dichotomies

Blomberg and Karasti (2012) reveal some of the dichotomies between PD and ethnography:

“such as being descriptive versus prescriptive, providing rich descriptions versus notational formalism, focusing on the particular versus seeking generalizations, identifying concrete examples versus abstract representations, orienting to the present versus pointing to the
future, and understanding the here and now versus intervening to bring about change.” (p. 96)

If we contrast this to our definition of what ethnography serves in Dæhlen and Joshi (2019):

“Our approach relies on immersion as a strategy to build up enough contextual knowledge about the users, their lives and everyday activities, to represent their voices in activities where they are not interested in, or unable to, participate themselves.” (p. 2).

When aligning these two, we can see a relationship between some of the dichotomies raised by Blomberg and Karasti (2012) to our own goal alignment in that we seek a bare minimum description, similar to notational formalism where we focus on general outlines to identify concepts we can generalize and later utilize in a design process. While I identify some of these as dichotomies, there are also some alignments to our work in that we sought a focus on the particular, unique cases that were only identified by concrete examples (Dæhlen & Joshi, 2019).

Relating to the last dichotomy raised by Blomberg and Karasti (2012) between PD and ethnography: “[...] understanding the here and now versus intervening to bring about change.” (p. 96) I want to stress how I actively promoted my views on design, PD and technology for people with ID when working in context. The reason for this is grounded in the attempt to enable a space for mutual learning, where they could learn, reflect and discuss topics that might occur because of my presence—which was later expressed by the manager and employees as an effect of my project. This kind of enabling of spaces for potential recruitment of participants can, among others, be seen in the works of Joshi and Bratteteig (2015) as well as Redhead and Brereton (2012), where word of mouth conveys the doings of design-activities to potential participants as well as enable discussions and reflection.

Descriptive versus prescriptive
Phase 1: Investigating possibilities for participation

PD is critical in nature because it seeks to be emancipatory, not just as an end-goal but as a part of the research we do, to give people the power to change their environment (Klein & Myers, 1999). This can contrast a central commitment in ethnography, which is to seek to describe ‘the here and now’ before prescribing change: “[this] has been viewed by some as slowing down innovation by anchoring change in the past or present and thus limiting future imagination.” (Blomberg & Karasti, 2012, p. 90). Crang and Cook (2007) suggest that this confusion might stem from ethnography’s predecessor anthropology, where historically, cultures were (mis)represented by foreign researchers seeking to describe the context from a detached, omniscient point of view. They contrast this notion of the detached researcher with the view of the researcher, and the researched as interconnected entities, equally positioned to influence each other and the context in which they co-exist. They postulate “In reality, research is an embodied activity that draws in our whole physical person, along with all its inescapable identities. What we bring to the research affects what we get, […]” (p. 9).

Van Willigen (2002) in introduction on applied ethnography, presents multiple scenarios where ethnographic research has been applied as a means of future change. Supporting this idea of change is Lucy Suchman (1993), as cited in Blomberg and Karasti, 2012, responding to the notion of ethnography as being non-interventionist that the early adapters of combining ethnography and participatory held: “[...] innovation is an imagination of what could be based in knowledge of what is, [...]” (p. 88).

Being reflexive

“In other cases, researchers may have spent a significant portion of their lives working in a particular profession and then, for whatever reasons, have gone (back) to college to do research which builds on this.” (Crang and Cook, 2007, p. 38)

One of the core tasks of social care workers in Norway is to “plan and implement health-promoting, preventative, rehabilitative and environmental-therapeutic measures” (Utdanning.no, 2018, Translated from Norwegian). I am not a
professional social worker, and as such, I only follow up activities that social care workers design, and make sure the day-to-day lives of the users are as good as can be.

How can ‘doing ethnography on the job’ affect your work? Crang and Cook (2007) say that the role of someone working in a familiar context can help them give something back to the community under study, however referring to Wax (1983) they state that we must take care as not to be bogged with work. Without discussing the impact, I must state that I have worked with and are familiar with some of the users of the activity center. It likely will have affected the conversations and ability to connect with some of the users as well as employees. My tacit knowledge coming from a similar community of practice has likely been an impact on the connections I have been able to make. I postulate that my principal flaw reveals itself in my lacking descriptions because what a more detached researcher would typically choose to describe is just commonly occurring events to any care worker. However, this tacit pre-existing knowledge about working with people with ID, I consider a significant strength to my research.

**My role as designer and ethnographer**

According to Blomberg and Karasti (2012) designers rarely reflect upon their participation in the same manner ethnographers do. For designers, participation becomes an issue in respects to how to best involve the users in the design process, while, for ethnographers, their participation and impact on the phenomena which they observe are often carefully reflected upon (Blomberg & Karasti, 2012). When we conduct participatory design, we sometimes face similar issues because we often seek to immerse ourselves into the context and community to gain access to means of mutual learning (e.g., Blomberg & Karasti, 2012; Redhead & Brereton, 2012; Holone & Herstad, 2013). Blomberg and Karasti (2012) say that “the designer in some sense must be willing to engage in a continuum of ‘roles’ with the ability to cycle between participation in the life of user practitioners and looking for new possibilities for change.” (p. 91).
Phase 1: Investigating possibilities for participation

Lastly, conducting and writing up ethnography, it can be essential to give ‘thick descriptions’ detailing not just the context or phenomenon, but both (Geertz, 1973).

4.1.2 Methods

The ethnographic methods include participatory inquiry, contextual observation, diary journaling and interviews as well as three traditional design activities in explorative workshops (see Table 3). The ethnographic methods, particularly the participatory inquiry, is inspired by geographers doing ethnography, Crang and Cook (2007). They summarize the ethnographic process as a three-step process where we first gain access, then live or work in the community, then create an account on that community. Table 3 outlines the different methods and participants. Figure 4 illustrates the outline of the process, where the black dot is the deadline for the research paper. The green ‘x’ is the summer vacation of the center, and the red ones are personal leave of absence.

<table>
<thead>
<tr>
<th>#</th>
<th>Research method</th>
<th>Participants</th>
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<tbody>
<tr>
<td></td>
<td>A</td>
<td>Participatory inquiry</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>Diary journaling</td>
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<tr>
<td></td>
<td>C</td>
<td>Contextual observation</td>
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<td></td>
<td>D</td>
<td>Interviews</td>
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<td></td>
<td>E</td>
<td>Thematic Analysis</td>
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<tr>
<td></td>
<td>F</td>
<td>Inter-rater reliability analysis</td>
</tr>
<tr>
<td></td>
<td>WS1</td>
<td>Explorative Workshop I</td>
</tr>
<tr>
<td></td>
<td>WS2</td>
<td>Explorative Workshop II</td>
</tr>
<tr>
<td></td>
<td>WS3</td>
<td>Explorative Workshop III</td>
</tr>
</tbody>
</table>

Table 3: Overview of methods Phase 1.

<table>
<thead>
<tr>
<th>Week</th>
<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
<th>Sep</th>
<th>Oct</th>
<th>Nov</th>
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Participatory Inquiry [A]

The participatory inquiry was conducted between June 2018 and November 2018, usually on Mondays and always in the context of the activity center. A total of twelve days was spent in the participatory inquiry which amounted to around 100 working hours. Each day there are some 20 users, and 15 employees present fluctuating depending on the day of the week. The participatory inquiry involved working on a volunteer basis as an uneducated social worker. The manager and I initially planned I work from 08:00 to 11:00 am, but after the first couple of days, we agreed on extending the volunteer-work to a full workday.

The main goal of the participatory inquiry aligns with Crang and Cooks (2007) take on the method that “participant observation should not be to separate its ‘subjective and ‘objective components, but to talk about it as a means of developing intersubjective understandings between the researcher and researched” (p. 37). This notion can also be recognized in the concept of mutual learning and relevant PD literature (e.g., Bratteteig et al., 2012; Holone & Herstad, 2013; Joshi & Bratteteig, 2015). The long-term commitment of the project can also bridge a potential power issue as potential participants might be hesitant to join design exercises because these are, alien academic practices (Redhead & Brereton, 2012). In the initial diary entries I addressed power issues as “The main goal of the observation is that I want to be able to come and go as I please without anyone batting an eye.” [B]. There were also multiple occasions where the care workers expressed their thoughts on how my presence could affect the dialog at the activity center. Addressing the issue of swapping roles raised by Blomberg and Karasti (2012), I focused entirely on acting out work as a care worker. A change of roles would not come into effect until later in the process.

The resulting data collected from this participatory inquiry was a total of 18 diary entries, detailed in the next section.

Diary Journaling [B]

I have called this method diary journaling because it differs from the field-notes that ethnographers take in-situ in that they are notes gathered after each workday,
Phase 1: Investigating possibilities for participation

more akin to a diary or journal. This was done because I wanted activities and communication to proceed as usual and not distance myself as a researcher. I planned an initial structure based on the ‘six-layered descriptions’ list forwarded by Crang and Cook (2007, p. 51). However, I was not able to capture the detail in the diary style method and it was not practically feasible to record audio. The diary entries describe activities, communicational and physical challenges the users met as well as events, concrete examples and the impacts of my research on the context. The entries varied from ~900 to ~130 words with additional illustrations and descriptions.

Contextual Observation [C]

The purpose of the contextual observation was to gather photographs representing the broad range of activities and objects. The photographs consist of: "technologies (e.g., audio systems, massage chairs, and light projectors), objects used in activities (e.g., instruments, games, and drawings), and places of interest (e.g., sensory rooms, resting places, and creative spaces)." (Dæhlen & Joshi, 2019, p. 3) The data amounts to a total of 50 suitable photographs—chosen by me. The photographs are zoomed in on the objects as picture collages and other items enabling identification of the center and people cover many walls, as seen in top of Figure 5.

Figure 5: Photographs and collages covering the walls
The photographs were taken after hours to ensure the academic practice did not disrupt any ongoing activity as well as practical reasons for protecting the privacy of the participants and the location of the activity center. Thus, they do not picture people.

Interviews [D]

A detailed description of this method can be seen in Dæhlen and Joshi (2019):

"An important part of the immersive approach was facilitating easier access to both contextual and domain knowledge which included in-depth details about the capabilities of each person who used the activity center. One of the main sources of information was ten semi-structured interviews with the manager of the activity center revolving around practical and organizational issues that were relevant to our facilitation of a PD process including both the users and their caretakers. These interviews revealed opportunities and limitations for participation, e.g., insight into the working schedule of the caretakers, as well as suggestions on suitable caretakers who could fit the role as proxy designers in later stages of our PD process. Each interview lasted between 30-60 minutes and was scheduled throughout the four months depending on the manager's availability." (p. 3).

The interviews were not recorded because, at the time of the inquiries, I did not view it as data and rather as conversations relating to the facilitation of the process of inquiry and future process of design. Thus, the data from these conversations consist of notes.

Thematic analysis

To analyze the data, I utilized Braun and Clarke's (2006) thematic analysis. They present a six-step “method for identifying, analyzing, and reporting patterns (themes) within data.” (p. 6). The thematic analysis was conducted over one month, from early October to mid-November. The eleventh and twelfth inquiry
Phase 1: Investigating possibilities for participation

was conducted during this time. During the thematic analysis, I took notes which, in Chapter 4.2.1, is a basis for presenting the analytical process.

Braun and Clarke (2006) offer a set of advantages of thematic analysis where particularly two stand out: Thematic analysis “Can usefully summarize key features of a large body of data, and/or offer a „thick description“ of the data set.” (p. 37) as well as a “Useful method for working within participatory research paradigm, with participants as collaborators.” (p. 37). The total of 64 lower-order codes generated in this thematic analysis was later used in the inter-rater reliability analysis in Dæhlen and Joshi (2019).

Exploratory Workshop I [WS1]

This exploratory workshop was conducted, with peers, to explore the possibilities of the data and what kind of analysis would benefit from it. Additionally, this workshop was the basis for the inter-rater reliability analysis where the two researchers did an individual objective coding of the themes and codes created in the thematic analysis (see Dæhlen and Joshi, 2019). The immersed researcher brought photographs, mind-maps, notes from interviews and diary notes which was used as a basis for discussing the possibilities for facilitating future PD-activities. The resulting notes from the workshop were used as inspiration for doing a thematic analysis.

Exploratory Workshop II [WS2]

The second workshop was a ‘thinking aloud’ exercise conducted as a response to Braun and Clarkes (2006) 4th phase: ‘reviewing themes,’ in which they describe how to review whether the data fits the themes crafted. When cross-reading the data to my themes I found that very little of the data related to what the care workers thought or had said about some of the themes I had created. Since the eventual design process was going to involve the care workers as proxies for the users, I saw a need to explore what the care workers thought about the themes I had coined.
The workshop spanned some 20 minutes where six care workers were asked two questions, wrote down answers, then presented and discussed their answers. The workshop was initially planned to be held after work on a Friday as a one-hour exercise, but after diminutive response I canceled the workshop. When cancelling the workshop the co-manager suggested we take 30 minutes from the morning meetings and arrange the workshop coming Monday. I spent the weekend re-creating a short-form workshop to be held Monday morning.

**Exploratory Workshop III [WS3]**

This workshop was conducted as a part of a ‘plan-day’ at the activity center (Figure 6) and was conducted around the submission deadline of Dæhlen and Joshi (2019), therefore not included in the article. This workshop had two main goals. First, I wanted to explore the possibilities to design during the workday as I had not yet figured out how I could utilize the knowledge about the context to create design-workshops to fit their otherwise busy schedules. Second, this workshop was used as a space for the employees to learn about the possibilities with PD and explore what a design activity can be by doing a ‘designerly’ activity (Figure 7), as well as to introduce the findings of how I understood the concept of activity and communication. I also wanted to anchor a common goal or vision for the future design process.

*Figure 6: The workshop*

*Figure 7: A 'Designerly' activity, exploring possibilities within PD and context*
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**Inter-rater reliability analysis**

In Dæhlen and Joshi (2019) we conducted an inter-rater reliability analysis to explore a possible distributed understanding of the context. See Dæhlen and Joshi (2019), p. 5 and 7.

**4.2 Part 2: Analysis and results**

This chapter is structured around Crang and Cooks (2007) method of ‘Writing Through Codes’ where they describe pulling together ethnographic accounts using codes and schemes generated in an analysis. Thus, this section presents the analysis and the resulting thematic map and which later, in Section 4.2.2, structure the presentation of intermediate results.

**4.2.1 Analysis**

This section gives an account of the inductive thematic analysis based in Braun an Clarkes (2006) guidelines for the method. The themes, *activity* and *communication*, were early explored as encompassing the core of anything that is conducted at the activity center. The center naturally has an intrinsic focus on activities and how to facilitate for these. This facilitation focuses around the different, individualized communicational capabilities of the users, who has an often-limited ability to express their wants and needs.

**Phase One**

The first phase of familiarizing myself with the data (Braun and Clarke, 2006) became the group exercise of Exploratory workshop I (Figure 8) where we discovered that a thematic analysis would benefit the project because of the diverse, and subjective nature of the data. This workshop also opened the possibility for my co-author and supervisor to access the data. His initial analysis contrasted greatly from my understanding of the context, which served as a basis for the inter-rater reliability analysis.
Phase Two

At this point, the data consisted of notes from interviews, diary entries, photographs, discussion summaries, mind-maps and data from Exploratory workshop I (Figure 9). While these codes are few, and not a long list of codes, such as Braun and Clarke (2006, p. 19) suggest before moving into theming, they were examples of a much broader set of activities and means of communication.

Phase Three

Here I started searching for themes that would describe over-arching concepts that would be important when designing for people with ID. Here the themes ‘feeling of worth’, ‘doing,’ ‘choice’ and ‘routine’ emerged as the main themes (Figure 10). Although worded differently in later sessions these themes were the foundation for understanding "what is an activity for the users" (see Figure 10). In this session, I tried to focus on making sure that the themes were not the results of a few anecdotal examples but instead representative of the entire data set.

Figure 8: Exploring the possibilities within the data.

Figure 9: Examples of raw data (left) and resulting first thematic map (right)
Phase 1: Investigating possibilities for participation

(Braun and Clarke, 2006). Noteworthy in this mapping process was that I started to analyze how the theme ‘choice’ was ‘locked’ to a set of routines and human factors. Another interesting observation is that ‘doing’, which later became ‘practice’, is not fleshed out. The most important I take from reviewing this thematic map is that I attached meaning to activities, which is later fleshed out in Exploratory Workshop II, conducted during Phase Four.

Phase Four

Braun and Clarke (2006) describe this phase in a two-step process where you first review your themes and whether they represent the sub-set of codes, combine codes into new themes and combine or collapse themes. Second, you review your themes in relation to the entire data set.

When reading through the data set, I discovered that the data specifically lacked insight into what constituted meaning-makers for the users. Thus, I decided to facilitate a workshop to further explore how the care workers understood meaning-makers for the users.
The question we addressed in Exploratory workshop II was: *What makes the users want to come here; what are the elements in their workday which makes them feel happy and what could enhance the enjoyment of the workday?*

After the session, I coded their notes and here present the most prominent ones in Table 4. The care workers had a distinct focus on social aspects as meaning-makers, with less focus on activities themselves as meaning makers. Five out of six participants individually noted ‘social’, ‘change of environment’ and ‘together-ness’. When talking about ‘change of environment’ the care workers allude to the change of environment that *going to work include*. ‘Together-ness’ encompass the focus on friends and people, a sense of belonging to the community of friends and co-workers. There is also a broader focus on feeling safe, acknowledgment, pride and general happiness.

<table>
<thead>
<tr>
<th>Meaning makers</th>
<th>Number persons who coded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social</td>
<td>5</td>
</tr>
<tr>
<td>Change of environment</td>
<td>5</td>
</tr>
<tr>
<td>Together-ness</td>
<td>5</td>
</tr>
<tr>
<td>Have a job</td>
<td>3</td>
</tr>
<tr>
<td>Activities</td>
<td>3</td>
</tr>
<tr>
<td>Fun</td>
<td>3</td>
</tr>
<tr>
<td>Mastery</td>
<td>3</td>
</tr>
</tbody>
</table>

It is apparent that—seen from the perspective of the care workers—the most important meaning-makers for the users is not necessarily what is done as long as it is social. There are, however, some exceptions where the care workers talk about routines, exemplified by one of the participants: “For some, it is a little crisis to have a day off, it is a break in routines.”, as well as some specific activities and how they might intrinsically generate meaning in different ways.
**Phase 1: Investigating possibilities for participation**

**Phase 5**

Emerging from the workshop was the new codes ‘community’ and ‘context’—which encompass the codes from the workshop relating to ‘social’ and ‘change of environment’. The result of the thematic analysis culminated in a thematic map detailing the top-level themes (Figure 11).

![Figure 11: Thematic map, detailing the highest-order themes](image)

### 4.2.2 Intermediate results

This chapter utilizes the thematic map to assist in structuring presentation of the empirical context and give ‘thick descriptions’ of the context following Crang and Cooks (2007) guide of ‘writing through code’.

In the Participatory Inquiry I was trained to work with two users, both a member of the living room group. The reason for working with the living room group was that they were a more constant, unchanging group, which did not rely on routines
and work in the same manner others did. Another reason was that the manager thought it would benefit myself and the users to work with one group of people over time, rather than spend sporadic time with all—I would still be able to go and talk to everyone as many things were happening between the groups. Thus, much of my knowledge comes from extensively working with the living-room group, sporadically visiting the others.

**Practice**

*Profession*

Some of the activities resemble traditional vocational work, themes as ‘profession’; these include a pottery and woodworking workshop (Figure 12), and a sewing room (Figure 13), custodian services and a cantina.

There are multiple different tools to help the process of making things at the center, one of these tools is a complex analog Japanese machine sewing machine seen in Figure 13, which simplifies the process of making larger, intricately detailed garments. What is especially interesting with this machine was how the care workers and users operated the device: the care worker used small needles, thread and different mechanics to create patterns and the user pulled the large white handle, across to finalize the pattern.

I was not able to join pottery or woodworking but some of the resulting objects can be seen in Figure 14. Cups, fridge magnets and beer or wine cases are some of the things made in the workshop.
Phase 1: Investigating possibilities for participation

Figure 12: The wood working and pottery workshop

Figure 13: The complex Japanese sewing machine.
Stimulation, Recreation, Training, and Chores

When working with the living-room group, most of the activities fell within this category as the users, on Mondays, are almost exclusively people with severe to profound intellectual or physical disabilities. These activities often seek to maintain capabilities, e.g., sensory-stimulation tools that can either help relax and stimulate for activity. Some seek to activate different kinds of sensory experiences, e.g., the massaging chair (Figure 15), supporting relaxation as well as contributing to maintaining physical capabilities. Ball-pit (Figure 16), most often used by some of the more challenged individuals as a sensory stimulation activity, the users can throw balls, listen to music, or communicate using the pit, out of frame there is a mobile elevator to enable wheel-chair users’ access. The white room (Figure 17) is dedicated to stimulating different senses using a water bed, light and sound installations as well as some tangible tools and is mostly used by people who need a break. The sensory wall (Figure 18), doubles as a sensory stimuli tool and exercise equipment, specifically tailored to one of the users.

Examples of some different activities are recreational activities like going for walks, playing board-games, reading, singing or listening to music. Creative: painting, drawing or pearling. Chores: cleaning, re-stocking household goods. Lastly, simple vocational tasks like shredding paper (Figure 19) and feeding the fishes. Some tasks are vastly more popular than others, e.g., shredding paper, drawing, and reading. I will shed some more insight into why that is in the next section.
Phase 1: Investigating possibilities for participation

Figure 15: The massaging chair

Figure 16: The ball-pit
Figure 17: The 'white-room', a sensory experience room.

Figure 18: The sensory experience and exercise wall.
Phase 1: Investigating possibilities for participation

Flexibility

All these different tools and activities speak to a broader need for flexibilities in what activities are available. Users have highly individualized practices for conducting a task, and often activities and spaces are specifically tailored to individual needs. E.g., one person doing the ‘paper-shredding’ activity might conduct a seemingly simple activity very differently from another, as showcased later with a participant saying:

“*She wants to be included into everything, even though she cannot participate much with her body she loves to be included socially. For example, I tried to fold papers once with her* [which is a part of the paper shredding activity], *and it can be very fun.*” (See Chapter 5.2.2)

Some of these sensory stimulation activities, hint at the essential flexibility needed in almost all facets of the activity center. Some of the activities are directed at helping alleviate both physical and mental stress, like the white-room and ball-pit, designed to help cope with the uncertainty of not understanding what happens and of sometimes being overwhelmed by too many social stimuli. Some have
bodily configurations that call for flexibility in carrying out activities as they need
time to prepare for the task of going to the bathroom or eating, exemplified with
the need for a personal mobile elevator in the bathroom (Figure 20). Often these
bodily configurations and stimulatory activities call for flexibility in that they
require care workers to assist one another, leading to pauses or breaking of
activities.

Figure 20: Bathroom with elevator and a special bed.

Miscommunication between care workers and users also speak to a need for
flexibility in the planning of activities, as the care workers and users planned for
activities to be conducted, but when confronted with the more relatable act of
carrying it out, the real wishes of the user emerges as they finally are able to
cognize the implications.

Meaning

In one of the interviews the manager of the activity center offered a humanist
centered view: “The purpose of the activity center is for the users to come home
and feel like they had a nice day, with a wish to come back the next.”
Phase 1: Investigating possibilities for participation

Which means that an activity—in the context of this activity center—is anything that serves this purpose. In other words, the goal of the activity center is to provide the users with meaning makers. These meaning makers can be inherent in the activities conducted or as explored in Exploratory workshop II a result of the social environment of people and things. What is important to know is that meaning emerges in different situations for different people but there are indications as to what constitutes meaning for a majority of the users (social environment and a change of environment).

Community and Context

Any activity, be it shredding paper, drawing, knitting, cooking, listening to music, are all situated in a context which here is a place for work. In Exploratory workshop II the care workers most prominently suggested that meaning emerges as a social construct. This is apparent in the notes from the workshop relating to the first question: “What makes the users want to come here; what are the elements in their workday which makes them feel happy?”:

P1: “I can say that. I say that it is social, then I wrote that it is a safety, and then predictability, well-being, change of environment, learning and acknowledgement.”

P2: “I too had change of environment, social and work, conscientious. That is all.”

P3: “Eh yeah, I wrote to be seen and heard, it is kind of the same but. Yeah a togetherness, social, eh, to help contribute, the feeling of”.

P4: “Yeah, much the same. Change of environment, social, motivated by a community, comrades and buddies and other activities.

P5: “A different social setting than their living situation, the community in itself I think they enjoy, especially the community, the good community. [...] and to have a meaningful workday, a pride and sense of mastery when, do you remember [user], he was very, like proud when he sat at the chair and shredded paper, it was sort of something he liked and mastered. Yeah.”

P6: “I have written some more specific things like, eh, or I started with things like fun, social, work, habits, routines and go for walks, swimming, make lunch, carpentry- other hand-activities, drive, feed the fishes, music and read magazines.”
The care workers attribute meaning makers to the community of people and change of environment that occurs when they go to work. P5 talks about the sense of pride and accomplishment that comes from being able to feel mastery over something. Harking back to the process described with the intricate Japanese sewing machine (Figure 13), where a user participates by finalizing the pattern. Knowing that this happens in a social context of chatting with peers it supports that meaning emerges from the social aspect of doing something together, rather than the activity itself.

Another product of the social aspect is the sense of acknowledgment, pride, and mastery the users feel when they can display something. This can take shape in just receiving praise for the work that has been done, displaying the finished product of activity like going out with the trash and then, showing with pride, that the trash-bin is empty. The most critical facet is not how hard the initial task is, but what it feels like to receive praise for what is considered effort. After one of the workshops held in Phase 2, one user walked around the center, proudly displaying their work of art to others and received high praise from care workers and peers (Figure 21).

*Figure 21: The creations of one of the users in a later workshop.*
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Another instance of displaying work is in the shop, where they display clothing made, packages of fire-starters, candles, cups, cutlery, and more, selling them to locals and family (Figure 22).

As mentioned the task of shredding paper is a favorite. This activity is quite fascinating because it involves some very specific and arbitrary task-chains. First, we usually find old papers from Oslo Municipality (which sometimes were over 40 years old, located in the cupboard in (Figure 19). Then we go to the living-room table or the couch-corner, depending on where there are others to work with. Then take one paper, fold it once and continue untill all are folded. Lastly, they
are shredded in one of the two paper-shredders. What I think is particularly interesting about this is that it is quite a menial task, but it is still the most conducted activity. I think this activity might be popular for two reasons: First, as stated by P5 in Exploratory workshop II: “he was very, like proud when he sat at the chair and shredded paper, it was sort of something he liked and mastered. Yeah.”. It is a task that is easy to master, and it very much resembles what anyone would call work. Second, it always happens as a social activity where the users and employees sit together and chat. Another reason why this task might be a favorite is that it is straightforward for the employees to facilitate when they have other responsibilities; it is flexible.

Choice

Choice represents the different capabilities of communication that cognitive and physical disabilities effects and how they are worked with. In one of the first interviews with the manager, he said that “the relations we build is the point of departure for all the work we do.”. This theme is dubbed ‘choice’ because the communicational capabilities are most visible when it comes to presenting choices.

Language and Presentation

As mentioned in Chapter 3, language is power, and when the ability to cognize or otherwise express yourself is hard, the care workers have a responsibility to both try and understand and make things understandable. Anyone with intellectual disabilities has a harder time communicating their wants and needs, and what might be especially frustrating is when you know what you want or need but are not able to communicate that because of cognitive speech impediments or physical disabilities. At the activity center, some users cannot make themselves understood by word of mouth and exclusively rely on the care workers ability to interpret movements. Others can make themselves understood fine with speech, while some need a complimentary body language or sign language to communicate. Besides the spoken word, one of the most common assets of communication is the use of pictograms (Figure 23) and body language.
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The often-limited vocabulary of some users means that having a meaningful conversation hinges on the care workers ability to interpret the meaning behind the words. For the living-room group, the ability to interpret meaning is assisted by tools. These tools are sometimes systems of presenting a choice of activities (Figure 24), or individualized tools for communication that can serve to have more meaningful conversations, where the user refer to images or as a tool to train or maintain speech (Figure 25).

Figure 23: Pictograms for enhancing communication.

Figure 24: Systems of organizing and presenting choices visually.
The communication tool that I have used the most is the user diary. The user diary is a journal where care workers, family, guardians or any stakeholders usually write down short entries on things that happen in the day-to-day life of the user. The user I have worked closest with has a minimal vocabulary and some understand spoken words just fine. She uses the diary throughout the day as a point of reference, by pointing at words and sentences, sometimes handing it to the care workers to read entries from specific dates. The diary extends the care workers understanding of what is happening outside the activity center, and the user can hand it to anyone who has not necessarily been on the morning meetings, thus enabling for more meaningful conversations and less stressful moment of misunderstandings.

**Routines**

Routines constitute another essential facet that encompasses the communicational capabilities of the users. Routines are the structures which the users often plan their days around, and they paradoxically help increase autonomy and self-government. Structure, routines, and habits permeate the lives of people with ID and they are often vital to work with as breaking routines can lead to less meaningful communication and days.
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Planning and Autonomy

When working with the living-room group, one of the most basic routines were the conversations and planning that occurred during the ‘morning meetings’, which differs from the employee morning meeting. The ‘morning meeting’ takes place in the living room at the big table around 09:00 to 10:30 am depending on when users arrive at work. It is a process where the users, in turn, read from their diary with assistance from the care workers and pass the word on to the next and lastly make plans for the day. The employee morning-meeting is conducted from 08:00 to 09:15 am and is conducted by the employees and serve as a base of operations where they, each day plan out whom to work with and what the possibilities of the day given the resources available. While each week is planned on Fridays, the care workers have to work around issues that arise, e.g. health-leave from both users and care workers. This flexibility in care workers routines was observed at all employee morning meetings.

Another example of routines is the more personal, but often essential ones that govern how well a user can pay attention to the activities at hand. In one occasion I had to leave early from work which impacted the user’s ability to participate as they got ‘hung up’, as said by the manager, on what I was doing rather than paying attention to the activities at hand. After this occurrence, we planned for more extended stays and made sure I would be able to stay there for the entire day when working with this user.

To promote autonomy, the care workers continually create tools enable the users to choose, initiate and complete activities more independently of the care workers (Figure 26).
While I conducted a thematic analysis, as well as an inter-rater reliability analysis the analytical process has by no means been a structured one. It has been a continual process of thinking and rethinking the possibilities of design within this context since I first talked with the manager in April 2018, up until I created the methods chapter for Phase 2 in January 2019. In our paper, we conclude on three learning outcomes that we believed could structure the immediate design process (Dæhlen and Joshi, 2019, p. 8).

After the paper was submitted and analysis and Exploratory workshop III conducted, I had a deep understanding of the context. However, I still did not understand how I was going to facilitate for workshops, and at this point, I still thought that the ideal solution would be to arrange design workshops after work to ensure longer sessions with the care workers full attention. The results from Exploratory Workshop II and III shut down this idea when I saw that no one volunteered II, as well as the results from III, where no one subscribed to design activities after work. The care workers apparent reluctance to join workshops can be attributed to things they would have to consider: “for example, amount of time

![Figure 26: Two examples of 'day-planning' tools](image)
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to invest, personal interest in the process and subject at hand, and how the participation will affect their everyday lives in general” (Grönvall & Kyng, 2013, p. 399).

This stipulates one requirement: *If I am going to create a design process that is to be conducted during work hours I need to facilitate for the users’ participation and create a process that facilitates design to happen during work hours.*

4.3 Part 3: Learning outcomes

This part summarizes my understanding of the results in a findings chapter, then combine the findings with the learning outcomes from Dæhlen and Joshi (2019) to create some implications on the future design process which is then fleshed out in *Phase 2, Chapter 5.1*. The main findings were shortly presented in the article but were left hanging due to space. Here I will present the findings more in-depth and build design implications in combination with the design guidelines from Dæhlen and Joshi (2019).

4.3.1 Findings

To summarize my understanding of the context, I will refer to the article where we describe the four main findings as:

“Meaning outlines an understanding of the meaning bearers for the users. Practice describes the context and the various kinds of work and activities carried out at the activity center. Choice describes the challenges the users and employees face during decision making, as well as how they are resolved in situations involving different cognitive capabilities. Routine defines how we can understand the role and implications of the daily routines within the everyday lives of the users.” *(Dæhlen and Joshi, 2019, p. 6)*

First of all, seeking to understand these concepts is essential because of the limited cognitive capabilities of the users. If I want to be emancipatory, I must take a
position that seeks a deeper understanding of the users, their context and their doings. The four higher-order themes—meaning, practice, routines, and choice—are the resulting examples of issues that display different types of contextual insight gained through the immersion. However, more importantly, the themes present an overview of what needs to be considered when seeking to design in this context (Dæhlen and Joshi, 2019). In our paper, we present findings from the contextual insight in a table (Table 5) representing four themes, the main findings, the source material and key observations and quotes for each theme.

Table 5: Table 3 from Dæhlen and Joshi (2019): “Overview of the four themes and main findings.”

<table>
<thead>
<tr>
<th>Theme</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning</td>
<td>• Meaning emerges through the context in which the activities take place.</td>
<td>[A],</td>
<td>“Examples of meaning bearer are social relations, [B], [WS2] safety, predictability, well-being, change of environment, learning and acknowledgment.”</td>
</tr>
<tr>
<td></td>
<td>• The company of the caretaker can affect how meaning emerges.</td>
<td></td>
<td>(caretaker, [WS2])</td>
</tr>
<tr>
<td>Practice</td>
<td>• The practice involved in activities varies between users.</td>
<td>[A],</td>
<td>“Some activities require 1-on-1 assistance depending on the individuals involved and the context in which it is carried out.” (diary entry, [B])</td>
</tr>
<tr>
<td></td>
<td>• Activities need to be flexible regarding duration.</td>
<td>[B],</td>
<td>“During the first day, I had to end an activity with a [D] user because I was requested to help with something else” (diary entry, [B])</td>
</tr>
<tr>
<td>Choices</td>
<td>• Presentation of choices must be tailored to both the user and the context.</td>
<td>[A],</td>
<td>“The user was presented with two alternatives, which I [C] later discovered was a rather restricted choice considering the user’s capabilities” (diary entry, [B])</td>
</tr>
<tr>
<td></td>
<td>• Limited language and cognition skills inhibit the presentation of choices.</td>
<td>[B]</td>
<td>Representations of choices often require non-verbal forms of communication (see Figure 21 &amp; 23, [C])</td>
</tr>
<tr>
<td>Routines</td>
<td>• Structure and daily routines affect the users’ ability to participate.</td>
<td>[A],</td>
<td>“For some users, it is a crisis to have a day off as it [B] breaks routines” (caretaker, [WS2])</td>
</tr>
<tr>
<td></td>
<td>• Routines promote autonomy by facilitating learning over time.</td>
<td>[B],</td>
<td>“One user was frustrated when I communicated that I [WS2] had to leave early because it disturbed some of the users’ routines” (diary entry, [B])</td>
</tr>
</tbody>
</table>

Second, the themes are by no means mutually exclusive. E.g., cognitive and physical challenges are not something that only affects choice; it is also the baseline for how activities and work are conducted. I could also have coded communication as a sub-theme to activity as some form of communication is
Phase 1: Investigating possibilities for participation

integral to activities as either a facilitator or main component in conducting any activity. I hope that this section, in light of the contextual insight given, can be a springboard for understanding how the later design implication emerges.

Meaning

<table>
<thead>
<tr>
<th>Theme</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning (Activity)</td>
<td>• Meaning emerges through the context in which the activities take place.</td>
<td>[A],</td>
<td>&quot;Examples of meaning bearer are social relations, safety, predictability, well-being, change of environment, learning and acknowledgment.&quot;</td>
</tr>
<tr>
<td></td>
<td>• The company of the caretaker can affect how meaning emerges.</td>
<td>[B],</td>
<td>(caretaker, [WS2])</td>
</tr>
<tr>
<td></td>
<td>Users have individually tailored activities and contexts to situate specific kinds of meaning</td>
<td>[WS2]</td>
<td></td>
</tr>
</tbody>
</table>

Understanding meaning is essential because it emerges differently for everyone. For the users I worked closest with in the living room group—and work closely with in the coming design session—the social fabric, the community and change of environment was what I identified as most important. Another vital meaning-maker is that which happens together with the care workers: when the users feel a sense of pride and accomplishment from the praise they receive—or for others, it might be the act of creating something, seeing it displayed and sold, or appreciation for the food they have made. Most likely, meaning does not emerge through individual activities but, rather as a sum of the whole experience of the activity center, its community, the friends, and change of environment. As for the users, I have worked closest with, primary activities are things that could be considered menial or un-skilled like shredding paper, drawing, reading, listening to music. However, relative to capabilities, it does require skill and concentration. Relating this to Schmidt’s (2011) definition of work as activities that require “effort and concentration” and are “[...] ‘necessary or useful in a practical way’, either in terms of the concrete fruits of the labor (food, clothing, timber, tools, machines) or in terms of some other reward (remuneration, recognition).” (p. 375). Emphasis on some other reward.

Understanding this and acknowledging the activities we do as work where meaning in some way emerges is important because when designers in the future
design with people with ID, we need to create work-like activities, familiar to the concepts which bring meaning to everyone. To create meaningful design-activities, we need to understand the contextual practice, which I will present next.

**Practice**

<table>
<thead>
<tr>
<th>Theme (Activity)</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Practice (Activity)</td>
<td>The practice involved in activities varies between users.</td>
<td>[A], [B], [D]</td>
<td>&quot;Some activities require 1-on-1 assistance depending on the individuals involved and the context in which it is carried out.&quot; (diary entry, [B])</td>
</tr>
<tr>
<td>Practice (Activity)</td>
<td>Activities need to be flexible regarding duration.</td>
<td></td>
<td>&quot;During the first day, I had to end an activity with a user because I was requested to help with something else&quot; (diary entry, [B])</td>
</tr>
</tbody>
</table>

I needed to understand Practice because to create something interesting and meaningful for the users—and familiar enough of an activity for the employees I needed to understand what constitutes work for each user and how they conducted that work. This user-group has a very different set of capabilities when it comes to communication, cognition, and physicality, and we need to work with these capabilities. I have experienced mood swings, issues pertaining to bodily functioning, physically or cognitively fatigue, or the users can lose interest. Because of this, all activities have a flexible nature, both when it comes to duration as well as employees having to help others in time of need.

**Routines**

<table>
<thead>
<tr>
<th>Theme (Communication)</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Routines (Communication)</td>
<td>Structure and daily routines affect the users' ability to participate.</td>
<td>[A], [B]. [WS2]</td>
<td>&quot;For some users, it is a crisis to have a day off as it breaks routines&quot; (caretaker, [WS2])</td>
</tr>
<tr>
<td>Routines (Communication)</td>
<td>Routines promote autonomy by facilitating learning over time.</td>
<td>[B], [WS2]</td>
<td>&quot;One user was frustrated when I communicated that I had to leave early because it disturbed some of the users' routines&quot; (diary entry, [B])</td>
</tr>
</tbody>
</table>

Routines are the often-artificial structures with which the users structure their days and activities around. While I am sure anyone can identify routines in their daily...
Phase 1: Investigating possibilities for participation

lives, it simply permeates the lives of people with ID, and for some, they are very important if they are to have meaningful interactions. Routines can affect autonomy and a sense of ownership over your own life and doings in that it fosters a learning over time and thus, your ability to do things independently of others. Thus, routines can be an important meaning-makers for some, as many rely on the structuring of the day around objects and people to feel in control. No matter the capabilities, you still want to understand, feel safe and like you are in control. Not knowing and not understanding an unfamiliar situation has been observed to lead to distractions that takes away from possible meaningful communication.

Choice

<table>
<thead>
<tr>
<th>Theme</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choices (Communication)</td>
<td>• Presentation of choices must be tailored to both the user and the context. [A], [C], [B]</td>
<td></td>
<td>“The user was presented with two alternatives, which I later discovered was a rather restricted choice considering the user’s capabilities” (field note, [B])</td>
</tr>
<tr>
<td></td>
<td>• Limited language and cognition skills inhibit the presentation of choices.  [A],[B]</td>
<td></td>
<td>Representations of choices often require non-verbal forms of communication (See Fugyre 21 &amp; 23, [C])</td>
</tr>
</tbody>
</table>

Lastly, I needed to understand choice and how users are presented with choice, what physical and cognitive challenges they face and how these factors impact each user’s ability to participate in a session. To create future design with people with ID I need to understand choice because, to be emancipatory in our designs I need to understand how choice occurs, how they will affect a future design process and the possibilities for meaningful interaction.

Choice is two-fold. First, it is understood to utilize current knowledge about choice to create a design process that includes the user into the process by giving them choices that they understand using the knowledge obtained about each user’s physical and cognitive capabilities. Second, the lower-order themes of choice also represent knowledge about the users’ capabilities beyond just taking choices but the general possibilities of communication, understanding and physical capabilities (See figure 8). To note, while this is called choice here the more operationalized version, used throughout rest of the thesis is, is the sub-codes
‘cognitive’, ‘physical’ and ‘language’ or sometimes referred to as ‘communicational capabilities’.

4.3.2 Implications – adapting process to fit practice

This section presents two design implications based in a requirement to involve users into the design process. These utilize the already existing learning outcomes from Dæhlen and Joshi (2019): “The PD process should facilitate for the participation of caretakers as proxies”, “The PD process should be organized as a long-term commitment” and “The PD process should be built on top of already established forms of mutual learning”. Phase 2 will be shaped according to these implications and learning outcomes.

As indicated in Chapter 4.2.2 Exploratory Workshop III, the coming design-process require that I facilitate for the participation of the users in the design activities. To manage this requirement, I need to facilitate design activities in such a way that 1. the care workers can facilitate for their own participation by including the users into ‘design-like’ activities. 2. Design activities need to be tailored to fit with existing practice, meaning-makers, routines, and choice.

(1) Facilitate for the care workers to facilitate their own participation

To enable the care workers to do their job as care workers and maintain their responsibility for the users’ well-being, I need to facilitate design-activities that can occur as a long-term commitment. As a researcher, I must focus on conducting the workshops and I cannot hold responsibility for each user’s well-being. Thus, I need to make sure the care workers know how they can include the users into the workshops. To make this easier for the care workers, I need to build on already established practice.

(2) Build the process on already established forms of mutual learning and practice

To ‘Facilitate the users’ participation’ and enable the care workers to do the main facilitation I must utilize my knowledge about how meaning emerges, the different practices, routines and their importance to the users at hand and how
Phase 1: Investigating possibilities for participation

each can be presented with choice, based in their communicational and physical capabilities. I need to utilize existing practices where mutual learning occurs to enable planning, execution and spaces for discussion.

We can now extend on the overview figure with the findings and implications, as well as how the techniques informed the different knowledge (Table 6).

Table 6: Overview

<table>
<thead>
<tr>
<th>Theory</th>
<th>PD principles</th>
<th>Phase 1 – Immersion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Means of genuine participation</td>
<td>Having a say; mutual learning</td>
<td>Activity: Practice Meaning</td>
</tr>
<tr>
<td>(1) Informing the researcher and the participants own understanding and imagination of possibilities.</td>
<td>Long-term commitments, Contextual inquiry: ethnography</td>
<td>(1) Build on the process of already established forms of mutual learning and practice</td>
</tr>
<tr>
<td>(2) Tools and techniques to extend a space for understanding and making.</td>
<td>Telling, making and enacting (Brandt et al., 2012), Generative tools and techniques (Visser et al., 2005)</td>
<td>Darhlen and Joshi, (2019)</td>
</tr>
<tr>
<td>(3) Participation by proxy and, or presence to tackle challenges of genuine participation when facing cognitive, physical and organizational challenges.</td>
<td>Having a say;</td>
<td>Communication: Choice Routines</td>
</tr>
<tr>
<td></td>
<td>Long-term commitment, adaptability, proxy-design, facilitating your own participation.</td>
<td>(2) Facilitating for care-workers to facilitate their own participation.</td>
</tr>
</tbody>
</table>
Chapter 5

Chapter 5

**Phase 2: Facilitating participation**

This chapter details the PD process with 10 care workers and eight users. In this phase, I utilize methods that enable telling, making and enacting as a source of allowing the participants to express not just their current and past experiences but future aspects like dreams, fears, aspirations and ideas (Visser et al., 2005). The overarching goal of Phase 2 is to enable participation by putting the implications from Phase 1 into action.

5.1 **Part 1: Generative Techniques and Methods**

Part 1 introduces the generative techniques and how they specifically have been tailored to the requirement of user participation and implications from Phase 1:

1. **Facilitate for the care workers to facilitate their own participation**

2. **Build the process on already established forms of mutual learning and practice**

The specific techniques applied later build on the concept of *telling, making and enacting* (Brandt et al., 2012), *techniques for contextmapping* (Visser et al., 2005) and *‘probes, toolkits and prototypes’* (Sanders and Stappers, 2014). This chapter complements Chapter 3 *Theory: Understanding Participatory Design*, and extend on some of the concepts, specifically co-realization methods that utilize telling, making and enacting (See Table 7). The generative techniques used were first explored through Brandt et al. (2012), going through their examples of related work, actively looking to find techniques and tools that could benefit the implications. The two implications from Phase 1 are broader implications on the design process, which next, are augmented by specifying some more operationalized implications based in knowledge about *activity* and *communication*, as well as channels of mutual learning.
5.1.1 Requiring user participation

One of the major challenges of conducting a PD process in the context of the activity center is the limited time I have with each of the care workers to conduct workshops as they are busy, and their attention should almost exclusively be with the users’ well-being. The purpose of the activity center, as stated by the manager, is for the users to ‘have a nice day’ and so I needed to create sets of generic tools that could enable the meaning-makers (see Section 4.2.2 Meaning). The generic tools had the goal of allowing the users to conduct ‘design-like’ activities, built on knowledge about existing practice, in the same social sphere as the PD activities. To further engage all participants, it should also be fun and working with Joshi and Bratteteig’s (2016), concept of immediacy, making sure the threshold is low by utilizing knowledge about creative games and activities that revolve around simple tasks of making, like creating collages, pearling, drawing and traditional games like Ludo or picture Lotto.

To facilitate for the participation of the users, I have crafted generic creative toolkits using techniques and tools that are similar to existing practice, seeks to cope with routines, and utilize the care workers knowledge about users’ physical, cognitive, and communicational capabilities. However, as discovered in Phase 1 the requirements for activities are highly user dependent and varies from user to user and, thus, the generic creative toolkits crafted is a baseline that seeks to include the main aspects of how meaning emerges. These generic creative toolkits are designed to:

(a) include a social component

(b) appear similar in form to existing activities

(c) be flexible in form so that they can be carried out in different contexts depending on users’ wants and needs.

5.1.2 Facilitating care worker facilitation

Throughout the long-term immersion into the context of the activity center I have gained insight into users’ practice, meaning-makers, routines, and
communicational capabilities. While I can tailor for something that similarly fits practice, carries meaning and builds around routines, I cannot facilitate a process that specifically tailors each activity to different user’s physical, cognitive or communicational capabilities—I need to utilize the care workers ability to break down language barriers (as seen in Dæhlen and Joshi, 2019 and Boyd-Graber et al., 2006):

*Throughout the immersive process the proxies have been vital in bridging communicational gaps and is best exemplified by cases where the users have mixed forms of communication, using hand signs, body language and words to express themselves where either contextual knowledge, like having read the users diary (some of the ID keep a diary), or having the care-workers explicitly tell you what they think the users are communicating.* (Dæhlen and Joshi, 2019, p 8).

I need to prepare the Care workers on their role as both facilitators and mediators by committing long term, utilizing knowledge about mutual learning, planning, organizational and personal routines to recruit, time and ensure a continuity (Joshi and Bratteteig, 2016) to achieve these points I need tools and techniques that:

(x) Introduce care workers to their roles using established forms of mutual learning: morning meeting, employee work log, personal relationships etc.

(y) Give the care workers a chance to reflect on those roles using tools and techniques that allow for reflection.

(z) Chance to inform themselves about roles using tools and techniques that support existing practice and forms of mutual learning.

With these operationalized implications I can now further develop the overview table, adding requirements for tools and techniques (Table 7). These operative implications will be utilized to explain how the specific tools and techniques were adopted.
### Phase 2: Facilitating participation

**Table 7: Overview**

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Gather participants and form of support, guides, and forums.</td>
</tr>
<tr>
<td>2</td>
<td>Conduct initial focus groups and discussions.</td>
</tr>
<tr>
<td>3</td>
<td>Explore the role of facilitators and barriers.</td>
</tr>
<tr>
<td>4</td>
<td>Implement strategies to enhance participation.</td>
</tr>
<tr>
<td>5</td>
<td>Conduct final focus groups and discussions.</td>
</tr>
</tbody>
</table>

**Summary of Findings**

- Enhance communication and engagement.
- Foster a sense of community.
- Encourage feedback and participation.

**Implications**

- Promote understanding and engagement.
- Enhance communication and collaboration.
- Facilitate feedback and participation.

---

**Phase 1: Understanding participation**

**Theory**
Data gathering guide

Before conducting the sessions, I crafted a data gathering guide that constitutes a possibility to explore a multitude of different kinds of participation through qualitative notes but also possibilities for more metrical data (Appendix 2). However, not all gained as much attention as the foci of the results rests on specifics.

5.1.3 Methods

"Every user study starts with a preparation phase. Setting up the study involves the formulation of goals, planning, selecting participants, choosing techniques, etc." (Visser et al., 2005)

First, I present the methods and techniques based on the works detailed in the previous sections. Second, I present the specific tools used and how they were crafted. Table 8 outlines the different methods used, its governing techniques, tools of inquiry and participants.

Table 8: Overview of methods, techniques, tools, and participants.

<table>
<thead>
<tr>
<th>#</th>
<th>Research method</th>
<th>Techniques</th>
<th>Tools</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Preliminary Interview</td>
<td>Semi-structured</td>
<td>n/a</td>
<td>Researcher and manager</td>
</tr>
<tr>
<td>B</td>
<td>Participant Interview</td>
<td>Open/semi-structured</td>
<td>data from [D, E, F]</td>
<td>Researcher and Care workers</td>
</tr>
<tr>
<td>C</td>
<td>Recruiting and introducing</td>
<td>Discussion</td>
<td>n/a</td>
<td>15 Care workers</td>
</tr>
<tr>
<td>D</td>
<td>Generative workshop</td>
<td>Sensitization</td>
<td>Diary and Polaroid</td>
<td>3 Care workers and 3 users</td>
</tr>
<tr>
<td>E</td>
<td>Generative workshop</td>
<td>Picture collaging</td>
<td>Creative toolkit</td>
<td>10 Care workers and 8 users</td>
</tr>
<tr>
<td>F</td>
<td>Generative workshop</td>
<td>Drawing</td>
<td>Creative toolkit</td>
<td>1 Care workers and 2 users</td>
</tr>
</tbody>
</table>

To enable making, telling and enacting, I organized the three generative workshops, that sought to challenge the care workers to create ideas and artifacts which they could to use to tell stories about. To encompass the third concept of enacting—where the users could be included into more immersive enacting of the different ideas—I originally wanted to facilitate for a fourth generative where higher-fidelity prototypes could be a vehicle for ‘setting the stage’ (Brandt et al. 2012).
Phase 2: Facilitating participation

Participants

The total number of participants actively engaging in the generative sessions were 10 care workers and six users. See the illustration in Section 5.2.2 for an overview of participation. Users mainly participated in the three generative workshops while the care workers participated in all activities.

Preliminary Interview [A]

This interview was conducted before the generative techniques and steered some of the decision-making presented later in this chapter. Thus, I present the main results of the interview here. The goal was to present the sensitization, collaging and drawing activity to gain feedback and input, as well as plan the overall process.

We discussed which days were optimal for participant continuity: Mondays and Fridays. The activity center and the municipality has had some experience with prior attempts at “innovation” which could lead to some employees resenting workshops. The manager postulated the importance of spending proper time introducing the employees to the design activities, thoroughly following up any questions and possible misunderstandings. We discussed whether it would benefit the research, and whether it would be possible to include other than the living-room group into the design process. The conclusion was—supporting my understanding of routines—that the user at the other parts of the center “was there to do a job” and their routines surrounding work would require more specific attention to each user. The manager explained that “Some combinations of people also do not function well”.

After the meeting with the manager I conversed with one of the care workers who told that, inspired by my earlier session before Christmas, they had started a session with one of the users where they explored using magazines to expand possibilities for communication—creating a booklet of different images from magazines as a means of communicating.
Participant interview [B]

These interviews were conducted as a follow-up to the generative techniques. The interviews were open-ended to further explore the participants answers to the different techniques and for them to reflect on their doings. Some of these interviews were arranged and planned because I saw that some of the participants needed to talk about their experiences rather than writing them down as planned. These interviews were held in the common rooms (Figure 27), planned either ad-hoc, or in most cases, the same morning during employee morning meeting or a few days in advance. Some interviews were intended to be an opportunity for the Care workers to ask questions on possible uncertainties of the design-session.

Recruiting and introducing participation [C]

Having an understanding of the existing forms of mutual learning and practice let this activity be an ongoing iterative process where I used the employee morning meeting to engage the care workers by having one of the care workers set up official meetings in the logbook, used to plan work. During Phase 2 The manager had a longer leave of absence, and most of the planning was with the person I perceived as second in command. Most often one, two or three employees could participate (Figure 28) in the planned introductory sessions. However, much of the recruiting and introduction happened ad hoc either as workshops were ongoing, or as I were present most of the time.
Phase 2: Facilitating participation

I created a guide to prepare me for introducing the employees to their role as mediators for their own participation (Appendix 1). While I in the initial sessions spent over half an hour introducing the participants this time shrunk as I got more familiar with questions.

As noted in the preliminary interview, the manager presented a need to thoroughly introduce the project, the scope and make sure the care workers had no insecurities concerning the project. This is supported by Visser et al. (2005) and Brandt et al. (2005) who emphasize a focus on creating a common goal. Thus, alongside the sensitization phase, I also focused on introducing to all, making sure everyone was invited to the project, especially if they could not participate in the sensitization.

**Generative Workshop [D]: Sensitization**

This sensitizing technique is one of a set of several generative toolkits outlined by Visser et al. (2005).
“In the sensitizing phase, participants perform a series of small exercises designed to let them think about past experiences, and make them ‘reflective practitioners (Schön, 1983) of their present experience.” (Visser et al., 2005).

A key point here is the very last “of their present experiences”, which in this case is about trying to understand others’ past experiences, which I would argue can be even more challenging. Worth mentioning, is that the care workers are already used to being proxies as their day to day work is about understanding needs and wants of others, then putting it into action. While they might already be “groomed” for the role of being design-proxies, my perception is—and remarked several times throughout the project, by both manager and Care workers—that the care workers rarely reflect on their role as proxies.

William and Sanders (2002), state that “a toolkit is specific to its purpose” (p. 5). Which here is based in some of the operative implications (see Table 7), and is specifically an attempt at (a) creating something social, fun and intrinsically meaningful, (c) flexible in form, as well as giving an opportunity for the care workers to (y) reflect on their roles, which can help in developing ideas and questions which can be directed at the researcher, effectively giving them a (z) chance to inform themselves about their roles.

Moreover, the goal of this sensitization is summed up by Visser et al. (2005), saying that “The basic principle of the exercises in the package is to let people express memories, opinions, dreams, etc around the central topic of the study.”—Which here is to enable a space to participate, utilizing their knowledge about the individual capabilities of the users. While Visser et al. (2005) advocate that the participants reflect on personal relations, I want to use this method as an opportunity to reflect on their role as proxies and decisionmakers on behalf of the end-users.

To achieve this I have developed a small toolkit. Examples given by Visser et al. (2005) are postcards, diaries, workbooks, and disposable camera. While Visser et al. (2005) say these can be used as a source of data, initially, their main goal was
Phase 2: Facilitating participation
to provoke reflection and to prime the participants. However, I later found that the diary reflections and follow-up interviews were essential data points. In this study I have applied a diary-style workbook (Figure 29), both inspired by the already existing, and familiar to all participants, user diary, as well as giving the users and care workers a polaroid camera (Figure 29) with instructions designed to provoke reflection on how the Care workers facilitate for meaningful communication. To ensure successful application of sensitization, Visser et al. (2005), details six points: it should be playful, yet professional; broader subject than that of later sessions; inspirational and provocative to inspire reflection; enable reflection over time; sufficient space for comments; not require more than ten minutes per day.

![Figure 29: (left) Workbook and (right) a polaroid photograph captured by one of the users.](image)

Generative Workshop [E]: Picture Collaging

First of all, these sessions were planned before the sensitization and preliminary interview with the manager, however, not detailed till *during* the sensitization process.

“*With each exercise the participants are triggered to express deeper levels of feeling or knowing.*” (Visser et al., 2005, p. 128).

Visser et al. (2005), present three generative examples: ‘Collaging toolkit, ‘Cognitive Mapping Toolkit’ and ‘Velcro-modelling toolkit’. Other generative techniques can be seen in Foverskov and Binder (2011), Hussain, Sanders, and Steinert (2012) and Sanders (2000), as expressed by Brandt et al. (2012) there are a limitless number of possibilities.
Chapter 5

The collaging toolkit has been adjusted to (see Table 7) (b) appear similar in form by having an activity that uses tools, familiar to both care workers and users like games and generic creative tools—making it a (a) social activity (Figure 30), focusing on using tools that peak interest and invite for discussion and ensure continuity. Lastly, making sure it is (c) flexible, allowing for recruiting and timing to happen when there is a window of opportunity (Joshi and Bratteteig, 2016).

“A session usually has two to three exercises, and last about two hours” (Visser et al., 2005, p. 128). However, due to the empirical context of this study I had to split into two separate sessions which again, was separated into bulks of design-activities whenever we could facilitate for it. Further, the collaging session is designed to enable making and telling.

The specific technique of picture collaging was chosen because it resembles creative work most people have conducted throughout their lives using familiar tools like scissors, glue and visual objects to create creative collages and should be a natural activity to engage a broad range of people. Another reason was that it resembles the act of playing the picture-based game of Lotto, observed being played by several users on different occasions. Third, and maybe most important, is because it can help the care workers to elicit memories and emotional responses, as well as make associations and revive memories (Stappers & Sanders, 2003), which I thought would be extra critical when initiating design as proxies to such a vulnerable group.

The collaging and drawing sessions followed the setup described in by Visser et al. (2005), who presents a rough timetable of each session whereupon after making, the care workers present their collage then discuss in plenum if possible.
Phase 2: Facilitating participation

Initially, I wanted to use Norwegian gossip magazines as a source of creativity, because they are very familiar to some of the users, but in their earlier studies, Visser et al. (2005) found that the participants were distracted by the contents of the magazines. To conduct a successful collaging session, they have left us with some guidelines when preparing which I will utilize later when explaining the kits.

**Generative Workshop [F]: Drawing**

To further the ideas created in the collaging sessions I created a drawing session intended to converge the ideas into more concrete prototypes who potentially could help the Care workers when later, they create higher-fidelity prototypes. Drawing is a straightforward activity, which both care workers and users are familiar with. While drawing is mentioned as a session in the related literature, I cannot find anyone detailing it (Brandt, Binder, & Sanders, 2012; Sanders, 2000; Visser, Stappers, van der Lugt, & Sanders, 2005).

This method was a session of low fidelity prototyping where the participants created their first draft of what their design possibly could look and function like. The activity was conducted with instructions to use the different tools available to create a first draft based in the picture collage created earlier.

Initially, I planned for a second, higher fidelity prototyping session where the participants would create more concrete products utilizing materials like wood, Velcro-paper, and buttons, cardboard, laminated paper and more (see Figure 32). This thought comes from Dawe (2007) and Brereton et al. (2015) who found that inclusion of people with ID into testing and design after design to be beneficial in exploring possible new interactions. Supporting this though is also Joshi (2017) who focuses on embodied interaction, utilizing the end-users lived experiences to explore possibilities. Thus, the goal of this higher fidelity session was to let the care workers create more tangible ideas with which they could easier enact possible scenarios together with the users, thus, including the users in a similar fashion to Dawe (2007) and Brereton et al. (2015). While I did not get to conduct this planned prototyping session due to the extent of the previous sessions and limitations on time, I found that enacting did, in fact, occur in the other phases.
5.1.4 Crafting the kits

“Today the generative tools describe a design language ideally suited by non-designers. It is a full palette of predominantly visual components that enable participants to explore and express playful landscapes of past, present and future experiences” (p. 159)

Polaroid Diaries

The goal of using the Polaroid Diaries (Figure 31) is to provoke reflection by the Care workers on what their role in the design process is going to be. This was achieved by handing a camera to the care workers with instructions to take one picture on behalf of the end-users, where they ask or otherwise communicate with the users what it is they want to take a picture of. The specific instructions can be seen in Appendix 3, but the gist of the instructions given in the verbal introduction was:

This camera can only take one picture per person and only you, the Care workers can take the picture. Your instructions are to take a picture of the activity that the user you are currently working with likes the best. Try your very best to talk to or otherwise communicate with whoever you are currently working with what it is they want to take a picture of. From prior experience, doing what is already known and following routines is often the easiest for the both us and the users, so try to challenge what your perceptions of what you think they like the best with what they express and how you present choice, as well as challenge their answers.
Phase 2: Facilitating participation

The polaroid task in itself succeeded four of the six points of Visser et al. (2005), and so I crafted the diary to complement the polaroid, making sure to also leave space for impromptu comments as well as reflection over time. To complement the diary and make it personal I wanted the participants to decorate the diary by using simple creative tools. While I could fashion ‘professional’-looking diaries I wanted them to have a handcrafted feel, lower the threshold as well as keeping it personal by showing the commitment to making them. The questions posed in the diaries were:

Day 1:
Task one: Take one photograph of the most useful tool
Task two: Did you face any challenges with this task? (Think choice, presentation and communication.)

Day 2:
Task one: Take one photograph of the funniest thing to do at work.
Task two: How did you work in communicating purpose, possibilities and wishes?

Picture Collage

For the collage I crafted a more diverse toolkit, also intended to support higher fidelity prototyping with Velcro paper, buttons and tape as well as lamination machine and paper, etc. (Figure 32).

The images and words (Appendix 4) chosen to make up the toolkit was crafted around the points left by Visser et al. (2005) and focused on giving a range of different technological modes of interaction, technologic possibilities, emotions,
iconography and some contextual maps, activities, technologies and pictograms (Figure 34). Some of the images were specifically targeted at individuals who potentially could be harder to include. Adding to the imagery were markers, pens, post-its, etc. The drawing session utilized the same tools and are not detailed further.

Figure 32: Higher fidelity toolkit
Phase 2: Facilitating participation

Figure 34: Collaging imagery
5.2 **Part 2: Analysis of participation**

Ending *Phase 1*, I specified one requirement which was that the users’ need to be included, and two implications to enable participation:

(1) **Facilitate for the care workers to facilitate their own participation**

(2) **Build the process on already established forms of mutual learning and practice**

This section outlines some results on participation, focusing on typical cases representing the most exciting findings relating to the implications posed in *Phase 1*. To see a more detailed, chronologic account of the data see Appendix 5.

### 5.2.1 Conducting the analytical process

The analysis was conducted by re-reading the summaries of each session (Appendix 5) and compiling bullet-lists detailing the primary learning outcomes from each day. Initially, I generated four themes relating to participation and color-coded a printout bullet-list (Figure 35):

1. *Facilitating participation* (yellow), emerged to investigate implication (1), specifically, looking at operation implications x, y and z, and whether I had been able to introduce the care-workers properly, using established forms of mutual learning and practice.

2. *Care workers facilitation* (green), emerged to investigate whether the care-workers were able to utilize the tools and techniques, specifically whether operational implications a, b and c had been successful in helping them facilitate for the users’ participation. Thus, enabling a space for their own participation.

3. *Care workers exploration* (pink), emerged inductively from the data, as I saw that the care-workers utilized the presence of the users to *enact* and explore their ideas and assumptions about capabilities of the users.
Phase 2: Facilitating participation

4. Mutual learning (orange), was a reaction to care-workers utilizing the sessions and existing spaces for mutual learning to discuss and reflect.

Lastly, after considering the originality of each theme, I chose to focus on the two contextually dependent: 2. Care workers facilitation and 3. Care workers exploration.

5.2.2 Resulting participation

First, I give an account of the overall participation and the chronologic unfolding of events in Table 9. Results presented are focused around five care workers and four users. Second, I present results of how building on established practice let the Care workers facilitate their participation by the inclusion of the users, and third, how this, in turn, let Care workers extend their own understanding of the capabilities of the users.

Overview of participation

Here I give a summary and overview of the most relevant participation, showcasing the chain of events and detailing some information about participants. Table 9 presents a visualization of the process, where the X-axis represents days, numbered according to Appendix 5 and Y-axis represents the different activities. Care workers are coded with CW and colored, and users by U. While the activities engaged users and care workers not represented in Table 9 I did not collect this data, and it only represents those who were able to conduct the sessions or otherwise contributed to mutual learning. The six care workers outlined have been so because they best exemplify the two themes: Care workers facilitation and Care workers exploration:
CW2 (red): Female, young adult, unskilled, 2 years employment.
CW4 (yellow): Female, adult, social therapist specialized in activities.
CW5 (brown): Female, adult, a specialist in public health, 5 years employment.
CW6 (black): Female, adult, social and health worker, 8 years employment.
CW10 (teal): Female, young adult, ergo therapist, 2 years employment.
CW11 (pink): Female, young adult, unskilled, on-call employee.

As well as four users: U1, U2, U3 and U4, all adults in their 40s and 50s, ranging from profound intellectual and physical disabilities to severe intellectual and minor physical disabilities.

Some, like Care worker #7 (blue) who participated in a total of four activities, and Care worker #1 (green) struggled to complete the sessions, however, actively participated by contributing to discussions in interviews design sessions. Care worker #12 (purple), an adult on-call employee, was present during some of the earlier activities but did not join until the last day, where he was introduced to the project and the collaging task. Care worker #12 (purple) had clear ideas and did not direct his work towards a single user and worked out his ideas without interacting with the user, who enjoyed drinking coffee, watching the others. This manner of completing the design sessions, where the user did something arbitrary, albeit alongside in the social sphere, was more like the user inclusion that I hypothesis would occur. However, this was the only time these kinds of interaction happened. Care workers #3, 8 and 9 were introduced to the overall process but, all worked in different parts of the center during the PD process. Throughout the results, I mostly refer to the different sessions by using the day they were conducted, e.g. [1-3] [1, 4, 10], which refers to the different parts of Appendix 5. Some of the generative sessions were quick and lasted 30 minutes [9] while most sessions required at least two to five hours to conduct smaller 20-minute sessions [5]. During the days of generative sessions, I sometimes had to assist the care workers in regular care work as they often had to assist others. One example was during [2] where I assisted Care Worker #2 (red) and #1 (green), by spending lunch with User #. The morning meeting before the last workshop [10], the care workers helped facilitate the session by initiating a discussion on how they would conduct both the routinely singing session and the collaging and drawing session. Consulting me on how much time we would need we arranged
Phase 2: Facilitating participation

and planned for conducting both, taking some 60-minutes off the singing, and were able to follow through.

Table 9: Overview of participation.
Care workers facilitation

Facilitation to accommodate communicational capabilities

During [1 – 4] I discovered how the care workers utilized their knowledge about the communicational capabilities of the users to conduct and reflect on the generative sessions. Throughout these initial sessions—where my data relies on interviews and discussion, not observing—the care workers focused on topics that can almost exclusively be attributed to the ‘communicational’ aspects with a primarily focusing on physical, cognitive and language-capabilities.

The first example is the diary where Care worker #4 (yellow) describes how she accommodated the user’s cognitive capabilities as well as reflecting on how to present choices (Figure 37):

“With this user group there will always be challenges with communication, either in relation to the user’s ability to understand language, hearing, having a good day, etc. In this case the user was asked in several ways what she herself thought about her supporting tools. I also have to be careful with not asking too leading questions, as this user can have a tendency to answer “yes” on most things.”

Figure 37: CW4 Reflects on the presentation of choice and cognitive capabilities.
Phase 2: Facilitating participation

During a follow-up interview Care workers #1 (green) and #2 (red) discussed how they ‘angled’ the diary questions from the sensitization session to make it easier for the user to understand:

“When we talked about tools User #1 said “Hammer” and we angled it towards tools she uses. Toilet-chair, elevator etc.”. (Care worker #2 (red), [2])

The resulting participation from the sensitization was three diaries (Figure 38).

![Figure 38: Three diaries.](image)

Facilitating for meaning and practice

After a period of struggling with personal health, User #2 had not been able to join the sensitization. Before [7], Care workers #5 (brown) and #2 (red), who had been working with User #2 the previous week, discussed how Care worker #5 (brown) could work to facilitate for their participation, how to introduce, talk to and include into the activity. The week prior, in one of the follow-up interviews, Care worker #2 (red) talked about how it was important for the user to be a part of the social sphere and reflected on how to present the collaging session:

“User #2 wants to be included into everything, even though she cannot participate much with her body she loves to be included socially. For example, I tried to fold papers once with her, and it can be very fun. But it is hard to present this without it becoming too much.” (Care worker #2 (red), [2])
In a later generative session [7], Care worker #5 (brown) included User #2 into the social sphere by showing pictures, talking about them and helping the user direct her hand-movement, cutting out pieces and in general enabling her own participation (Figure 40). Care worker #5 (brown) was able to use the collaging tools, combined with her knowledge about User #2's communicational and physical capabilities, as well as meaning-makers of inclusion into the social community context, all this despite User #2 having had a bad time of it lately [1 - 2 & 4]. The successful inclusion of the user resulted in a collage, detailed around an idea of making choices more relatable and tangible for the user (Figure 39).

![Figure 40: CW5 including U2](image1)
![Figure 39: The resulting collage.](image2)

During session [7], Care worker #11 (pink) and User #3—whose mood often governs what activities can be carried out meaningfully—participated in the activity by helping make some cutouts and talking about the images (Figure 41). The result was an idea, revolving around how to facilitate for having better days, focusing on making it easier for the user to express how she feels.
During session [10], Care worker #5 (brown) prepared a place for User #7 to sit and draw and helped with cutting images from the collage (Figure 42). However, Care worker #5 (brown) did not complete any design activity as there was an outside interruption. After the session User #7 walked around with his creations, proudly displaying the drawing and cutouts to other users and care workers.

Facilitating to accommodate personal and organizational routines

Some of the last generative workshops [7 & 10] were planned during the employee morning meeting at 8:00 am. and during the later user morning meeting, the care workers kindled the idea with the users. It was especially prevalent how the care workers helped facilitated around routines when they helped prepare for
the last workshop as they initiated a discussion on whether we should conduct the join singing session that is routinely conducted on Fridays.

**Care worker exploration**

This section showcases the results related to how the care workers utilized the users’ presence and participation to explore their assumptions about capabilities and possibilities for future use.

*Utilizing and creating tools*

The first and most prominent example is from Collaging workshops [5] and [6] where Care worker #6 (black) had a strong desire to create something that User #4—who is profoundly ID—could she interact with to assist in becoming a more active decision-maker. After several attempts at conducting the collaging technique, we chose to put it aside and focus on exploring the capabilities of the user in making choices. Through attempting the collaging, Care workers #6 (black) saw—even with seven and a half years working with User #4—that she still needed to further understand the user’s capabilities before moving on. Specifically, she wanted to explore how the user makes choices and how she would handle the abstraction that happens when representing known objects on a 2D-surface. Most of session [5] went in to exploring that there was a gap in understanding the capabilities of the user and conducting the collaging, while in between and during session [6], we utilized the collaging tools (Figure 43, left), existing activities that User #4 enjoys (right) and a mock-up on an iPad (middle), to facilitate for further exploring capabilities and possible spaces for technology.
Phase 2: Facilitating participation

An interesting find is that Care worker #6 (black) had already created some tools to facilitate for better communication. The “talk-book” of another user, was a tool to assist in maintain communicational capabilities (Figure 44). Another was two sets of laminated pictograms (Figure 445) one similar to picture lotto, used as an activity (left) and another made to help the users be more active in making choices (middle). The last (right), which had been prompted by Exploratory workshop III in Phase 1, was a booklet with cut-outs similar to the collaging images, which Care worker #6 (black) had made as an attempt to explore design and how the users could participate.

Figure 44: The talkbook “Talk-book”.

Figure 45: (left) Lotto pictograms (middle) Picograms, (right) Booklet with cutouts.

Throughout the two sessions, Care workers #6 (black) and #7 (blue) discussed and reflected on how to facilitate for more meaningful communication. One example is when they showed me the white booklet, where one of the pages had one image of a cat and another of a woman holding a baby—Where the user pointed to the image of the woman, saying “cat!” Which prompted the care workers to swap the image to a page on its own and a discussion on how to present images. In between sessions, Care workers #6 (black) told me she had used the
activity of ‘weaving’ (Figure 46), and the small pegs, to explore whether the user was able to distinguish colors and how she answered questions.

Another example was in generative session [8], where Care workers #2 (red), similarly to Care workers #6 (black), focused on exploring User 3’s capabilities and created a collage vaguely focused on the concepts she explored rather than a single idea. Care worker #10 (teal) on the other hand used the session to specifically develop one idea and utilized the user’s participation to explore some specific ideas. The two Care workers discussed how the users understood images of objects and how users would understand what more images entailed. Care worker #10 (teal) used imagery she created, to ask the user questions seeing if she would understand what the activity would entail (Figure 48). Care worker #2 (red) used both tools from the collaging, and others to explore more general capabilities and understanding of images (Figure 47).
Phase 2: Facilitating participation

Figure 48: Icons on post-its, used to explore the users understanding.

Figure 47: CW2 exploring U3s capabilities

5.3 Part 3: Learning outcomes

Table 10 presents a summary of the two main themes identified in the data during Phase 2, the generative sessions and interviews. These two themes represent the most prominent findings while also listing the sources and some key observations and quotes.
Table 10: Overview of main findings Phase 2.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
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<td>• Care workers can facilitate for engaging user participation.</td>
<td>[B], [D], [E]</td>
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<td></td>
<td>Care worker #6s (black) inclusion of User #4 (Figure x)</td>
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<td></td>
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<td>Care worker #2 (red) ‘angling’ the question to facilitate for the user to better understand the question. [2]</td>
</tr>
<tr>
<td></td>
<td>• Care workers utilized and created tools to facilitate exploration.</td>
<td></td>
<td>Carer worker #6 (black) and User #4 exploring capabilities. (Figure x, x and x).</td>
</tr>
<tr>
<td></td>
<td>• The Care workers exploration opened possibilities for discussing with peers and researcher.</td>
<td>[B], [E]</td>
<td>“[..] I thought it would come like that, and she would immediately understand it… that is very interesting.” (Care worker #2 (red) [8])</td>
</tr>
</tbody>
</table>

5.3.1 Care workers facilitation

<table>
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<th>Main findings</th>
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<td></td>
<td>Care worker #2 (red) ‘angling’ the question to facilitate for the user to better understand the question. [2]</td>
</tr>
</tbody>
</table>

Although I intended to ‘facilitate for Care workers to facilitate their own participation’ —the Care workers, to a much larger degree than intended, included the users into the workshops, as active participants, using the different generative tools to engage them into the activities. My supposition was that the care workers would facilitate for the users to do similar or arbitrary activities, like shredding paper, while the care workers would do the design task. Both during the introduction and throughout I focus on how they could facilitate for their own participation by using their knowledge about the users’ capabilities to facilitate for the users to do other, similar albeit arbitrary activities, alongside the Care workers (see Appendix 1). However, the Care workers utilized their understanding of the users, their communicational capabilities and understanding of practice and meaning makers to include them into the generative design
Phase 2: Facilitating participation

sessions in an unforeseen manner—effectively making them participants, more directly involved in the design activities than first intended. In fact, not once did the Care workers propose to the users that they do something else while they did the design sessions. This benefitted the Care workers ability to further explore the users’ capabilities but might have made it harder for some of the participants to conduct the sessions. However, the cause for some of the care workers difficulties in conducting the workshops might be because of other limitations to the study.

5.3.2 Care workers exploration

<table>
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<td>Care workers utilized and created tools to facilitate exploration.</td>
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</tr>
<tr>
<td>The Care workers exploration opened possibilities for discussing with peers and researcher.</td>
<td></td>
<td>Care worker #10 (teal) and #2 (red) exploring capabilities (Figure x, and x)</td>
</tr>
</tbody>
</table>

Throughout all stages of the process, the care workers actively engaged the users in exploring their ideas about the users cognitive and physical capabilities. Through testing assumptions about capabilities and ideas, the care workers informed both themselves and the researcher about future possibilities. Throughout the co-realization, the care workers tested assumptions about capabilities and ideas, effectively engaging the users as more genuine participants that impacting the decision-making of both researcher and care workers. Lastly, the inclusion of the users opened up a possibility for the care workers to further explore through discussion with peers and researcher, sharing ideas and furthering their understanding of capabilities and technology.

5.3.3 Implications

First, I argue that when designing with people with ID, (1) The PD process should facilitate for proxies, to themselves facilitate the inclusion of the users into design activities. This can allow (2) people with ID transcend from ‘merely informants’
to ‘legitimate and acknowledged’ participants. With these, we can now build further on the overview table (Table x).

(1) When designing for people with ID, the PD-process should enable appropriate proxies to facilitate the inclusion of the people with ID into design-making activities.

As a response to some authors stating that the inclusion of people with ID is hard because of their individual forms of communications (Francis et al., 2009), I propose that indications are suggesting the care workers can bridge any apparent gap capabilities. This perhaps addresses the issue of whether proxies are good representatives, raised by Hendriks et al., (2014), as the care workers utilize the presence of the users to explore their assumptions.

(2) Inclusion of people with ID by the proxies, lets people with ID transcend from ‘merely informants’ to ‘legitimate and acknowledged’ participants.

While studies are talking about the inclusion of people with ID into the testing phases of design (Brereton et al., 2015; Galliers et al., 2012; Dawe, 2007), here propose that there is a possibility for the users to be included into the making stages of design. Effectively transforming their roles from informants to legitimate, acknowledged participants (Robertson and Simonsen, 2012).

With these learning outcomes in mind I update the overview (Table 10).
### Phase 2: Facilitating Participation

**Table 11: Overview of Learning Process**

<table>
<thead>
<tr>
<th>Phase 1: Understanding Participation</th>
<th>Phase 2: Facilitating Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theory</td>
<td>Theory</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Main findings and discussion

This chapter recap the main findings from Phase 1 and 2, outlining the chronologic events of knowledge generated and how the methods applied emerged from an understanding of the context (Hendriks et al., 2014). Utilizing these learning outcomes and examples from data I apply relevant theory in a broader discussion on the implications of these outcomes.

6.1 Overview and summary of learning outcomes

6.1.1 Research question

*How can we facilitate design with people with different intellectual capabilities using Participatory Design?*

To answer the research question, the main objective of this thesis has been:

1. To explore how ethnographic immersion into the context can bridge potentials for facilitating design with people with ID
2. Explore how a PD process might be fitted to the contextual needs of an activity center

6.1.2 Phase 1: Investigating possibilities for participation

This thesis started with a long-term, ethnographically inspired study into the context of an activity center in Phase 1. The initial motivation and goal of the study were to utilize a long-term engagement into the context to explore possibilities of designing *with* people with ID. The immersion was conducted,
Main findings and discussion

based in PD values of emancipation and democratization with ethnographic means of gaining access, and informing the researcher on the context.

The first findings in this thesis were communication and activity—explored in the ethnographic immersion. These two themes were a basis for conducting a thematic analysis (Braun and Clarke, 2006), where the four higher order themes and 64 lower-order codes emerged (Figure 49).

![Thematic map from 4.2.1.](image)

The resulting four higher-order themes were Meaning, Practice, Choice, and Routine (see Table 12). Meaning makers for the users emerge in the context, are dependent on the care worker and often constitutes a social component. Practice varies for each user, one common is that activities need to be flexible regarding duration. Choice is governed by the cognitive, physical and language capabilities of the user.
Routines are especially crucial to some as it structures the day-to-day activities and often impacts the users’ ability for meaningful interaction.

Table 12: Overview of main findings from Phase 1

<table>
<thead>
<tr>
<th>Theme</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning (Activity)</td>
<td>- Meaning emerges through the context in which the activities take place.</td>
<td>[A], [B],</td>
<td>“Examples of meaning bearer are social relations, safety, predictability, well-being, change of environment, learning and acknowledgment.” (caretaker, [WS2])</td>
</tr>
<tr>
<td></td>
<td>- The company of the caretaker can affect how meaning emerges.</td>
<td>[WS2]</td>
<td></td>
</tr>
<tr>
<td>Practice (Activity)</td>
<td>- The practice involved in activities varies between users.</td>
<td>[A], [B], [D]</td>
<td>“Some activities require 1-on-1 assistance depending on the individuals involved and the context in which it is carried out.” (diary entry, [B])</td>
</tr>
<tr>
<td></td>
<td>- Activities need to be flexible regarding duration.</td>
<td></td>
<td>“During the first day, I had to end an activity with a user because I was requested to help with something else” (diary entry, [B])</td>
</tr>
<tr>
<td>Choices (Communication)</td>
<td>- Presentation of choices must be tailored to both the user and the context.</td>
<td>[A], [B], [C]</td>
<td>“The user was presented with two alternatives, which I later discovered was a rather restricted choice considering the user’s capabilities” (diary entry, [B])</td>
</tr>
<tr>
<td></td>
<td>- Limited language and cognition skills inhibit the presentation of choices.</td>
<td>[B]</td>
<td>Representations of choices often require non-verbal forms of communication (see Figure X, [C])</td>
</tr>
<tr>
<td>Routines (Communication)</td>
<td>- Structure and daily routines affect the users’ ability to participate.</td>
<td>[A], [B], [WS2]</td>
<td>“For some users, it is a crisis to have a day off as it breaks routines” (caretaker, [WS2])</td>
</tr>
<tr>
<td></td>
<td>- Routines promote autonomy by facilitating learning over time.</td>
<td></td>
<td>“One user was frustrated when I communicated that I had to leave early because it disturbed some of the users’ routines” (diary entry, [B])</td>
</tr>
</tbody>
</table>

The four higher order themes, in combination with relevant literature, were then distilled into three learning outcomes in Dæhlen and Joshi (2019):

A. “The PD process should facilitate for the participation of caretakers as proxies”
B. “The PD process should be organized as a long-term commitment”
C. “The PD process should be built on top of already established forms of mutual learning”
Main findings and discussion

The three learning outcomes from Dæhlen and Joshi (2019) and higher order themes were then utilized, in combination with the ever-ongoing analysis of design and the overarching requirement to facilitate for the inclusion of the users into the design activities, to create two theoretical implications for the future PD process:

1. Facilitate for care-workers to facilitate their own participation

The care workers needed to do their job as care workers and maintain their responsibility, while still participating in design activities. Thus, I needed to facilitate for the care workers to be part designers, part facilitators—ensuring their own participation by including the users into the spaces of design activities, just like any other activity.

2. Build the process on already established forms of mutual learning and practice

To enable this interaction with the care workers and users, I needed to ‘set the stage’ using already established forms of mutual learning and practice. And Utilizing my knowledge about the users: (activity) meaning makers, practice and (communication) routines and choice. These implications were later, in Phase 2, operationalized into more concrete examples of how I could facilitate for a final participation.

6.1.3 Phase 2: Facilitating participation

This phase was an effort at operationalizing and testing the two theoretical implications. To support the requirement that, users have to be included I created some more contextually operationalized implications, based on an understanding of Activity and Communication:

   a. Include a social component
   b. Appear similar in form to other activities
c. Flexible in form so that they can be carried out in different context depending on the users’ wants and needs

Next, I created some implications that the later generative techniques would need to utilize in order to complete for the first implication, based in related work with proxies and understanding of established forms of mutual learning.

x. Introduce care workers to their roles using established forms of mutual learning: morning meeting, employee work log, personal relationships etc.

y. Give the care workers a chance to reflect on those roles using techniques that allow for reflection.

z. Chance to inform themselves about roles using tools and techniques that support existing practice and forms of mutual learning.

The resulting data was then analyzed, leading to the findings that Care workers can facilitate for the users participation the PD process, which led to the Care workers exploring their ideas and assumptions about the users’ capabilities utilizing the user’s presence and participation (Table 13).

Table 13: Overview of main findings from Phase 2

<table>
<thead>
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<td>Care worker #10 (teal) and #2 (red) exploring capabilities (Figure x, and x)</td>
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</tbody>
</table>
Based on these findings, I presented two implications:

1. **When designing for people with ID, the PD-process should enable appropriate proxies to facilitate the inclusion of the people with ID into design-making activities.**

While an absolute requirement to this study—that we include the user into the process for any design process to be conducted at all—I have will propose that when designing for people with ID, they should be included into all stages of design, by having care workers facilitate for the user’s participation.

2. **Inclusion of people with ID by the proxies, lets people with ID transcend from ‘merely informants’ to ‘legitimate and acknowledged’ participants.**

While authors propose that people with ID or CIS be included into the initial inquiries, and later testing stages of design, I argue that we can include them into all stages of design. This effectively transforms people with ID, who traditionally have been informants (Galliers et al. 2012 and Dawe, 2007) to ‘legitimate and acknowledged’ participants (Robertson and Simonsen, 2012).

Making a final contribution to the overview Table 14, I add the learning outcomes from *Phase 2* as well as an indication of where these final implications might contribute to a discussion.


<table>
<thead>
<tr>
<th>Phase 2: Facilitating participation</th>
<th>Discussion</th>
<th>Theory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1: Understanding participation</td>
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</tbody>
</table>

Table 1: Final overview table
6.2 Discussion

This section utilizes the implications from Phase 2 as well as some examples from the data to discuss the relevance of these findings in the broader scope of the field of PD and design with people with ID.

6.2.1 Enabling people with ID in unforeseen ways

**Implication 1:** *When designing for people with ID, the PD process should enable appropriate proxies to facilitate the inclusion of people with ID into design-making activities.*

While it was an absolute requirement in this study, to include the users into the process to allow for any design process to be conducted at all, the first learning outcome is one of broader implications on how people with ID might be included into the decision-making phases of design.

I propose that the facilitation for the direct involvement of the users should be conducted by proxies. To achieve this, the co-realization process needs to be facilitated in such a way that lets the care-workers be *two different kinds of designers.* First, taking the role as a traditional PD participant and, second, more like any scientific design-endeavor, a facilitator for the inclusion of the users employing their knowledge about the highly individualized forms of communication, cognitive or physical challenges of users. However, for researchers to facilitate this duality, there needs to be a thorough understanding of the context.

**Engaging proxies as design facilitators**

In Phase 2, while conducting the generative sessions Care workers #2 (red) and #5 (brown), worked with User #2’s wellbeing, making sure she felt included, and not overwhelmed by the tasks, mainly working with recent physical discomfort. In one session, Care worker #5 (brown) included the user into the session by enabling the user to utilize their love for drawing, making a very simple collage. In two different sessions, Care workers #5 (brown) and #4 (yellow) worked with...
User #2, including her into the session by utilizing the importance for social inclusion by continually talking about what they were doing, holding up images and helping the user make cutouts. In the initial interviews, Care workers #1 (green) and #2 (red) discussed how they had facilitated for the users understanding by «angling» the questions, directing them at her in a more meaningful way. Care worker #4 (yellow) in describing how they conducted the polaroid diary reflected on how they had to be careful how to ask questions with that particular user.

There are multiple studies using proxies to engage in decision-making processes when the end-user has cognitive or physical disabilities that hinder their direct involvement (Putnam & Chong; 2008, Brereton et al., 2015; Havgar, 2016 (Master thesis); Dawe, 2007). Some researchers suggest that including people with cognitive disorders is problematic due to their individual means of communication, cognitive and behavioral difficulties (Francis et al., 2009). In their study with people with Autism Spectrum Disorder, Francis et al., (2009) specifically suggest some issues which in this thesis has been mitigated by the use of care workers as facilitators for the user’s inclusion. They discuss a need for designers to have a sound understanding of the subject, their capabilities, patterns of thinking, communications challenges, inappropriate behavior, a need to be aware of signs of discomfort or mental overload. Here, issues such as the ones described by Francis et al., (2009) has been mitigated by facilitating for the care workers to take on the role as designers, facilitating the participation of the users. However, it is not as straight forward as just inviting them to do this facilitation.

**Long-term commitment to build on established practices of mutual learning**

Some raise questions on the reliability of proxies as good representatives (Hendriks et al., 2014). There is an apparent disconnect between what participatory design require through the different levels of abstraction, and the capabilities of people facing cognitive challenges. Hendriks et al. (2014) suggest that PD might be too stressful for people with dementia. In Phase 1, this was reflected in the need for flexibility in activities and, which later in Phase 2, were mitigated similarly to Joshi and Bratteteig (2015), by utilizing long-term commitment, making sure there were several iterations of the same design.
activity, enabling participation facing both organizational as well as physical or cognitive challenges. Long-term commitment has helped me to work out a method for approaching design during work hours at the activity center, effectively working with the already established practice, crafting the generative sessions to be native activities, closely resembling existing ones. In Phase 1 (Chapter 4.2.2), the care workers showed a reluctance to join the workshops outside work hours, which understandably so, could be because these are not design activities that seek to enhance their personal lives. Effectively they have to evaluate their goals versus that of the study (Grönvall & Kyng, 2013). This notion is supported by Redhead and Brereton (2012) who states that when designing with a community, the method needs to recognize “the rhythms of local community life and work within the reality of these, […]” (p. 4).

Redhead and Brereton (2012) describe how their long-term commitment, enabled them to build prototype systems which suited the time frame of the local community, not the timeframe of research inquiry. Further, they reveal that their long-term commitment lets the people bridge their existing practice with the use of the new system. In this thesis, I observed that the care workers over time were able to bridge the gap between their everyday work, and the work that I wanted to implement. As they got more comfortable with the tools and techniques they started planning and working with the design activities as they were any regular activity (see session [10]). As postulated in Dæhlen and Joshi (2019):

“that long-term engagement is a way to converge on the uniqueness of each situation (Hendriks et al., 2014), as well as a way to avoid communities rejecting opportunities for collaboration due to short burst of facilitation (Redhead and Brereton, 2012)”. (p. 8)

In Phase 2, only a few of the user-care workers’ interactions played out similarly and, based in the tools and techniques tailored to users and context, the care workers and I managed to converge on the uniqueness of each situation. This is demonstrated with Care worker #6s (black) need to put the techniques aside, utilizing different tools to further explore her understanding of User #4s capabilities. Looking to Joshi and Bratteteig’s (2015) five points: recruiting, timing, continuity, representativity, and immediacy, it was the care workers who
handled the users need for flexibility in making sure recruiting, timing and immediacy were conducted according to individual needs. Specifically, they utilized knowledge about users meaning makers to recruit, time and make sure there was appropriate immediacy surrounding the activities.

**Tools to fit contextual needs**

I would argue that the activity center, is much like any private home environment, where “the control is in the hands of the inhabitants” (Grönvall and Kyng, 2013). Thus, I am not in a position to shape the layout of the center, because it already serves highly individualized needs. Because of the requirement of designing in context, I had to—like the healthcare professionals in Grönvall and Kyng (2013)—adapt the process, techniques and tools, to the context which the participants already inhabited. Ballegaard et al. (2008) take a stance where the main focus is “to develop healthcare technology that fits the routines of daily life and thus allows the citizens to continue with the activities they like and have grown used to [...]”. The insight into activities—“they like and have grown used to”—also let me design techniques and toolkits, with an understanding of what I should facilitate for, and what the care workers should facilitate for (see Table 14).

**Shared participation**

While the sensitization task itself proved interesting results, only three care workers and users directly engaged with it, and yet, care workers who did not conduct the sensitization equally helped facilitate for the participation of the users. To someone unfamiliar with PD, this might make it seem like the sensitization was not important and it might seem superfluous. However, PD researchers suggests otherwise. Joshi and Bratteteig (2016) talk about a successful mutual learning process as one that:

“[…] enables all participants to widen their imaginative capacity and build on each other’s ideas […] They need to spend time together: over time, their imagination about design possibilities, about needs and wishes for technology solutions change as they learn more.” (p. 3).
Main findings and discussion

This notion is also seen in Redhead and Brereton (2012) where word of mouth conveys the doings of design-activities, effectively helping recruit potential participants, informing them about the possibilities of participation. A PD process is not one single technique, applied with a single goal, but rather as a contributor to the total sharing of power that goes into a PD project:

“Users can contribute to creating choices, selecting a choice, concretizing choices, and seeing/evaluating a choice. Users do not need to participate in all these (parts of) design moves to contribute to a participatory design result” (Bratteteig and Wagner, 2014, p. 32)

Bratteteig and Wagner (2014) say that particular choices are products of ‘inextricably intertwined’ series of choices; thus, identifying participation in decision-making is a complex endeavor. Apparent when conducting the generative sessions, the interviews and discussions in Phase 2, was that whenever there were two or more care workers conducting activities, they talked—effectively informing each other about possibilities, opening up their ideas to be challenged and informed. Care worker #5 (brown) had throughout Phase 1, showed great interest in the project but were unable to participate during the first weeks of Phase 2 because of a leave of absence. When she came back, Care worker #2 (red)—who had been working with User #2 the last few weeks and participated in all design activities thus far—discussed with Care worker #5 (brown) how she might include User #2 into the collaging session, which revolved around the same issues discussed she had with Care worker #1 (green) in an earlier interview. To me it is apparent that the long-term engagement of this thesis has enabled a space for mutual learning to grow over time.

6.2.2 Enacting through bodily presence

Implication 2: Inclusion of people with ID by proxies, lets people with ID transcend from ‘merely informants’ to ‘legitimate and acknowledged’ participants.

What I claim is that the presence and inclusion of people with ID into generative workshops lets them directly inform the proxies about their different capabilities
during the decision-making stages of design. In the generative collaging sessions, the care workers utilized the presence and participation of the users to test their ideas and assumptions about capabilities of the user. Thus, enhancing ideas on how people with ID can contribute to a design process. This was especially prevalent in sessions [5 – 10]. Care workers #2 (red), #6 (black) and #10 (teal), used the participation of the users to explore their assumptions and ideas. Throughout the generative sessions, #2 (red) tested her assumptions, exploring the capabilities of different users and eventually developed a vague idea, centered around the results and consequent discussions she had with others. #10 (teal) utilized the tools to ask questions directed at furthering some requirements for her idea while #6 (black) found that—even though she had known the user for almost eight years—lacked relevant understanding about the users capabilities, in relation to modes of technological interaction and making choices. I postulate that this is because the care workers, while knowledgeable about relevant problems and issues the user might have, do not know how technology fits into the scope of their capabilities because there are none.

Researchers has sought to broaden the scope of both what participation is and how people can participate when facing different challenges (Joshi and Bratteteig, 2016; Brereton et al., 2015; Foverskov and Binder, 2011). Some contribute that prototypes can be an essential aspect when seeking to empower people with intellectual or physical disabilities (Brereton et al., 2015; Galliers et al., 2012; Dawe, 2007). What is apparent in design studies for people with ID, it that it is for, and not with. There is an apparent lack of success or attempt at including people with ID into the decision-making stages of design. In fact, in their extensive literature review on the inclusion of developmentally different children into different phases of design, Börjesson et al., (2015), finds zero studies where children with ID are included into decision-making. Prototypes in studies like Dawe (2007) and Brereton et al. (2015), made it possible for the users to “show, share and interact” in later testing stages of design. In this thesis, as a result of the enabled participation of the users, and the need for me to include the users into the design process: I have found that people with ID, specifically people with profound and severe disabilities, can be included with methods that not
Main findings and discussion

intrinsically seek to enable enacting, but rather enable it a result of the nature of the care work that occurs at the activity center:

“With enacting we refer to activities where one or more people imagine and act out possible futures by trying things out (by use of the body) in settings that either resemble or are where future activities are likely to take place” (Brandt et al., 2012, p. 164).

Brandt et al. (2012) say that in order for enacting to happen it needs ‘staging’. There are multiple ways of ‘setting a stage’ (e.g., Halse et al. 2010; Foverskov and Binder, 2011 and Kuutti and Ranta, 2000). In Phase 2 the stage is set by design activities that are closely related to that of any activity at the center. This enables possibilities for trying things out in context, by having activities that address people with ID in a familiar way (Ballegaard et al., 2008); enacting has been enabled with design activities that were not inherently made to. Galliers et al. (2014) reveal a similar possibility to facilitate for participation when facing Aphasia, utilizing long-term commitment to building a foundation for communicating with people, using other means of communication like hands-on physical activities. The active engagement of people with ID into generative sessions can let proxies ‘try things out’, utilizing the bodily presence of the end-users, informing their own and the researcher’s imagination of possibilities earlier in the design process. I also argue that this can address one of the issues raised by Hendriks et al. (2014), where proxies under or overestimates the capabilities of the end-user, which was observed in this study and promptly addressed due to the possibility to enact.

While acts of telling, making and enacting are inherently rather complex imaginative tasks, the acts of taking part in, or otherwise being an active component in the stories someone else tells or enact with you does not necessarily require the same imagination.

I postulate that the inclusion of people with ID into the design process by care workers, effectively allowes the care workers participation to occur. This can lead to enabling a form of bodily enacting by the participants, which makes the people with IDs participation in the process more ‘genuine’, moving from being ‘merely
informants’ apprising the different design results or informing the preliminary studies, to becoming ‘legitimate and acknowledged’ participants, directly impacting the decision-making process (Robertson and Simonsen, 2012). I argue that this sharing of power, and whether or not participants can cognize it—they can actively direct the generative session and have a say by helping the researcher and proxies imagine future possibilities, grounded in a more rigorous knowledge about each person’s capabilities. The process leading up to the final implications, in both Phase 1 and 2, enabled a space for mutual learning to occur between all participants—Both as an effect of the co-realization process in Phase 2 and the ethnographical immersion and workshops in Phase 2.
Main findings and discussion
Chapter 7

Contributions and salient questions

This chapter presents some pointers on how possible beneficiaries might apply the implications in different contexts by, utilizing existing practice, exploiting care workers' knowledge and immersing yourself into the context. In the final section, I present some salient questions that might direct future work.

7.1 Possible beneficiaries

Among others, the total learning outcomes presented might contribute alongside PD authors exploring possible tools and techniques (e.g., Hussain et al. (2012), Galliers et al. (2012), Kanstrup et al. (2014), and Nicholas et al. (2012)), as well as researchers seeking insight into how we can design with people with cognitive or physical disabilities (e.g., Boyd-Graber et al., 2006; Brereton, Sitbon, Abdullah, Vanderberg, & Koplick, 2015; Dawe, 2007; Francis, Balbo, & Firth, 2009; Galliers et al., 2012; Havgar, 2016 (Master thesis); Hendriks, Huybrechts, Wilkinson, & Slegers, 2014; Rogers & Marsden, 2013). These learning outcomes presented might also contribute to a more general understanding of how people with cognitive or physical challenges can impact the critical decision-making processes that ensue when designing (e.g., Grönvall & Kyng, 2013; Joshi, 2017; Joshi & Bratteteig, 2016; Yakhlef & Essén, 2013). I hope these contributions can help shed some light on the issues raised by Bigby et al. (2014) on the feasibility of including people with ID as well as what might go into making a conceptual framework for doing inclusive research with people with profound to severe intellectual disabilities.

7.2 Applying this knowledge
Contributions and salient questions

I hope that what is apparent in this thesis is the bold red line of long-term commitment, which in itself is not what engages participants. Playing with the title of Brereton et al., (2015), long-term commitment can be the bridge between design and people living with cognitive impairments. To call these pointers for future work, ‘implications’ would be a mistake. To anywhere near adroitly apply the different kinds of knowledge thesis means taking a value stance of how you want to design, not utilizing single implications. Emancipation, sharing of power, having a say, mutual learning and then co-realization does not come easy, but I find that when designing for people with ID, long-term commitment seems to be the bridge we might need to cross if we want to live by these principles.

The pointers for how to apply the knowledge presented in this thesis are mainly addressing people with profound to severe ID and might not apply to people of higher capabilities. However, I argue based in my experience of working with people with ID and this thesis, that including proxies to engage people with ID into the decision-making phases of design can only further enhance persons with ID’s participation no matter their capabilities.

Persons with ID can affect the making-stages of design by including them into the spaces where making occurs. The result can allow for ideas to spring from the contextual needs of the users, letting the proxies actively test ideas and assumptions about the user’s capabilities in relation to technological possibilities.

7.2.1 Utilize existing practice

Researchers should utilize existing workplace, home and personal practice surrounding the person with ID to create a reference point for both researchers and proxies in facilitating a future design process. Design with people with ID should adapt design-practice to the contextual space of already existing activities and communicational capabilities. Along other authors I suggest using long-term commitments to ‘get to a starting line’ (Holone and Herstad, 2012), and as a means to gauge enough contextual knowledge (Dæhlen and Joshi, 2019).

7.2.2 Exploit proxies knowledge
Create design processes that allow the researchers to exploit proxies’ knowledge about persons with ID to including them as facilitators for the inclusion of the persons with ID. Care workers and people in general who works closely with people with ID are already used to facilitate for their presence in everyday activities, including them into every day chores, assisting with personal hygiene, cooking, work, activities, games, etc. What we as researchers need to do is bridge their understanding of what they need to do to facilitate their participation with what they are already doing. Hopefully this study can contribute alongside authores like Brereton et al., (2015) and Galliers et al., (2012) on how me might implement long-term commitment to engage proxies knowledge.

7.2.3 Immerse yourself

While any long-term commitment might yield in-depth knowledge about persons with ID, I would argue that by specifically immersing yourself into the context; you will find a world of very personal issues and create connections that otherwise would be impossible. Some people with ID will never understand your role as a researcher, scientist or designer and you will often have to say that “you make things” or “go to school”, simplifying what you do to whatever you think the person can understand. However, by immersing yourself into the context you create familiar bonds that they too can cognize. I would also argue that the proxies too will have a much stronger familiar bond, after all, you are taking an interest in their daughter, friend, or co-worker, and they will not just extradite information about lives—who they know depend on them—without care.

7.3 Salient questions

7.3.1 Does participation transfer?

Does participation transfer into later, higher-fidelity stages of design? This question is directed at what a continuation of this thesis might look like if I keep investigating possibilities for users to impact decision making in the co-realization phases of design. This thesis showcase an early PD process, focusing
Contributions and salient questions

on the earliest iterations of a co-realization process. However, how does the implication that users can participate in co-realization translate to later stages with workshops of higher-fidelity prototyping, and possibilities for impacting more concrete design choices in further iterations? The tools and techniques used here are based on simple tools known to all participants. How would participants handle higher fidelity tools and what would these tools’ contextual grounding be?

7.3.2 Need for initial inquiries?

Some interactions, especially Care worker #6 (black) and #2 (red) (see Chapter 5.2), hint at a requirement for some sort more in-depth investigation into the capabilities of users before moving into co-realization stages as they spent most of the workshop time exploring the capabilities of the users relating to how they make choices and possibilities for interaction. Particularly, relating to exploring capabilities in relation to technological possibilities: understanding how the persons with ID understand some of the technological modes of interactions, e.g., screens, touch, voice, tactile, etc. In plain words, there might be a need to create workshops focusings on establishing a set of requirements in relation to technological possibilities before moving on to generating ideas. Harking back to the illustration presented by Bratteteig et al. (2012) (Figure 50), the lower part of the figure illustrates an iterative process of identifying needs and wishes, describing requirements and materializing ideas.

![Figure 50: Bratteteig et al., 2012 PD cycle](image)
A salient question regarding this model is the data from Phase 2 can be understood when utilizing this model as reference—How did the different generative workshops iterate on different parts, some participants, like Care worker #10 (teal) (see Chapter 5.2.) moved straight to concretizing, and yet worked with identifying needs during the session. While some, like Care worker #6 (black) had to thoroughly describe requirements and needs before moving to materializing any idea (see Chapter 5.2.)

7.3.3 Does long-term equate total hours?

Others describe time commitments as a means to ‘channel access’ to the context and co-inhabitants (Blomberg and Karasti, 2012) and describe it as a way to get to the “starting line” (Holone and Herstad, 2013). Francis et al. (2009) support this with their find that customization of techniques required intimate knowledge of the user, their context, capabilities, and nature—which can be accessed by engaging the context long-term. However, I do not know when the starting line appears, or when you have enough knowledge about the user, their context or capabilities. While Phase 1 in this thesis was conducted over four months, I do believe that with a more concrete initial research objective, you could amount to similar results spending equal hours over a significantly shorter period.

7.3.4 Disparity in understanding

While not given space through this thesis, the color-coded figure was used to showcase the results of the inter-rater reliability analysis conducted in Dæhlen and Joshi (2019) (Figure 51). It indicates the different understanding of a researcher, immersed in the context and another, with only access to the data. While this analysis points in a difference of understanding, is that difference as a result of the difference in understanding, or would we see the same disparity with two equally immersed researchers?
Contributions and salient questions

- No difference
- Only difference in some sub-codes
- Difference in code

Figure 51: Inter-rater reliability analysis Figure from Dahlen and Joshi (2019)
Chapter 8

Conclusion

This thesis has sought to answer how we can facilitate design with people with different intellectual capabilities using Participatory Design (PD).

I have conducted a long-term ethnographic inquiry of an activity center for adults with Intellectual Disabilities (ID), called *Phase 1* and a latter PD process, called *Phase 2*. *Phase 1* was a basis for a research paper on ‘Immersion as a Strategy to Facilitate Participatory Design Involving People with Intellectual Disabilities and Caretakers as Proxies’ by Dæhlen and Joshi (2019). *Phase 2* was conducted as the initial stages of a long-term engagement into the context, exploring how people with ID might be included in the making stages of design, by utilizing tools and techniques, fitted to contextual needs, which enabled the care workers to facilitate the inclusion of people with ID into making stages of design.

I postulate that participation of people with ID by the proxies, lets them transcend from ‘merely informants’ to ‘legitimate and acknowledged’ participants (Simonsen and Robertson, 2012). This ensues as a result of a PD process that enables all participants to inform themselves, and researcher about imagination of possibilities for participation and co-realization—effectively giving the researcher the ability to create tools and techniques that build on already established forms of mutual learning and practice, which enables proxies to facilitate their own participation, by including people with ID into the making stages of design, consequently, assisting in the sharing of power between all participants when designing for people with ID, helping tackle challenges of both organizational nature as well as cognitive and physical challenges.

This thesis presents two main implications from a co-realization stage of design. First, I have found that researchers *should facilitate for appropriate proxies to themselves facilitate the inclusion of people with*
Conclusion

*ID into design-making activities.* This was based on an understanding of the context and the highly individualized communicational capabilities of the people with ID that I could and should not facilitate. The results emerged as the proxies utilized generative tools and techniques fitted explicitly to individuals’ capabilities, as well as their own understanding of the people with IDs' needs and want to include them into the workshops in unexpected ways.

A result that emerged from the IDs’ inclusion into design-making alongside proxies was that inclusion of people with ID by proxies, lets people with ID transcend from ‘merely informants’ to ‘legitimate and acknowledged’ participants. The people with IDs' inclusion effectively let the proxies engage the users in unanticipated ways, utilizing their presence to test their design ideas and assumptions about the capabilities of the persons with ID. While there are studies including people with ID into the inquiry stages, and later testing stages of design—there is a limited amount of studies that include the end-users with ID into the making stages of design. Finally, this thesis contributes to a possible discussion on how people with ID might be included into more phases of a PD process and contribute with some final implications on how others might apply this knowledge.
Chapter 9

References


References


References


References


Appendix

Chapter 10

Appendix

Appendix 1: Introducing employees to their roles

What

To answer what it is we are going to do: We are going to have a total of two to three different activities where the goal is to create something based in these toolkits I have made. They are crafted to stimulate your creativity, show you what is possible and let you explore this space. You probably have lots of questions right and that is ok, this is a process of exploration, of what we call mutual learning. You aren’t designers and will have lots of questions and that is a good thing, shoot straight and ask whenever you feel uncertain about something. My role here is to facilitate for you to create something within the limits of your imagination. What we make here is not important, this brings us to the next one.

How

To answer how we are going to do it: We are working within a very specific context and it sets the practical limits of what is possible. First and foremost, you are going to do your job, taking care of, helping, managing and facilitating so that the users can “come home and want to go back the next one”. We are still going to be here for the users. These workshops has been created with the users in mind and I’ve designed a general outline for how we include the users, but I’m not closely familiar with each of them, so this is where your role is going to be important. You know what and how each user likes to do things. So while we, the caretakers, are doing something like this, creating picture collages some users might like to play lotto, while others would like to join in creating things, or simply be there as a part of a social activity. Thus, I really need you to help me
Chapter 10

facilitate so that the users are still our main priority. I think, that there is a space for design and the key to that space is activating the users.
Appendix 2: Data-gathering guide

Pictures

What people say

What people do

Who participated?

How they participated?

Length of participation

When someone breaks an activity

When the users lose interest

Summary of each day:

Write, reflect and document what happened
Appendix 3: Polaroid Guide

HEI ALLE SAMMEN 😊😊

Dere har nå fått noen dagbøker hvor jeg har laget noen enkle oppgaver som skal ta sirka 20 minutter over to dager.

Oppgavene handler om at dere (arbeiderne) skal ta bilder som svarer på spørsmålene i de små bøkene. De er rettet mot brukerne og dere skal ta bilder på deres vegne hvor målet er at det kanskje kan introdusere refleksjon rundt deres roller som stedfortredere i den kommende design-prosessen.

Prøv deres beste å kommunisere med de dere jobber med for å ta bilde av det de ønsker. Forsøk å utfordre deres egne oppfatninger og men viktigst av alt: ha det gøy med å ta bilder!

Det skal foregå over to dager, det er det samme hvem dere er med eller hvilke dager dere gjør dette.

Hvis dere ønsker å skrive mer en det er plass til i bøkene så gjerne skriv på A4 ark og legg ved.

Bildene skal limes inn over de grønne illustrasjonene i bøkene.

Jeg kommer med noen oppfølgingsspørsmål når jeg henter inn bøkene 😊
Appendix

Vennlig hilsen

Åsmund Dæhlen

Telfon hvis det er noe: 45 86 21 35!
## Appendix 4: Collaging tools

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<tr>
<th>Toalett</th>
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Appendix 5: Results P2

These results presented here are more akin to those of the notes taken during the different sessions and summarize some of the most important data points from these. Images are not captioned, and the text might be messy. The goal of this Appendix is to open up the context to any who is interested. This section presents the essentials of the results that either directed future decisions, results or participation. The section will be outlined chronologically, presenting some of the resulting artifacts and ideas, but will be kept to a minimum.

Whenever I talk about ‘user configuration’ I talk about the pairing of care-workers with specific users which especially relies on working alone or through routines and would need special attention to implement new activities.

[1] 28.01.2019

Introduction to project and sensitization

Total amount of possible participants: 10 (Five employees and Five users)
Resulting participation: 4 (2 Employees and 2 Users)

Spent the morning introducing three employees to the sensitization task and the project, one of which(D3) ended up not conducting the polaroid task due to the daily user configuration. The interview lasted for 35 minutes, from 0815-0850. I was at the activity center from 0800 to 1030.
During the interview we had 2 interruptions. The first interruption was because of a user arriving at work and needed escort from the taxi. The second interruption was in the middle of the introduction when the employees seemed to start to understand their role as they had to, before the users arrive, discuss the user configuration, where they also discussed how they could work with sensitizing with the different configurations. Overall the introduction to the project was satisfactory. We discussed some issues pertaining user health that would most likely limit the possibility for conducting the activity, because one user (U2) had: “been down lately”, which they suspected was because of the new wheelchair. Their—"vi får ta det som det kommer.” Which roughly translates to we will just have to go with the flow”—attitude was positive.

The care-workers expressed worry of what data I would collect and asked if I would write down and record how they interacted with the users. I then clarified that I am only interested in participation and what I recorded was only what they told me through the diary or interviews.
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As a follow-up to help create a stronger commitment to the sensitization we planned to meet the next morning for an interview and discussion.

Before leaving I got to talk to D4 and introduce the sensitization task. This care-worker has already showed some interest in earlier talks and was already familiar with some of the scope of the project.

[2] 29.01.2019:

Follow-up interview and introduction to sensitization and project.

First, I travelled to the activity center to see what they had worked with the day before, took pictures (x), then planned with the custodian service to get a ride to the brother center where the two employees worked that Tuesday. Then, we conducted a 30-minute interview with the two care-workers which ended when the users arrived. I then called back to the custodians for a ride back to the activity center where I interviewed three care-workers, introduced them to the project and sensitization. One of the care-workers (D6) showed special interest in the work I had done and talked about her project with one of the users, earlier discussed in X, where we then planned to meet the next week to conduct the initial picture collaging session.

Follow-up interview

Participants: D1 and D2. 30 Minute open interview with some questions to lead the conversation. They were not needed as the employees directed a very constructive discussion on their own.

First, they discussed how they communicated with each user and whether they felt the users’ understood the tasks:
Chapter 10

D1: “I tried to communicate the task to different users, it was successful with all but one user [U2] where it was a little too much.”

D1: “When we talked about tools she [U1] “Hammer” and we angled it towards understanding tools the she uses. Toilet-chair, elevator, etc.”

D2: “I am not quite sure U5 understood the task correct but U5 does say “yes”. U5 ended up showing us her soles which help her walk correctly.”

D2: “It didn’t quite work with U2, I could see it building. We tried to work with the task with U2, but it became a little too much for U2, just then.”

D1: “U2 Can give signs as to what she wants but this task is hard. I asked: “Am I asking too much questions now” to which the user replied YES with her body language. U2 doesn’t have her voice, but she has her sight. I mean this is what we are working towards, U2 has the language but not the voice.”

D2: U2 Wants to be included into everything, even though U2 cannot participate much with her body she loves to be included socially. For example, I tried to fold papers once with her, and it can be very fun. But, it is hard to present this without it becoming too much.”.

Lastly, they discussed the possibilities within the U3s capabilities:

D1: “We think it could be nice if we did more manual stuff. Give U3 more choice. I will talk to the teacher today whether we can create some cards that could help with that. It could contribute to easier days.

D2: “For example we could ask: “do you want us to eat lunch with the living-room gang, or do you want to go to the grocery store? But, it can be hard to understand if U3 understands what we mean.”
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The result after the first sensitization were 2 polaroid pictures, seen in images 11 and 12.

What did I learn:

- The employees did not have time to answer the question. They spent quite some time trying to work with the user in the sensitization.

- Polaroid seems to be a nice way to engage in a simple yet reflective task.

- The participants talked uninterrupted for almost 30 minutes, discussing and reflecting on the different aspects of how the users understood the task etc.

Interview, introduction to project and sensitization:

Interviewing D4

B5 and another user, normally present in the sewing room, was present during interview.

The interview lasted 10 minutes. The care-worker has written about activity and has some prior insight into design in general through education.
After discussing the main goal of the project—to explore participation and the requirement for the users to be included into the design sessions—we discussed how we can facilitate for the users’ participation and the importance of the care-workers knowledge about everyone’s challenges:

D4: “It is all about the individual, I know their challenges very well, for example with U5 now [The user needed help with choosing the right trashcan (trash sorting) because of bad eyesight. The trashcans are all white but with different-colored bags as well as one for paper products].

D4 then points to another user who is shredding paper:

D4: “Like with him, he doesn’t have much language and it is hard to communicate unless you understand what the words mean.”

Lastly, we shortly talked about yesterday’s sensitization which they had not completed so I asked who she had worked with and how they worked:

D4: U1 Drew and I drew a little while we talked about the different kinds of chairs she used and tried to use different synonyms to try and talk about U1 thinks is best. It was very challenging yesterday because U1 was very drowsy and it makes it difficult for U1 to do anything.”

Introducing project and sensitization: D6

D6 mainly works at the brother center. We had 5 minutes to talk before D6 had to leave to continue work where we talked about the personal project she had started with U4 at the brother center. (The results from their project can be seen in Phase 1, Intermediary results, image X).

After giving a short introduction to the project we decided to skip the sensitization task—because there were already people conducting it, using the camera at the activity center—and go straight to the collaging task. When discussing participation and how to include the users into the sessions D6 said that:
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“When we are working with U4 and asks what U4 wants, the answer is always the last thing we said, even if we change the order of it the answer is always the last thing we said. But, if we place the things [physical objects] in front, U4 picks what they want. For example, the user likes yellow syrup best, but if you ask if they want yellow or red they call out red.”

What did I Learn

- The workers show an extensive ability to reflect on the overall implications of the activity, e.g. how reflecting on the user’s ability to understand abstract concepts, language and communication, etc.

- D6 has reflected on how the user makes choices and how to present them.

- Even though I worked with U5 throughout phase I I did not know she had special soles or shoes.

- The care-workers discussed future possibilities and how they could work with the given capabilities of each user.

- The care-workers had not filled out the questions, but given a chance to discuss in an interview.

- While I am not researching the polaroid task itself, or sensitization, I think it would be interesting to give this out to more people, following it up a little more closely and see what they produce.

- They did not discuss their role in the process, while it can be a at fault of the task it could also be because the care-workers do not fully know much about the process, other than the introduction I have given.

[3] 01.02.2019

Introduced D7, D8, D9 and D11 to the sensitization. D7 and D4 was introduced to the overall project after the morning meeting, D11 and D8 was introduced later when they were available. Talked to D2 about supporting the others if they had
any questions and told other care-workers they could direct questions at her. Only D4 was able to conduct the sensitization task.

Discussed with D2 whether or not she would be able to continue doing the sensitization task with U2. She said it might be difficult right now but that she would ask if the situation arose. D2 talked a little bit about how important it was not to talk about unfamiliar concepts like vacation, especially ones requiring plan-rides as the user had never done it, and it could cause a great deal of frustration.


The goal of this session was to follow-up the introduction from 01.02.2019. I also introduced D5 to the project and sensitization task. D5 had had a couple weeks’ vacation and had not been able to join until now. The participants in the group-interview D2, D4, D5 and D7. D4 did not participate in the interview but the results can be seen in image X.

**Group-interview:**

D7 explained that they did not get time to conduct the task:

> D7: “The user has some set routines on Friday, joint singing, music and then a couple of toilet visitations so we didn’t have time… after lunch it kind of disappeared out of mind and we were ready for the weekend, however I did think about it during the weekend when I went skiing.”

D7 followed up on their thoughts when skiing where they had thought about a communications tool called Rolltalk, which they had observed being used as a communicational tool. (Rolltalk is a communicational tool where pictograms are used to support normal conversation.)

D2 talked about the user having a hard period and it was hard to contribute since it did not fit into the day. They thought it might be because it was hard to process new things, or that it had been some hard days lately. D2 expressed that, since they started working here, it was the first time U2 had experienced such a complicated period. In relation to this, the care-workers discussed among
themselves about U2s use of the ball pit and how they had expressed a liking for the ball pit as an activity.

D5 could did not work with the living-room group and could not participate in any sensitization today but got an introduction. D5 was also set to work with this user all week and did not think they would be able to participate.

In the diary, D4 had written:

Q: Did you meet any challenges with this task? (Image x)

D4: “With this user-group it will always be challenging with communication, either in relation to, understanding language or [cognition], or the users form of the day. In this occasion the user was asked in several ways what she meant about her supporting tools. I also have to be careful in not asking to loaded questions, since this user has a tendency to mostly answer “yes””.

Q: How did you work with communicating purpose, possibilities and wishes? (Image x).

D4: “Asked straight what is the funniest thing to do and got the same answer twice. It is worth noting that this is a user who can express what they want very good if they really want too.”
Chapter 10

Oppgave 2:
Hva måned jobber døve før å kommunisere formål, muligheter og økonomi?

Spurte rest ut hva som er det morsomste å høde på med og fikk samme svarer to ganger.

Vurder at man kan se og at dette er en bruker som kan utvikle hva hun ønsker svaret godt hvis hun vil det.

Dag 2:

Oppgave 1: Ta et bilde av den morsomste tinget å gjøre på jobb.

Tegne 🖤
What did I learn:

- D7 stated that he had thought about how to facilitate for communication outside of both work and design sessions.

- Being available to talk, and plan ad-hoc is important as people are busy and can not necessarily join my sessions.

- Being able to conduct the sensitization was, for some, dependent on ‘having a good day’ (Joshi and Bratteteig, 2016).
  
  o Scheduling activities beforehand was hard and had to be tried and tested to see if the user felt like doing it.

- While D5, who has showed great interest earlier, usually works in the living-room group, she did not do it this week and was unable to conduct the sensitization. She did get a proper introduction though.
• With more time, or several iterations I am 100% sure that we would be able to conduct more sessions with more people.

• Some users can understand simple questions. One care-worker reflected on this and how to not ask loaded questions.

[5] 06.02.2019

Collaging Workshop

Care-workers: D6, D7 was present and joined in on discussions and the introduction, however, D7 did not participate in the session after lunch.

User: U4 has severe physical and cognitive challenges as well as a limited expressed language.

Introducing the collaging kit 0945 to 1000

This is the planned workshop with D6 at the brother center. First, the user we conducted the session with is one I am unfamiliar with as I have only briefly been introduced. While we sat down in the morning to introduce the collaging task, we did not get to conduct the session until three hours later, after lunch. While I throughout have stated multiple times that they, the care-workers, are proxies and does not need to include the users into the design activity itself, but rather as a part of something similar, D6 utilized U4 presence to explore possibilities.

I arrived at the brother center at 0830 and I started introducing the workshop at 0845. Since I had not gotten the chance for a proper introduction and wanted to make sure they all understood the task I introduced that I am only interested in participation. Technology and whatever we come up with is not important. Neither of these participants had been able to conduct the sensitization task and I had to spend extensive time expressing what their role would be as facilitators, and how they could work with the activities I had created. While we did not get to conduct the workshop until after lunch, we meanwhile discussed the project, the possibilities and the role of the care-workers and user throughout.
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In introducing the communication tools that they had made D6 and U4 showed it by using it:

Asking the user D6 said: “can you point to a picture, so we can cut it out. When we are rifling through the folder U4 points at the images and say what is on them.”

When going through the folder together with the user (image x) U4 had pointed at a picture with a woman holding a baby next to a picture of a cat, saying “cat”, so D6 switched the picture of the cat to a new page. While D6 might not have realized it now, she later talks about how this improved her understanding and importance of simple imagery that only has one meaning.

Talking about another activity they have created to maintain physical capabilities:

D6: “U4 really loves magazine and can walk pretty far to get one… like everyone else U4 is going to physically decay and so I think it is important
that she can do these kinds of activities. I have created an activity that involves me going up in the reception and leave a magazine in the mail and later telling her that she has “gotten mail” so then we walk together and get it and she is really happy for it.”

D6 introduced me to several activities they had made. Some of them are specifically tuned to each users’ need relation to communication capabilities (see image x and x):

D6: “U4 likes to help with washing clothes and so we got a picture of a washing machine, and I was thinking that maybe we should replace it with a picture of our washing machine to make it easier to understand the relation.”
Another activity they have made is the simple activities of ‘weaving’. Explained in phase 1 (see image x) where D6 explains that:

D6: “Many doesn’t have fine motor-skills”
Conducting the collaging session

Initially the care-worker tried to initiate a session at 1030, but, had to break the activity to go do something else. U4 then did some ‘weaving’.

While I earlier had stressed the care-workers roles as proxies and decision-makers D6 conducted the task by asking the user to choose images while D6 cut them and glued them to the paper (image x). After the small session we discussed it and D6 found it hard to figure out how she could include U4 into the sessions without paying full attention to the user and helping her in doing the task. I introduced that maybe she could do something she likes alongside, like the ‘weaving’ activity to facilitate for her own design participation.
Conducting a proper session

From 1155 to 1255, after lunch, we got to conduct one full hour of workshop and discussion where we explored the capabilities of the U4. What we discovered was that there was a gap in our understand of a mutual goal and D6 had a hard time conducting the design-activity because she could not grasp how technology could be used to help U4 make choices. Initially we tried to conduct the collaging task but soon had to move on to try and discover the capabilities of the user when it came to ‘choice’ and understanding abstraction. As the activates that D6 has made earlier suggest, there is a need to explore the capabilities of U4s understanding of abstraction.

We spent a great deal of time to discuss what possibilities technology served as D6 expressed that: “I think I am the most un-technological person you have ever met”. When discussing choice, and how technology could present a greater width of options for the user, D6, in trying to grasp the possibilities said:

D6: “I am having trouble understanding this. Like now I just asked if she wanted something to drink and she said milk. But this table (referencing the table-screen in the collage) can present more, like yellow syrup.”

To which I presented that this tool could help explore things that the user doesn’t know is a possibility, like going for a walk.

D7 they brought up a point of discussion that:

“We shouldn’t make language obsolete by having them pint at things instead of talking, it is important to maintain the language they have.”

To which we discussed whether or not different modes of communicating where mutually exclusive. We ended on an understanding that this way of presenting choice could also be a way of extending or maintain language if it is facilitated for both.
I then tried to take the session back to the collaging and tried a different, more creative approach, where I introduced that they could try to make something that isn’t necessarily realizable at first, but rather as a vehicle to explore. To try and get them back into the collaging task I then asked: “what is the most fundamental things that are needed in order for the U4 to be able to use it?” to which they replied:

D6: “I think the answer is the language and the hands.”

D7: “Yeah, she has a language, although limited it is a language.”

D6: “And if she sees a magazine outside her reach she will go and get it, she is missing some balance, but she can use the table to stabilize.”

D6 then came to the idea of a shelf that where all the activities the user liked to do would be presented and possible for the user to go and take what it wanted to do. I then tried to see if we could angle that idea towards technology, which could do exactly that but more, how it can present endless possibilities, it can be a big screen showing a shelf, and a place where we could make plans, have games, etc…

D6 sits back, thinks for a while then says:

D6: “I am unsure whether or not she would understand the connection between the thing on the screen and the thing.”

She then picked up and folded the small picture of “Se og Hør” and walked over to U5 which was relaxing in the couch and asked what it was, the user was unable to understand or communicate it. D6 then tried with “Hjemmet” and asked the same question and the user replied. “Donald!”.

We then, discussed what it would require for the user to understand that the picture of a magazine on a screen was a magazine, or the act of reading a magazine rather than any specific. After some thinking D6 said:
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D6: “what about making it 3D?”

To conclude on the following discussion, we had; A fundamental concept would have to be to make sure that cognitive skills are maintained, technology that enable the user to use her body as well as her language. However, to make something like this would require for the user to understand this conceptual change. Which we then discussed how we could explore. D7 proposed that we could print a picture of a magazine or cut out a front page. D6 then said:

D6: “I think she might just see that as a picture now”

Because of this discussion we moved away from creating a picture collage to try and investigate the central issue explored: the concept of understanding the abstraction that goes on between a screen and a real object, and how the user understands this.

Ending the session, we discussed whether we should try to test conceptual change now, but D6 suggested that the user needed to relax. Besides U4 was already sitting with the magazine and rifling through it so it probably would have had little meaning to ask about now. We decided that I come back Friday (2 days later) and try it in a more natural setting to see if we can learn anything.

What did I learn:

- Extensive presence is paramount to be there when the possibility to conduct the session arises.
- Understanding the capabilities in relation to abstraction and mapping of the individual user had to be done to continue the collaging task. Even though the employee has known the users for X amount of years they have never tried to use screens and we must explore this possibility before we go further.
- When U4 was present, D6 sometimes used her presence to “test” her assumptions.
- The presence of the user allowed us to explore capabilities further.
- While D6 kept blaming her “un-technological-ness” I would argue that why the design-activity was hard was not because of technology or the
task itself but rather that it was hard for D6 to imagine future possibilities because, even though she has worked with U4 for seven and a half years (which might be the reason why), could not imagine how U4 could utilize technology.

- As we will explore later, some care-workers ideated solutions for user with less capabilities.
  - So, another reason might be that D6 simply was very adamant in creating something that U4 could directly interact with even though I presented multiple times that we can also create something that we interact with.

- Care-workers reflect on different aspects of users’ well-being throughout: how to maintain physical and cognitive ability, autonomy, etc:
  - D6 had crafted, together with U4, different tools to facilitate this maintenance.
  - Later D10 were very involved in a discussion on how we should create technology to support those whose health condition constitute an often rapid loss of capabilities to ensure that future care-workers know what the person likes when they no longer can express it.

**[6] 08.02.2019**

**Inquiring into capabilities**

Since D6 showed such a great interest in exploring capabilities I wanted to foster this engagement and created an interactive mock-up, both to show the possibilities with technology—how fast we can create these kinds of tests—using Adobe XD and an iPad (image x).
Interactive mock-up can be found here:

https://xd.adobe.com/view/92d62213-6b9a-498e-595d-a0b2a74b8cb3-e4e7/?fullscreen
The goal of this session was to further explore the capabilities of the user by using a tabled, some pictures of what we perceive as images of things that are familiar to U4.

Before we started the session, D6 talked about how she had tried to get a better understanding of U4’s vision and ability to distinguish colors by using the pegs used for weaving (see image x), asking U4 what colors she held. However, U4 just ended up blurting out colors before D6 could show them. She had also tried to show her a magazine that had the Norwegian prime minister on the cover, to which she had replied “woman”. Starting the session, D6 sat down with U4 on the end of the table, and the user started pushing, tapping and dragging on the screen when the tablet was placed before her (see image x).

The user riffed through the different screens and after some time D6 asked: “What is that?” and pointed at the screen, to which the user replied “magazine!” which was correct. While we are talking the user is clicking around on the screen, often without direction or paying attention to the what it is doing.

On another screen D6 asks: “What is that?” and the user replies: “Strawberries” when it was a picture of her ‘weaving’ activity. The picture is a little bit small and there could be multiple reasons for the confusions.
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Later we tested the prototype we made the last workshop (image x), the employee put it together and placed it in front of the user and asked, “what would you like to do?” and the user replied that she wanted to weave. Then the employee looks at me a little surprised and says: “I thought she would pick the magazine.”

We asked another user (U1), after she showed interest by coming up and watching the tablet, which has both higher physical and mental capabilities if he wanted to try the mock-up. U1 tried it and clicked through, used the buttons and was clearly familiar with touch screens. However, she quickly lost interest after going though once.

**Learned:**
• After this, I personally thought that there is a space for exploration on how to present choice using a screen, while, as we will see in the following interview, the employee thought that we could move away from screens and into physical solutions.

• Both care-worker and user are active participants in all phases of design. The user is included into the early phases of decision-making.

Follow-up interview

This section details a short, 20-minute interview following up the prior session where we discuss what we presented in the prior section.

Leading into this interview I talked presented my thoughts, that this shows there is a possibility for further exploration into using a screen-based solution to see how we can present choice to the user. D6s first response was that:

D6: “I think we should move away from a screen because U6 needs concretes… I think that we could look to make something physical”.

Where I asked her to elaborate:

D6: “I am thinking that: it is a little… The benefit of a screen is that if you have learned something, for example, if you have ever sat in a plane, and it is like… like U4 could more easily identify the choice [of going to fly]. U4 needs to have experienced the concrete thing to understand what something means. Let’s say the choice between traveling by fly, bus and train, it would be hard to choose between the three.”

What did I learn

• I think that had I known the user, and care-worker better prior to trying to act out this sessions.

• U4 has a very complex set of capabilities that seems to be tremendously hard to understand. Even after working with U4 for 7 and a half years, D6 still does not quite understand U4s cognitive capabilities.
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- Including the users into early generative sessions to explore possibilities is possible and might help care-workers make more informed decision when exploring mediums of interactions that the user usually does not or have not used.
- The inclusion of the user into the design process let the care-worker ‘enact’ possible scenarios, and explore the users capabilities by enacting her ideas.
- Harking back to the reflection of Visser et al. (2005) these individual session did take very long time to conduct and the participant sometimes stressed that she was sorry she was so technologically inept, or unable to produce “results”.
- Neither participant was part of the sensitization.
- While we did not ‘make’ what I initially planned for through picture collages, we made some simple tests by using objects that was familiar to the care-worker and user which the care-worker then used to tell stories about the user’s capabilities.


Since the preliminary interview with the manager, he had been away from the center and I planned each session with what I understood as the “second in command”, because she earlier was the one taking control in different situations.

Starting collaging at the activity center

This section outlines the second collaging session, and the first to be conducted at the activity center. This time, as an adaption to the issue of getting “stuck” the last time I made some altercations to the introduction of the collaging session. I explicitly said that I am not so much interested in the technology and the outcome itself, if they are unsure whether something will work—just try it, tell us what you think in the later discussion and we can work with that later. The nature of these iterative sessions lets us first explore ideas, then iterate on these ideas. This
session is first and foremost about creating a breadth of ideas so that we can inspire each other to build on these ideas.

Initially there were five possible care-worker participants today, however two conducted the collage. Initially three started the task but one of the users broke off. The manager had been away for a couple of weeks because of other work-obligations and offered to buy any materials we might need. We had the possibility to start at 0845, but in discussing with the care-workers we concluded that it might be best to start later when the users arrived to make sure they felt included.

During the morning meeting and the later introduction, D2 and D5 discussed how they could work with U2 to make sure they could join the activity. U2 is the user that has been having a bad time lately. After the introduction they discussed how to specifically arrange for doing the task with U2, which is severely limited
physically and can only really communicate with simple yes or no using their face.

In planning the collaging D5 said: “It is good to get something else to do for a change. This can be an activity we do together before lunch”.

D5 spent a total of 40 minutes conducting the task and 10 minutes explaining the collage. From 1010 to 1050. During the task D5 actively worked with U2, making sure she showed all pictures, talking about them and showing her cutting them (see image x). D5 also placed the scissors in the hand of the users and helped cut the pictures.
Originally D2 and U1 joined the task but it might have been a little too overwhelming for U1 as they can understand a great deal but might get flustered when they do not understand what is happening. In this case D2 could not have complete attention to the user and U1 ended up to their own device.

D11 started the task at 10:25 with U3. When D11 is holding the collage of feeling she includes the user into the task by asking what U3 what she sees on the pictures. To which the user responds it looks like people.

While D2 had to break the session she takes the initiative to use the collages to show the user and talk about the different technological artifacts and how they work (see image x).
At 1035 D5 had to help D2 with getting U1 out of the massaging chair. She is only gone for about three minutes. At 1040 D5 started looking for other things, markers, stickers and asked if she could write on the paper. I pitched that she could write on post-it because then she can move them around. Around this time D11 puts on some music.

At 1007 D11 and U3 had to break the activity because of bodily configurations.

**D5 telling 1050-1105**
«My thought is that we can use this at the start of the day to plan. So how it works is that I hang it up in front of her, point on an alternative, and ask her if she wants to read a book, where she then smiles, or don't smile. Then I can chose that as an activity and then move on to the next.»

D5's idea is one where the paper itself is the prototype of a physical board, with these pictures stuck to a surface.

D5: «I thought it could be some sort of bulletin board with activities. New daily plans every day, made out with this. Meaning the whole paper is the technology. It can be a little smart too. [...] This could be smart because then everyone can have a package to use, then we have a lot of set nice activities we can work with. Especially when there is someone who isn’t working often with U2. It would be very nice and neat because we are already doing this just in our heads»

I then introduced how technology could possibly enhance the purpose of this idea. How we can use chips to read of what activities is planned, what has been done, and automatically store these in e.g. a diary or any journaling system so that
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family and other care-givers can get more contextual insight to communicate with the user.

D5 then turns to conversing with the user and explain how it is going to work. Spends time holding up the pictures, explaining each and then emphasize that nothing is going to change and that her days will remain the same as it always has.

Finally, I introduce how we can work with exploring her idea further, working with creating a higher fidelity prototypes to explore how we can work with exploring the design with the users.

From 1105 to 1215 I helped by being with U1 as D2 had to direct her attention someplace else and I spent lunch working with U1.

**D11 telling 1230-35**

D11 is working with a user that has major mood swings and the daily doings of the user relies very much on how she feels. However, expressing how she feels can be hard.

D11 introduces the collage (image x) by talking about how the user slowly is losing some of her capabilities.

D11: “The goal of the device is that she could be able to point at pictures to tell how she feels. She known how to use a computer, so it could be an iPad, a kind of program that had communication so that when she arrives at work she can point to how she feels. Or that she can have a text, because she ca read, It can say sad, or that tired or happy, having fun. So that it can be a two-way communication between us. Like D5 I thought that it should be for one specific user. She likes to join many activities, but she likes shredding paper, reading magazines, listen to audiobooks. This can also help her plan the day herself.”
D11: “If she could in forehand say how she is, so that we can plan the day accordingly. It can be very important for the user to express herself because she does not have very good speech and it can be hard to understand. So, it would be nice with a tool that can help with understanding this.”

D11: “There could be a small like perm, where you on an A4 paper, one the first page, it can say «Hi U3 how are you feeling today? [...] if you ask a question it could be that she just answers yes to everything, so it can be important that she can see and manage it herself. I think these kinds of things can be important because there is a possibility that she loses some of what she has [capabilities].”

Ending the session, we planned for having a new session the coming Friday where we would explore these ideas. I also planned with D2 and D10 to have workshops at the brother center Tuesday and Thursday. Throughout the day some of the employees express that they feel bad for not being able to join the activities. I emphasize that that is why I am here for an extended period; to make sure they get the possibility to participate.
Collaging at the brother center

The goal of the day was to conduct the collaging task with D2—which so far has had the possibility to participate in sensitization, and collaging, but been unable to—and D10, which has not been able to participate because she has worked with one of the users who work in isolation at another part of the center.

D10 worked with U1 and D2 worked with U3. There was a third user present who likes to work on her own and did other activities while the rest did collage.

Here the session lasted in a continual process from 0945 to 1110. Especially D10 and U1 was able to work with the task the whole time. D2 and U3 had to break off the activity quite often to attend physical needs. D2 did not have time to present until 1355 and I had to stay around a little later to make sure she could present her idea.

Starting the session D10 talked about some challenges to interacting with an eye-tracking pad that another user, U2, uses and how the context of the season and how, snow, sun, rain etc. impacts what decisions should be available:

D10: “Have you seen U2’s eye-tracking machine. It is one way to do it for Us, but we don’t think it works for the user. It is a little too hard. Also, she can’t choose to go on a trip because it is 15 minus and if she chooses that then, well she doesn’t know the context of what she is saying.”

To which I respond that it could be smart and be able to individually tailored to the contextual challenges the users face.

D2 then talks about the challenges that U3 faces, and in close approximation to what D11 talked about in the last session U3, has a strong dependency on her mood, which often constitutes what she is able to do any given day:
D2: “She doesn’t really think it is cool with some of the activities she does, but she likes calm tasks like sitting in the massaging chair or using sound-proof headset. It is like the user moves out of her body and is addicted to calming supportive tools.”

In talking about U3s challenges, the two care-workers discuss how they can design for her capabilities, where they discuss how presentation of choice can be limited:

D2: “She likes to pearl and thinks it’s fun, reading magazines…”

To which D10 interrupts and says:

D10: “But that is only because she doesn’t know any other alternatives to what she can do or because… well yes.”
D2: “That is a very good question D10… I have not really thought about that.”

As they start to make the collage the two care-workers had this conversation:

D10: «alright I am thinking that this program has to be dependent on the year»
D2: «are we here talking about this being an ipad?»
D10: «Yeah I am thinking that it is an ipad with an app, a touch screen»
D2: «But then it is important that it is individual. »
D10: «Yes I’m thinking that an app is good because then it can be individual»
D2: «okay so then this is my app then [points to the paper, asking D10 questioningly]»

From 0955 to 1000 they are interrupted by one of the other users coming to work and they cater to make sure her needs are met, making coffee and preparing a place to sit etc. Throughout the session D2 helps this user and spends some time making sure she is alright. There are also some interruptions like reading the user diaries and making sure their physical needs are met.
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From 1010 to 1030 they have the morning meeting with the users, reading aloud from their diaries and discuss the content.

In the collage there are a pair of glasses however, both this session and the former one the care-workers have simply drawn them on a post-it.

In creating the collage D10 talks to the user about how she would like to interact when planning the days:

D10: “U1, if you were to make a plan for the day, how would you do it, would you like to plan orally or would you like pictures?”
U1: “I am very appreciative of when you make pictograms.”
D10: “Would you then only like picture or would you also like someone who literally said what it is?”
U1: “I would very much like for you to say it.”

D10: shows the picture of the ball pit (image x) and asks:

D10: “If you had seen this picture and asked if you wanted to do this, what would you have said?”
U1: “I would have said ball pit, and then I would have jumped straight in!”.
Next, D10 tries to emphasize the point expressed earlier that U1 might not see the contextual requirements of doing activities by asking a leading question, knowing that the answer in reality is ‘no’, but asks to make a point:

D10: “So when you see this ball pit, and hear a lady saying, “ball pit” [D10 imitates a robot voice], do you then think about relaxing, throwing balls, listening to music, that we have to find a pillow, those kinds of things?”.
U1: “yes.”

D10 keeps asking questions about some of the activities to further explore how she understands the different images. One of the images is one of an emoji, where the user replied that it was too small for her to see. (image x).
Meanwhile D10 is exploring D2 is exploring U3s understanding of the images by showing a picture of the massaging chair (image x):
When D2 were exploring U3’s understanding of the image of the massaging chair she says:

D2: “This is very interesting because I thought it would come *snaps her fingers* like that, and she would immediately understand it… that is very interesting.”

In response to this D10 says—reflecting on how to present certain vaguer concepts:

D10:” I have not seen any pictures that means to relax, even though some might think that the massaging chair, most people might just think massage.”

After some thinking D2 says:

D2: “In relation to the massaging chair I thought it would come immediately, and I thought the user would understand. And then I started thinking on whether she understands what it means to sit in the chair and why it is different. The same with the stress less because it is straight backed, and you can’t lie down. I have tried with some individual photos and she can see [relating to sight], so a nice thing could be pictograms with pictures av banana, apple, oatmeal and for example presented fire different pictures so she could point at what she wants, and maybe that would make her choice more safe.”

D10 “So to use it like in a chosen activity, for example when she is eating lunch she can chose more what she wants rather than just answering ‘yes’ when we ask if she wants oatmeal?”

D2: “Very often she just answers the last thing we’ve said. My thought is very simply that when we present simpler pictures we will get other results. But then I specifically think about this girl and that it is very reliant on how she feels that day.”
D10 then draws a hand holding a football, and seeks to explore whether or not the user would understand this in relation to the ball pit, (image x) asking:

D10: “What do you think when you see this?”
U1: “It looks like a hand.
D10: “And what can you do with the hand?”
U1: “It’s holding a ball.”
Both care-workers continue exploring as they create the collages. D2 is a little hesitant to put her ideas down on the collage.

**D10 telling: 1047 – 1100.**

The result is an app D10 calls an “activity bank” which lets the care-workers create individualized banks of activities to fit each user capabilities. It is based on time of the year because of the contextual requirements that follows from snow, temperature, etc. because, the users can not necessarily understand these requirements, planning to do an activity, then find that we cannot conduct it later can lessen how meaningful a day feels. It also takes into considerations some “primary needs” like eating, going to the toilet, and then some funny activities as well as productive ones where we produce something.

D10 then presents some specific requirements of the product like:

**D10:** “When you push on an activity it plays a sound: “ball pit”.

Explaining the different possibilities of use D10 says:
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D10: “For example she can chose what she wants to do in the application but it can also be for the care-workers: so it is also information for the care-workers so that they know what each activity entails and what to do. It is a bank of different activities so that we don’t all stand here doing the same things”.

D10 continues going through the different sub-categories explaining different functionality. In short it should be modifiable by care-workers to make it easier to create new activities. It needs to be individualized and it will require a lot to use this app and start expanding on the bank.

D10: “It can also be an app that can help communicate between the different institutions because we can have a common login.”

D2 Telling 1355 to 1400:

When D2 presented her collage (image x) it turned into a discussion where they continued on the notion of how important the different contextual requirements are:

D10: “Any trip is different so…”
D2: “Yeah, for example going to x, or x”
D10: “Yeah any displaying of going on a trip has to be specific”
D2: “And it is really important to find a way to include them into decision-making. Most people just thinks it is really funny to be able to “join” shredding paper when we [care-workers] do it, and the user participate by just watching what we do, just being present.
D10: “It is actually extreme how much one user just wants to be included.”
D2: “Make an app then that makes it so you can feel included in every way.”
Finishing the day we planned for the next session to be held the coming Thursday, where we would continue on this idea, creating a higher fidelity prototype.


The goal of this workshop was to further explore D10’s idea of an activity bank. D6 was present during the session but only joined in sometimes by discussion. While we planned for the session ahead D10 was not sure whether we would be able to conduct but I decided to show up, just to be sure. We were able to conduct a session but had to stop when the user arrived because the user D10 was with required hundred percent attention from D10. I had never interacted with the user before either, so I think it was for the best to not push it.

Interview on participation

Before the session we had a 10-minute discussion where the care-workers discussed some aspects of participation as well as how it could be improved, specifically talking about a user—who really likes music—whose physical and communication capability deteriorates fast:

D10: “She says [referring to one of the users] what I want her to answer, anyways I think that user participation is important, if it is going to
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function in praxis one needs to include them and not work over their heads.”

To which D6, which thinks she has struggled in impacting the project because she has not provided any “results”, answers:

D6: “No it is very abstract this project.”

D10: “I mean the idea I have, if it had been included early into the lives of someone it could for example… a user could have an entire activity bank, like things to use as point of reference in, because this user is losing some capabilities which makes it harder to communicate. We often do the same things over and over because we don’t know everything the user can do.”

The care-workers talk about how they had guessed that the user had been to Germany, purely based on the contextual queues.

D6: “It was pretty sick that we actually wildly guessed that the user had been in Germany.” [Earlier the care-workers, in conversation with one of the users had guessed that she had been to Germany to visit her family.]

D10: “I understand 50 percent of what the user says.”

D6: “Not even that.”

To which I asked a question on what will happen when they get older, and there are only new care-workers left:

D10: “That is where I am thinking the idea-bank idea could work, user could also made playlists with all the songs she liked, which she thinks is lovely… then in a couple of years when the user can’t necessarily do much anymore, it would be so lame when employees never put on the music the user likes.”

D6: “Yeah, then music is going to be extremely important.”
Making the presentation

D10 spent 20 minutes making the drawing, stating it was quite easy since she had already detailed much in the former session, which she used as a basis (image x).

To exemplify how easy we could make higher fidelity prototypes and how we could possibly explore the idea further I spend the same amount of time creating a mock-up in Adobe XD. Since there was little talking I thought that I might aswell use the chance to further a little mutual learning (image x). I showed D10 the mock-up after she had presented her paper-prototype.

D10 Telling 0920-0930:

D10’s low-fidelity prototype can be seen in image x.

D10: Først så kommer du inn på denna siden,
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D10: «Først er det logo»

D10: «Så kommer alle brukerne som er på jobb opp på skjermen som bruker det»

D10: «Og hvis det er flere brukere på jobb som benytter seg så kan man svipe bort som en ipdad, det må være litt størrelse på bilden slik at man kan finne seg selv. Kanskje det må være noe passord, når jeg tenker meg om så ikke andre brukere kommer inn.»

D10: «boop, så kommer du inn på dette er person x» her har vi informasjon om personn hva slags motivasjon, interesse, hvordan du kan motiverere til aktiviet og hvordan en skal kommunisere med de.» Hvis en er ny så er det greit å ha den informasjonen.

D10: «Så kan man trykke seg inn på aktivetsbank, «boop»»

D10: «Der kan en velge mellom inne og utaktiveter ut i fra hvilken årsider og være det er»
D10: «Så i dag tenker jeg at det er kaldt og snøstorm så da vil vi gjøre ting ute.»

Jeg: ide om yr som viser at det er vær

D10: «Derfor trykker iv her: «inneaktivitiet»,

D10: «Da kommer vi på aktivitetsbank inn.» «her er det mange ulike valg av aktiveter, og her kommer det lyd når vi trykker på det «ballbinge» (siri-stemme) og så kommer vi da inn på siden til mballbinge og her kommer det info om
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tilrettelegging, om heis, skal en ta av heisen, eller skal vi ta av heisen fordi kanskje bruker er redd for den, eller masse små ting.

D6: «du kan jo bare skrive at den er detaljert informasjon om hvordan bruker vil gjøre det.»

D10: «Litt tillegsaktiveter som en kan ha til den aktiviteten, sånn som bruker sa at liker å kaste ball av og til.» Aktivitet i aktivietet() Eller at du kan høre på musikk mens du er i ballbinge.

D10: «Nå lurer jeg på om bruker kom så jeg skal bare gå å hjelpe.»

D10: «da kan en for eksempel trykke på musikk, så si de har spotify, da kommer det opp spillelister med ulike temaer som allerede er forhåndslagdte, danse glad, etc.»

D10: «Det var litt gjennbruk av lappene, så hvis du synes noe mangler er det fordi de ble med over.

D10: «nå hadde jeg klart før meg hva jeg hadde tenkt så det gikk veldig fint». 

After the workshop D6 asked U4 if she wanted syrup and used the opportunity to explore wheter or not smell could be used to identify which she wanted.

When all the users have arrived B6 tries to make a collage but is at a loss of what she can do. I try to tell her that her participation has been very helpful despite what she might think.

[10] 15.02.2019 08:00 - 1400

Summary:

First arrived at 0800 to join the morning meeting and got the word at 0830 ask them how we should proceed with the day. Every Friday there is a joint music
session where some of the care-workers play instruments and everyone sings songs. This session is very important to some and D2 suggested that we should shorten the singing session to make time for collaging, which we originally planned to start at 1000 but some of the users came in late. There was a lot of people in the living-room group today which made it a chaotic period before everyone settled down.

There was a total of six care-workers working in with the living-room group, two of which got to conduct the session properly, one half-way and two who attempted to conduct the drawing session but had to sporadically keep their attention elsewhere. The session lasted from 1030 to 1130.

While D5 started the session, and the user she was with actively participated (image x), she had to take a phone call with one of the other user’s guardian.

D5 started at 1030 but had to break soon after. D12 and D4 started around 1040 – 1045. Before starting D12 had some things to discuss relating to how the users would understand «new» choices, and where the problem of choice originates:

D12: «We need to break the patterns, give choices and then adapt to these choices. The employees are used to taking the subway or seeing the subway map, but does the users know what the picture means? If it is a person who has a more limited capacity, the user would need time to learn in order to understand things and opportunities. If it is a digital surface then the users need to be able to understand what is on it and then individual factors

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comes into play, factors in the employees together with user, whether or not something has been successful several days in a row.

Throughtout D7 each session, while he has given valuable input in the discussion, has always been a little hesitant to join the sessions and here asked whether we could try again next week and try with another user. However, he does give it a go. He was with U1, which D10 had one session with earlier.

D7 expresses that he thinks it is difficult and asks how he can include the users. He tries to include the users by trying to have discussions about the pictures, asking for comments from the user (image x).

D4 conducted the task in pretty much the same way D5 did earlier with U2 where they actively talked about the images with the user (image x)
While some of the results has been very specific ideas, D4’s thoughts revolved around some more general thoughts on the possibilities with technologies. D4’s presentation was very short, only two minutes.

D4: «I have tried to focus on communication. In relation to U2, which talks with her eyes, that for example on the start of each day, we use a board where we can hang pictures of routine activities and present it each day what the activities are, but that means that you have to have a good relationship[with the user] and ask questions right. You have to spend time with the users’. Like now [it is soon lunch] I could have used the board, eat here or in the kitchen?»

While D4’s presentation and thoughts were not very fleshed out we can clearly see some similarities with what D5 developed earlier.
D12 Telling 1115-1125

D12 is a part-time worker and has not joined any previous activities. We spent some, 10-15 minutes, discussing what I was looking for, what my understanding of activity, communication and the overall goal of this session was before he started working on it.

D12’s idea was a smart travel planner that would be made to fit each individual. The goal of the application was to have a device that could be brought, and used, to help the users make decisions based on things like weather, time, location, and present the individualized information in such a way that users could make choices themselves:

D12: «in realtion to your goal [of wanting to create tools that support acitivites and communication] the goal of using the program is as a travelling planner that claim cognitive competense and can help making choices. Whether it is a user with good communication, or a user with less
cognitive or communicational capabilities the user should be able to use this.»

D12: «For example, any outside activity is governed by time and weather. It is an app with pictures of things that are reliant on places, for example nature. And under the category nature, there are sub-categories with pictograms where the user can be a part in deciding where to go as you go there. However, it is very, very important that it is adapted to individuals. For example if you travel to Tøyen, then you need options that fit with Tøyen so that when you are there you get choices based in what you have done before and so and so.»
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Immersion as a Strategy to Facilitate Participatory Design Involving People With Intellectual Disabilities and Caretakers as Proxies

Shaping spaces for participation through contextual insight

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Abstract — This paper reports from the early phase of a Participatory Design (PD) process where the goal is to design technology that involves people with Intellectual Disabilities (ID) and their caretakers as participants. The background of the study is a long-term collaboration with a local activity center for people with ID and 56 participants from this empirical context participated in this study. The presented methodological approach emphasizes immersion as a means of gaining access to and learning about the context to help identify crucial considerations for the facilitation of later PD activities. The paper presents two analyses of contextual data to reflect on how immersion as a strategy provides important insight into contextual considerations that can help shape future PD activities. Three learning outcomes are presented and discussed: involving users with ID and their caretakers as proxies, organizing long-term commitment, and lastly building on already-established forms of mutual learning.

Keywords — participatory design; Intellectual Disabilities; immersion; proxy designer.

I. INTRODUCTION

The increased attention devoted to the user perspective in the assessment of the quality of life has opened up possibilities for people with Intellectual Disabilities (ID) to involve themselves more in research activities [1]. However, including people with communicational issues due to cognitive limitations present obstacles for meaningful participation in PD. One such example is the often seen presence of alternative forms of communication, e.g., as mentioned by [2]. The background for our study is a long-term collaboration with a local activity center where the goal is to facilitate a design process where 40 people with ID and their caretakers can engage in the co-design of technology.

This paper reports from the initial phase of a Participatory Design (PD) process with users and caretakers of the activity center aiming at designing technology to support the users in their everyday activities. We consider PD appropriate as it embeds important underlying values that we believe are necessary to tackle the challenges found within our empirical context, e.g., power relations, mutual learning, and emancipation [3]. Our PD process emphasizes immersion as a strategy to gain the necessary contextual insight to facilitate future PD activities. We report from our initial phase where we have immersed ourselves in the context to help identify important considerations. This study involves 56 participants, including users with ID, their caretakers, and the managerial staff. The data gathered through immersion revealed two main topics overarching all contextual factors, namely activity and communication. We used these two topics to structure our analysis of what type of contextual insight we gained through immersion, and then later use the findings to reflect on why this knowledge is necessary to facilitate a PD process involving both people with ID and proxy designers. We end the paper by presenting three concrete learning outcomes: (1) the PD process should facilitate for the participation of caretakers as proxies; (2) the PD process should be organized as a long-term commitment; (3) the PD process should be built on top of already established forms of mutual learning. We discuss the implications of these three learning outcomes by summarizing why we advocate immersion as a strategy on how to gain the contextual knowledge necessary to facilitate a PD process involving people with ID and their caretakers as design proxies.

Throughout this paper, the word user describes someone using a facility or service. This notion derives from people being users of healthcare systems or services [4]. Linguistically, it also represents a neutral word that allows the caretakers to talk about people with ID without stigmatizing or revealing specific details about the users in everyday communication. We attempt to distinguish this notion from users in a design process by describing the latter as end-users rather than users.

This paper is structured as follows. We give an introduction of related work in Section 2, while Section 3 outlines our research methodology, empirical context, and the specific methods of inquiry. Section 4 presents the results from our empirical work. We end the paper in Section 5 by introducing three implications of our approach, as well as discussing the significance and relevance to ongoing discussions concerning design for people with ID.
II. RELATED WORK

Previous studies have explored the use of proxies in the context of PD involving both adults and children with ID (e.g., [2] and [5]). Brereton et al. [5] present the initial use of proxies as an important step towards realizing requirements, imagining possibilities, and ensuring successful inclusion of people with ID into the process of design after design. There are other examples of successful inclusion of people with ID in specific phases of design, e.g., [6]. Putnam & Chong [7] seek to gather information on software and technology use for people with autism through surveys directed at adult proxies, as well as some adults living with autism. Blomberg & Karasti [8] present an important perspective on ethnography in PD as a means of “channeling access” to the context. Holone & Herstad [9] also stress the importance of starting the design in the practice of users.

Redhead and Brereton [10] explain how short-term methods as a means to engage in design can be ineffective for communities of people. They argue that the researchers’ presence and activities are inherently academic, and might be too distant from the empirical context to understand and support local practice and interaction. Their suggestion on how to approach this challenge is by shifting from short-term to long-term commitment. A similar point is also raised by [11].

A common denominator in studies about people with cognitive impairments is the need for highly contextualized understandings of the participants and their challenges and capabilities [9][12][13]. As Holone & Herstad suggest, working with kids with disabilities requires more time to get to a “starting line” where the design process can begin [9]. Francis et al. [12] also characterize how challenges caused by highly individualized forms of communications amongst people with Asperger’s and autism can be tackled with correct management of the co-design process. Brosnan et al. [14] also reflect upon PD practice, challenges related to engaging different stakeholders, and also points to pitfalls such as overlooking the value of inclusion. Finally, [13] advocates the uniqueness of each co-design study for people with cognitive and sensory impairments and the importance of understanding the context and people in-depth when adjusting the methods applied.

III. RESEARCH METHOD

A. Empirical context

The empirical context of our study is an activity center located in Norway for approximately 40 people with ID. Their ages range from 22-70 years with non-significant differences in gender distribution. The impairments range from mild to profound mental capabilities, but also extend to physical challenges as people may have bodily configurations that also complicate autonomous functioning. To support each person’s cognitive and physical capabilities, their everyday activities are individually tailored and organized to maximize the sense of autonomy. For some people, this requires one-on-one assistance from caretakers, while others can work in groups or even without any direct assistance. The caretakers’ background ranges from non-related or lacking a higher education to domainspecific competencies such as social workers, social educators, teachers, and ergotherapists.

The everyday dialogue between the people and their caretakers is highly contextualized (see, e.g., Figure 1). Certain users can only communicate when using a limited and tailored vocabulary; however, the caretakers rely on many forms of non-verbal communication, most of which are directly tied to the context, e.g., objects, places, activities, and routines found at the activity center. Examples of such non-verbal forms of communication include icons, signs, physical gestures, and photographs. The activity center offers a wide range of both educational and recreational activities for the users such as therapeutic activities (e.g., music and light therapy), ludic activities (e.g., games and audiobooks), creative activities (e.g., painting and sewing), and physical actives (e.g., swimming and field trips).

![Figure 1. Illustrations being used as an alternative form of communication](image)

B. Methodology

The methodological approach of this study is Participatory Design (PD) – a worldview that emphasizes the inclusion of the people who will eventually use the technology in the design process as equal co-designers [3]. Central principles of PD include mutual learning, co-construction, and having a say [3], and our approach attempts to create a space for engagement supporting these principles while simultaneously allowing us to design technologies for and with users with ID. One of the central challenges in our long-term PD process is to support co-creation and autonomy without necessarily demanding participation from users in all phases and activities.

Our approach relies on immersion as a strategy to build up enough contextual knowledge about the users, their lives and everyday activities, to represent their voices in activities where they are not interested in, or unable to, participate themselves. We see the PD process as a use-oriented design cycle that requires familiarity with both the real-life problem situation and the practice [3] before moving to elicitation of needs and requirement descriptions. As such, we use this paper to argue for immersion as a necessary component in studies involving proxy designers engaged on
behalf of users with an ID, especially when representing the users’ voices in the design of technology intended to support them with their everyday goals and activities.

Immersion in our context draws on ethnographic traditions and practices. More precisely, we align our view on immersion with Crang and Cook’s intersubjective perspective [15]: “participant observation should not be to separate its ‘subjective and ‘objective components, but to talk about it as a means of developing intersubjective understandings between the researcher and researched” (p. 37). We position ourselves as such due to the embedded emphasis on mutual learning in PD [16], and our argument is that the contextual knowledge gained through immersion during the earlier stages of a long-term PD process is vital to the facilitation of later design activities. Thus, the results, findings, and discussions of this paper revolve around how non-users engaged as proxy designers can better connect with the everyday world of the users and actively change it and create new knowledge through immersive participation.

The long-term commitment of the study was conducted on a weekly basis, where one of the researchers worked on a volunteer basis at the activity center. This means working closely with the proxies and the users of the activity center, engaging in everyday activities, learning about their different means of communication and lives in general. The nature of the communicational difficulties faced by the users means that the proxies were very important in bridging an apparent gap of knowledge that was required to have meaningful interactions with some of the users.

On an everyday basis the employees are working together in bridging their differences in knowledge and ask each other questions about how to perform specific tasks or activities. The care-workers are proxies to the users because they continuously try to mediate their wants and needs and facilitate for a workday which carries meaning in some way.

C. Research methods

This paper presents the results from the initial phases of our long-term PD process and the data involved was gathered through six research methods throughout four months. Our activities involved 56 participants, including users with an ID, their caretakers, managers, and researchers. Table 1 presents an overview of the six research methods and the participants involved in each activity.

<table>
<thead>
<tr>
<th>#</th>
<th>Research method</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Participatory inquiry</td>
<td>30 users and 15 employees</td>
</tr>
<tr>
<td>B</td>
<td>Contextual observation</td>
<td>Researcher</td>
</tr>
<tr>
<td>C</td>
<td>Diary journaling</td>
<td>Researcher</td>
</tr>
<tr>
<td>D</td>
<td>Explorative workshop I</td>
<td>2 researchers and 1 design expert</td>
</tr>
<tr>
<td>E</td>
<td>Interviews</td>
<td>Manager</td>
</tr>
<tr>
<td>F</td>
<td>Explorative workshop II</td>
<td>6 Employees</td>
</tr>
</tbody>
</table>

1) Participatory inquiry

One of the researchers in this study immersed himself into the context by taking on the role as a volunteer caretaker, receiving formal training and introduction similar to the training provided to all other caretakers. While the researcher still works part-time at the activity center in this voluntary role, the data presented in this paper originates from the first four months of work, which equals approximately 100 working hours. The goal of this immersive activity was to gain knowledge through first-hand experience of the context and the users we are designing for and with in our study. The methods of inquiry included observations and shadowing of colleagues and users during everyday activities, their interaction with technology, as well as their means of communication. The data produced from this activity consisted of notes, photographs, and mind maps.

2) Contextual observation

The purpose of the observation was to capture important contextual concerns in a medium suited for later design activities where participants might not possess verbal communication skills. As such, the data was documented in the form of photographs. 50 suitable photographs that described important contextual relationships related to everyday activities, interaction between people, and technology were selected. Most of these photographs were taken after working hours to ensure that the researchers’ presence did not disrupt or interfere with the users’ activities. Examples of relevant contextual concerns include technologies (e.g., audio systems, massage chairs, and light projectors), objects used in activities (e.g., instruments, games, and drawings), and places of interest (e.g., sensory rooms, resting places, and creative spaces).

3) Diary journaling

After each full day of volunteer work, an entry was written in an elicitation diary describing the activities and communication challenges encountered. Important events, major issues, and concrete examples of situations requiring contextual insight constituted the main content of the diary. Similar to the contextual observation, most of the diary entries were produced after working hours or in the absence of users as the goal was to allow everyday activities to progress as normal despite being the subject of investigation. Throughout four months, 18 journal entries were written down, ranging from a couple of sentences to a couple of pages.

4) Explorative workshop I

To explore design opportunities in the context of technology intended to support users with ID in their everyday activities, we engaged one researcher and one design expert in an explorative workshop. During the workshop, we presented data from the previous activities
such as photographs, mind maps, and transcribed interviews as the basis for a discussion of how we can facilitate future design activities in our PD process. Furthermore, both researchers conducted an individual objective coding on the same data set, which later served as the basis for a reflection of the insight gained through immersion and how contextual knowledge directly affected our interpretation of the same set of data.

5) Interviews

An important part of the immersive approach was facilitating easier access to both contextual and domain knowledge which included in-depth details about the capabilities of each person who used the activity center. One of the main sources of information was ten semi-structured interviews with the manager of the activity center revolving around practical and organizational issues that were relevant to our facilitation of a PD process including both the users and their caretakers. These interviews revealed opportunities and limitations for participation, e.g., insight into the working schedule of the caretakers, as well as suggestions on suitable caretakers who could fit the role as proxy designers in later stages of our PD process. Each interview lasted between 30-60 minutes and was scheduled throughout the four months depending on the manager’s availability.

6) Explorative workshop II

The final activity in our initial phase of the PD process was a second explorative workshop conducted with six caretakers at the activity center during a morning meeting. The goal of this workshop was to compare how the caretakers as potential proxy designers understood the everyday activities and communication challenges found within their own work context with issues we had identified. We also used their in-depth knowledge of users and everyday activities to facilitate a group discussion on how to scaffold the PD process around existing routines and preferences to best support our underlying PD principles, i.e., mutual learning, co-construction, and having a say.

IV. RESULTS AND ANALYSES

The data gathered through the six activities outlined in the last subsection consisted of diary entries, transcribed interviews, observation notes, discussion summaries, mind maps, individual data coding from workshops, and photographs. From the data, we identified two recurring topics that were common across all the activities and mentioned by all participants, both users and non-users, namely activity and communication. These two topics also embody most of the underlying issues that were discussed during the two exploratory workshops. As such, we used these two overarching topics to help us structure our analysis of whether immersion could contribute to any deeper insight to help facilitate the future activities of our PD process.

A. Results

1) Activity

The empirical context is an activity center, and as such, there was an intrinsic emphasis on activities. Both the caretakers employed at the activity center and the users with ID who used it shared an activity-centric focus. Already during the first participatory inquiry, we registered that the caretaker training revolved heavily around daily routines and how different users engage in activities. Concerning how to engage the caretakers as proxy designers in our PD process, the manager who was interviewed explained that the availability of these caretakers was highly related to their work schedule, which in turn revolved around activities. This point was also raised during the first exploratory workshop where the participants believed it would be easiest for both caretakers and users if the PD process were structured around activities.

From the users’ perspective, we registered through the diary entries that most of their autonomy, as well as the sense of pride and accomplishment, were related to both the activity and the context in which it took place. One of the reasons behind selecting activity as a common denominator was that users who engaged in activities experienced a multitude of personal reactions and rewarding sensations based on their particular capabilities and background. We also learned during the second exploratory workshop that the participation in activities was itself an important catalyst for the users’ sense of mastery. In some cases, the act of carrying out an activity was of greater importance to the user than the purpose or end-goal of the activity. The photographs from the contextual observation complemented this point by revealing that most of the equipment present at the activity center was not intended at problem-solving, but rather as means to enable engagement in activities without necessarily having a fixed end-goal. Finally, we made multiple observations of how successful participation depended on the activity’s ability to acknowledge the user’s vulnerability, e.g., sudden urges to use bathroom facilities.

2) Communication

One of the main challenges when working for and with people with ID is facilitating communication. Previous studies have discussed the need for compensating strategies (e.g., [2]). This is especially important to our PD process and the emphasis on mutual learning. In our empirical context, we found multiple examples of how the activity center compensated for the lack of verbal communication skills. One such example was the labeling of the shelf shown in Figure 1, where photographs rather than text communicated different activities.

Another prominent example was the users’ individual daily diaries where the caretakers registered all entries and then communicated a summary back to the user. In later situations, the diary itself became a means of non-verbal between the user and the caretaker. The caretakers who participated in the second exploratory workshop also
described how being heard and seen was vital to the users’ motivation. Most forms of communication were self-developed and internalized by the different users and the contextual activity at hand. As such, one of the contextual insights gained through the participatory inquiry and the elicitation diary entries was instances of different, but highly specific, combinations of gestures and speech employed by the users to communicate with their caretakers. To facilitate a proper dialogue where the users can communicate choices and selections, understanding these varying forms of communication is a necessity for all parties. In the most extreme cases that we observed, some users rely completely on the caretakers’ ability to interpret their language, or lack thereof, as well as the caretakers’ ability to reduce the dialogue to questions that the user can answer with a simple yes or no by using their bodies.

B. Analysis

We identified two recurring topics in our data, namely activity and communication, and we wanted to use these two topics to structure our analysis. While the emphasis on these two topics emerged from the empirical data itself, they align well with the goal of our overarching PD process, i.e., designing technology that supports people with ID in their everyday activities. The embedded nature of creating spaces for co-construction and mutual learning in PD also depend on our ability to facilitate communication between participants. As such, we used these two topics to structure our analysis. Figure 2 illustrates how the analysis included multiple people and different types of data.

1) Inter-rater reliability analysis

In the first analysis, we wanted to analyze to what degree our immersion strategy actually provided contextual insight. The individual coding of the same data set performed by the two researchers in the first exploratory workshop yielded a total of 64 overlapping first-order codes shared by the two coders. The data included in this analysis consisted of photographs, observation notes, elicitation diary entries, and documents from the activity center.

We compared these two sets of individual codes to examine how a researcher without contextual knowledge of the users and their everyday lives identified opportunities and challenges relatively compared to the researcher who had gained contextual knowledge through 100 hours of in-situ volunteer work during the participatory inquiry. More precisely, we wanted to use the inter-rater reliability between these two coders to examine whether the researcher without any contextual knowledge rated each code similar to the researcher who had immersed himself into the context. To study the consensus, both coders individually labeled each of the 64 codes as either activity or communication. We then used Cohen’s kappa to determine the exact level of agreement between the two coders. The result of the cross tabulation is outlined in Table 2, where Researcher A represents the immersed researcher while Researcher B represents the researcher without any contextual knowledge.

<table>
<thead>
<tr>
<th>Researcher B</th>
<th>Communication</th>
<th>Activity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher A</td>
<td>21</td>
<td>7</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>24</td>
<td>36</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>31</td>
<td>64</td>
</tr>
</tbody>
</table>

From the table, we can see that both researchers divided the number of codes between the two topics fairly equally: Researcher A labeled 28 codes as communication and 36 codes as activity, while Researcher B labeled 33 codes as
communication and 36 codes as activity. However, there were large discrepancies in which codes that were labeled under each topic. The coders agreed on 21 of the 64 codes (32.8 %) as examples of communication and 24 of the 64 (37.5 %) as examples of activity. However, the level of inter-rater reliability was still only moderate, \( \kappa = .409 \) (95 % CI, .189 to .629), \( p < .001 \). As such, we see that the two researchers had a different understanding of the latent meaning behind similarly identified codes in the same data set.

2) Thematic analysis

During the second analysis, we conducted an inductive thematic analysis of all the data gathered over four months to elicit themes related to our two topics activity and communication. The goal was to use the themes to summarize and exemplify the type of contextual knowledge that was accessible through our emphasis on immersive participation. To structure our inductive thematic analysis, we followed the procedure presented by Braun & Clarke [17], and used the two topics activity and communication as the overarching topics to tie together the different emerging themes. The preparation consisted of transcribing relevant audio recordings from workshops, annotating photographs, and a systematic structuring of all elicitation diary entries and notes from the participatory inquiry. We categorized the data into 40 first-level codes that constituted the lowest level of patterned responses and opinions. The codes were collated into 15 categories that were organized as four main themes. We ended our thematic analysis by mapping out the relationships between the different categories and themes, and by relating them to our overarching analytic topics activity and communication. Figure 3 illustrates the categories and themes identified. We omitted the 40 first-level codes as they were all collated into the 15 categories outlined in the figure.

V. FINDINGS

A. Contextual insight gained through immersion

Table 3 presents a summary of the four themes identified in the data during the thematic analysis: meaning, practice, choices, and routines. These four themes represent the type of contextual insight gained through our immersive PD approach; the two former themes relate to activity as an overarching topic while the two latter relate to communication. The table also lists the source methods for each of the themes along with key quotes or observations.

The four identified themes are examples of higher-order issues that we have separated to highlight the different types of contextual insight gained through immersion, as well as to demonstrate the variety of relevant considerations. As such, the themes are not four separate and independent examples of insight, but rather four overarching themes that represent a set of overlapping and intertwined factors.

Meaning outlines an understanding of the meaning bearers for the users. Practice describes the context and the various kinds of work and activities carried out at the activity center. Choice describes the challenges the users and employees face during decision making, as well as how they are resolved in situations involving different cognitive capabilities. Routine defines how we can understand the role and implications of the daily routines within the everyday lives of the users.

B. The distribution of difference in understanding

The four themes and the underlying categories from the thematic analysis were also used to assess whether the differences in interpretation between researchers with and without contextual knowledge pertained to specific themes.
or created divergence across all themes. The 64 codes used to assess the level of agreement between the coders in the inter-rater reliability were compared to the 40 first-order codes used to structure the thematic analysis, and the differences were visualized. Figure 4 combines the four themes with the analysis of inter-rater reliability to demonstrate how the differences in understanding of contextual factors were distributed across all themes and underlying categories. The white circles indicate a similar understanding for all underlying codes; the striped-colored circles indicate disagreements in only some of the underlying codes; and the grey circles indicate disagreements in all underlying codes, i.e., the whole category itself.

As we can see in Figure 4, the differences between the two coders were distributed across all four themes, as well as 11 of the 15 underlying categories. For instance, the two coders interpreted the whole theme of routine very differently, including all underlying categories. One such example would be profession, where only one out of several codes was read differently without affecting the affiliated theme. As such, the contextual knowledge gained through immersion was not limited to certain aspects of activity or communication but pertained to most categories branching out of the four themes.

Stimuli is another example of how contextual knowledge created a divergence between the coders.

![Figure 4. Distribution of difference in coding between the two researchers](image)

### TABLE 3. OVERVIEW OF THE FOUR THEMES AND MAIN FINDINGS

<table>
<thead>
<tr>
<th>Theme (Activity)</th>
<th>Main findings</th>
<th>Source</th>
<th>Key observations and quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Meaning</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Choices</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Routines</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Stimuli** is another example of how contextual knowledge created a divergence between the coders.

![Stimuli](image)
For the researcher with contextual knowledge, this code was considered an in-vivo code referring to a specific activity, while the researcher without contextual knowledge understood it as a matter of communication rather than activity. We saw similar differences with physical challenges: the researcher with contextual knowledge referred to communication challenges with this code as most users relied on bodily gestures to communicate, while the researcher without contextual knowledge saw this as a challenge related to participation opportunities in activities.

We argue that this distribution of the difference in understanding creates highly different outlooks for the facilitation of an inclusive and tailored PD process involving users with ID and their caretakers as proxy designers.

VI. DISCUSSION

In the immersive nature of our PD process, taking on the role as a volunteer caretaker has given the possibility to create and embed mutual learning in the context on the premise of the users and caretakers. We have used the contextual knowledge gained to analyze the importance of our presence and the type of insight it may provide. We end the paper by introducing three concrete learning outcomes that we believe can inform the next stages of our own PD process. We also use these three learning outcomes to structure our discussion and argue what these outcomes signalize in a broader context relevant to other PD practitioners working with users with ID.

A. The PD process should facilitate for the participation of caretakers as proxies

The use of proxies has been discussed in previous studies, e.g., as a way to help researchers learn about the goals of the end-users [7]. However, we argue that the caretakers specifically constitute appropriate proxies due to their ability to break down language barriers (as seen in [2]) that may prevent equalized power relations. Throughout the immersive process the proxies have been vital in bridging communicational gaps and is best exemplified by cases where the users have mixed forms of communication, using hand signs, body language and words to express themselves where either contextual knowledge, like having read the users’ diary (some of the ID keep a diary), or having the caretakers explicitly tell you what they think the users are communicating.

Balancing the power relations is a common challenge found within PD [3][5]. The caretakers’ presence during design activities also increases the researchers’ chances to successfully facilitate a space for mutual learning by supporting non-verbal and contextual forms of communication. This allows the users to express themselves, make choices, and be properly understood. Being able to speak your native (to the context) language in the design process can avoid issues of “model monopoly” and expand the universe of discourse [3]. Facilitating an arena that allows the users to practice collaborative working skills was seen as highly dependent on the presence of the caretaker in our study, and other studies are suggesting that this factor is often overlooked [14]. We also want to shed light on considerations related to the management of the design process [12], and advocate the use of caretakers to help lower the threshold for participation as they know how to initiate design discussions without disrupting ongoing everyday activities. One such instance is when the caretakers have approached the researcher during workhours to discuss topics of interest.

A final related topic not addressed in this paper but relevant to the balance of power relation is the inclusion of contextual probes [6][18] as another way to circumvent users finding themselves in a “passive role” [19] due to communication barriers.

B. The PD process should be organized as a long-term commitment

Identifying the appropriate point of departure in a PD process demands contextualized knowledge [9]. However, we argue that contextual insight over time contributes to mutual learning by allowing time and space to identify enough examples of the uniqueness of each situation being symbiotically shaped by the users, the context, and the caretakers’ intimate knowledge of the situations. As such, we argue that long-term engagement is a way to converge on the uniqueness of each situation [13], as well as a way to avoid communities rejecting opportunities for collaboration due to short-burst facilitation [10]. Furthermore, we saw from our empirical context that committing to long-term engagement also contributed to both respect and trust [9], and the development of social relationships and skills [7]. This gave the activity center more time to familiarize themselves with our academic practice, which may be unfamiliar to certain communities [10].

Finally, we also advocate long-term presence as a means to support “channeling” the access to the context and the co-inhabitants’ needs [8], which we argue is not a static matter, but rather something “[...] continually in the making through everyday contestations among neighbors, relatives, colleagues and the material world they co-inhabit.” [20, p. 15].

C. The PD process should be built on top of already established forms of mutual learning

One core concept of PD is to enable participants to take control over their futures by affecting the technology that will help shape it [3]. Technology intended to support vulnerable users carries a responsibility of not affecting the users’ everyday lives in a negative manner, for instance through use or even the inability to use. One such example
is stigmatization through technology, which has previously been reported within our empirical context. [21] discusses the importance of not disrupting the sense of feeling “normal” for people with ID through technology that separates them from the rest of the world. Similar challenges have been reported in other demographics as well, e.g., PD involving older adults [22].

As such, we argue that immersion offers a chance to learn about everyday activities where people with ID and their caretakers already have established mutual learning through their everyday activities. We argue for building on top of established means of communication, which may also contribute to the participants accessing a sensation of mutual learning quicker [7], as well as taking more ownership of the design process and its outcomes [23]. Scaffolding the PD process around existing routines and habits allows for easier participation for caretakers who find themselves in a busy work environment. This may also reduce misunderstanding as caretakers more familiar with the individual users can assist the researchers in their interpretation of non-verbal forms of communication [24]. The researchers’ knowledge of the context has allowed us to facilitate on top of already established arenas like using the “morning meeting” to conduct the Explorative workshop II.

VII. CONCLUSION

In this paper, we have reported from the early stages of a long-term collaboration with an activity center for people with ID. The PD process involved both the users and their caretakers as proxy designers. We argue for immersion as a strategy to gain contextual knowledge. The paper describes how underlying values of PD in combination with our immersive emphasis helped us identify examples of contextual insight that can inform future PD activities. We involved a total of 56 participants throughout four months. The data was gathered through six research methods, including participatory inquires, contextual observation documented through photographs, journal entries, explorative workshops, and interviews. The data was subject to two sets of analysis. The first analysis compared the level of agreement between one researcher with contextual knowledge and one researcher without, and the second analysis consisted of an inductive thematic analysis structured around two recurring topics (activity and communication). We ended the paper by presenting and discussing three concrete learning outcomes: (1) the PD process should facilitate for the participation of caretakers as proxies; (2) the PD process should be organized as a long-term commitment; and (3) the PD process should be built on top of already established forms of mutual learning.

REFERENCES


