Enabling People With Intellectual Disabilities to Participate in Design

An Immersive Strategy to Facilitate Long-term Participatory Design Using Social Workers as Proxies

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Abstract — **People with Intellectual Disabilities (ID) are often neglected in decision-making, and this paper introduces an immersive strategy for the inclusion of people with ID in Participatory Design (PD) processes by using the social workers as proxies. We present immersion as a methodological strategy on how social workers could use their knowledge of the end-users' capabilities to enable their participation in the design of technology. We draw on empirical data gathered through 180 workhours of voluntary fieldwork at an activity center in Norway for five months. Through immersion, we appropriated tools and techniques to the contextual concerns, and the results describe how the participation of people with ID enabled the social workers to co-explore concerns and ideas. This paper argues that the participation of people with ID can enable the social workers to explore their concerns through each user's means of communication, effectively giving people with ID a voice in the decision-making processes of technology design.**

Keywords — participatory design; intellectual disabilities; immersion; proxy designer; cognitive impairment.

I. INTRODUCTION

Participatory Design (PD) has long traditions of giving voices to different groups of overlooked or marginalized users by experimenting with ways to engage participants in co-design activities. This paper expands on previously reported results [1], and presents a long-term study of how we can include people with Intellectual Disabilities (ID) in the design processes of technology by addressing the overarching research question: "*how can we facilitate design with people with different intellectual capabilities using Participatory Design*?".

We report from a research project that involved collaboration with 82 participants and was conducted at an activity center in Norway. Our empirical work includes approximately 180 working hours of volunteer work, as well as the inclusion of participants in various ethnographic and design activities, over a period of five months. Our research project was structured into two phases: the first phase used an ethnographic approach where immersion was used as a strategy [1] to explore possibilities on how to include people with ID in future PD processes. This phase involved volunteer work and explorative workshops with both users and social workers at the activity center. Our empirical work generated a rich account of the daily activities, routines, and practices, on top of which we wanted to shape a PD process. The findings from this first phase included four themes governing future means of participation, and we operationalized these findings by shaping tools and techniques applied in the following phase. The second phase facilitated a design process where people with ID, along with their social workers, participated as co-designers. The goal of this second phase was to investigate whether the contextual knowledge gained during the first phase could inform a PD process where people with ID could participate in decision-making during the design of technology. The results and analysis of the participation from the second phase allowed us to reflect on the role of social workers as proxies for people with ID. Our findings demonstrate different ways the presence of social workers enabled dialogue in ways that supported non-traditional forms of communication, strengthened core principles of PD such as mutual learning, and allowed people with ID to engage in decision-making.

Based on our findings, we argue for the inclusion of social workers as proxies during PD processes involving people with ID. We point to concrete examples from our empirical context to demonstrate how including proxies have enabled new ways of engaging users that might otherwise not be included in PD activities. The findings presented in this paper offer both methodological and practical contribution to the PD community as well as other researchers engaging people with ID in design activities.

This paper is structured as follows. We begin by introducing three areas within PD literature in Section II that we find most relevant to our research project. Section III presents the framing of our study along with research objectives, the empirical context, and our research methodology. Sections IV-VI reflect the two main phases of our study by chronologically presenting methods, results, and findings. In Section VII, we return to our overarching research question to align our findings with ongoing discussions in related work. Our contributions and their relevance to the broader scope of discussion within the PD community end the paper in Section VIII.

II. RELATED WORK

In this study, we have conducted different ethnographic and design activities with people with varying degrees of

agency to direct their own interests and needs. In the current discourse available, there is limited work that evaluates how people with ID can critically influence their own future regarding the involvement of technology. We have structured past related work after three, not mutually exclusive, means of achieving participation when collaborating with people with ID.

A. Enabling stakeholders through mutual learning

Two of the main principles in PD is *mutual learning* and *having a say* [2]. We begin by presenting literature that relates to how we can operationalize these principles: with a process supporting the informing of both researchers' and participants' understanding and imagination of possibilities.

Redhead and Brereton [3] 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 involves shifting from short-term to long-term commitment. A similar point is also raised by Maraveji et al. [4].

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 [5]–[7]. As Holone & Herstad suggest, working with kids with disabilities requires more time to get to a "starting line" where the design process can begin [7]. Blomberg & Karasti present an important perspective on ethnography in PD as a means of "channeling access" to the context [8]. Holone & Herstad also stress the importance of starting the design in the practice of users [7].

B. Expanding the space with tools and techniques

The PD literature extensively covers the principle of *co-realization* [2], i.e., applying different tools and techniques, and how they extend spaces for both understanding possibilities and supporting co-creation [9]–[11].

The view of a method differs from the traditional view of a step-by-step recipe. It instead considers it to constitute general guidelines [2] that follow PD principles, which in combination with tools and techniques, stipulate how we can conduct design. Brandt et al. gather the essentials of what tools and techniques do into a framework of *telling, making,* and *enacting* [9]. They postulate that these principles are essential and happen in any situation where participation occurs. Hussain et al. elicit *telling* stories and explores possibilities using card sorting [12]. Galliers et al. utilize workshops where the end-users can enact current scenarios of use [13]. Kanstrup et al. propose a technique revolving around walking as a means to enable a sense of enacting and storytelling [14].

Tools and techniques can give people the possibility to "express themselves visually and verbally" [15, p. 1]. Focusing on early exploratory phases of design, Sanders & Stappers describe that "the focus is on using making activities for making sense of the future" and later "[..] the prototype is a vehicle for observation, reflection, interpretation, discussion, and expression." [11, p. 6]. In the case of a low-resolution prototype, which might itself be ambiguous, the collaborative act of *telling* or *enacting* stories of use can spur innovation [16]. These tools and techniques seek to be a bridge between the language gaps of designers and non-designers, where the physical objects can create visual languages [11], [15].

In the broader context of designing for and with people where limited cognitive or physical capabilities present different barriers to communication, offering several means of communication is crucial. Yekhlef & Essén argue for a phenomenological view and the body as a tool for innovation [17]. In the same manner as [18]–[20], they argue for a need to utilize already established practices to support the overall PD process.

C. Communicative challenges to participation

Previous studies also discuss the challenges of participation by proxy or mere presence as a means of tackling challenges that cognitive, physical, and organizational limitations present to participation. Brereton et al. argue that prototypes can be an important aspect in finding mechanisms that empower people with cognitive or sensory impairments and advocate alternative means of involving those in question [21]. Offering a similar perspective, Galliers et al. [13] and Dawe [22] suggest that words may not suffice if we want to empower users with cognitive or physical disorders.

Previous studies have also explored the use of proxies in the context of PD involving both adults and children with ID (e.g., [23] and [21]). Brereton et al. 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 [21]. There are other examples of successful inclusion of people with ID in specific phases of design, e.g., Dawe [22]. Putnam & Chong 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 [24].

Francis et al. also characterize how challenges caused by highly individualized forms of communications among people with Asperger's and autism can be tackled with the correct management of the co-design process [5]. Brosnan et al. also reflect upon PD practice, challenges related to engaging different stakeholders, and also points to pitfalls such as overlooking the value of inclusion [25]. Finally, Hendriks et al. advocate 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 [6]. One technique to approach the uniqueness of each situation can be the specific technique of probing [10], which 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 for the future" [11, p. 8].

III. Research Design

To frame our study, we formulated one overarching research question along with two underlying research objectives. Our goal was to inquire into how we can adapt the design process to better suit the needs and desires of people with ID. To address our two research objectives, we organized our empirical work in two corresponding phases, namely Phase 1 and Phase 2.

A. Overarching research question and research objectives

Our overarching research question was "*how can we facilitate design with people with different intellectual capabilities using Participatory Design*?". To address this research question, we outlined two research objectives:

1. To present a rich account that can provide implications for how to intertwine contextual needs into a PD process.

2. To demonstrate how a PD process could be adapted to the contextual needs of the activity center by carrying out the initial stages of the long-term process.

Phase 1 utilized an ethnographic methodology in combination with PD to explore potentials for facilitating design with people with ID. Phase 2 applied the knowledge gained during Phase 1 to contextualize and adapt a PD process that prolonged the exploration of opportunities for participation.

B. Empirical context

The empirical context of our study is an activity center located in Norway with services offered to 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 social workers, while others can work in groups or even without any direct assistance. The social workers' background ranges from non-related or lacking a higher education to domain-specific competencies such as social workers, social educators, teachers, and ergotherapists.

The everyday dialogue between the people and their social workers is highly contextualized, e.g., through the use of visual aids (see Figure 1). Certain users can only communicate when using a limited and tailored vocabulary. However, the social workers 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.

Figure 1. Illustrations were used as a visual aid offering an alternative form of communication

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).

The employees of the activity center are hereafter defined as social workers, understood in its broadest definition: "social work remains a service focused on disadvantaged and marginalized individuals and group" [26, p. 1]. In the context of the activity center, a social worker carries out work that is essential for the day-to-day functioning of adults with physical or intellectual disabilities, who otherwise lack the capabilities to direct their cognitive or physical person in any given situation. Directly translated from Norwegian, employees hold positions of 'environmental therapist' or 'environmental worker', which quite aptly explains their role: to facilitate an environment for people with different capabilities to thrive. Similarly, we apply the word *user* throughout the paper to describe people with ID using the facilities or services offered at the activity center. This notion is derived from people being users of healthcare systems or services [27]. Linguistically, it also represents a neutral word that allows the social workers to talk about the 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.

C. Research Methodology

The overarching methodological approach of this study follows the traditions of 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 [2], 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 both phases and all activities. As mentioned, the study was split into two phases, hereafter referred to as *Phase 1* and *Phase 2*. An overview of the key characteristics of the two phases is outlined in Table I.

Phase 1 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 [2] before moving to the elicitation of needs and requirement descriptions. One of the arguments we present in this paper is that immersion constitutes 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 [28, p. 37]: *"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"*. We position ourselves as such due to the embedded emphasis on mutual learning in PD [29], and we argue 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 every week, where one of the authors of this paper worked on a volunteer basis at the activity center. The volunteer work included 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 experienced by the users suggested 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 collaborate to bridge their differences in knowledge and ask each other questions about how to perform specific tasks or activities. The social workers are proxies to the users because they continuously try to mediate their wants and needs and facilitate for a workday that carries meaning to the users in some way.

TABLE I. OVERVIEW OF THE KEY CHARACTERISTICS IN THE TWO PHASES

Key characteristics	**Phase 1 – Exploration**	**Phase 2 – Facilitation**
Methodology	Ethnographically immersive/infused PD	Participatory Design
Focus	Exploring possibilities for conducting design with people with ID	Investigating assumptions about possibilities for the participation of people with ID
Methods	Participatory inquiry	Generative workshops, interviews and group discussions
In-situ workhours	Approximately 100 workhours	Approximately 80 workhours
Participation	Volunteer work and explorative workshops.	Including people with ID into design making by utilizing proxies' knowledge about capabilities
Participants	34 people with ID 18 social workers 2 researchers 2 fellow researchers	8 people with ID 17 social workers 1 manager
Results	Ethnographic account	Outline of participation
Main findings	Four themes governing possible future means of genuine participation	Two themes describing how social workers facilitated user engagement

Phase 2 is an attempt at operationalizing the learning outcomes from Phase 1 by utilizing the familiarity with the real-life situations, practices, and people to shape a PD process that seeks to include people with ID into the design-making. Facilitating dialogue when engaging participants with reduced communicative capabilities, which is often the case when working with people with ID, is one of the challenges addressed by previous studies, e.g., [13], [21], [22]. In their review, Börjesson et al. [30] found that children with ID are relatively seldom included in the design, and when they are, they have a passive role. They found that children with ID were only included during the initial inquiries and the later testing, never during design.

In Phase 2, we utilized some central concepts of PD: *telling, making and enacting* by Brandt et al. [9], which enables the participants to tell stories about what they make and enact scenarios of use. Sanders & Stappers [11, p. 6] say "the focus is on using making activities for making sense of the future" and that "[…] prototypes is a vehicle for observation, reflection, interpretation, discussion, and expression." [11, p. 6]. Brandt et al. [9] express that innovation can occur when combining low-resolution prototypes with the collaborative act of telling stories or enacting possible scenarios of use.

Visser et al. [10] created a set of generative toolkits that, among other, seeks "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." [11, p. 8]. The three techniques used in *Phase 2* are *sensitization, collaging, and drawing* inspired by [10]. Between designers and non-designers, there is a language gap that these methods seek to bridge by using physical objects to create a visual language supporting participants in an exploration and expression of possible futures [11], [15]. We align our view with the concepts of *having a say*, creating opportunities for *mutual learning,* and *co-create* the future. In combination, these techniques seek to give people a language to tell, make, and enact their own futures.

IV. PHASE 1 – EXPLORATION

The first phase emphasized generating contextual knowledge at the activity center that could later scaffold a PD process with the users. The data was gathered through six research methods involving 56 participants, including people with ID, their social workers, one manager, and fellow researchers. Table II presents an overview of the six research methods and the participants involved in each activity.

TABLE II. OVERVIEW OF THE RESEARCH METHODS

#	Research method	Participants
A	Participatory inquiry	30 users and 15 social workers
B	Contextual observation	Researcher
C	Diary journaling	Researcher
D	Explorative workshop I	2 researchers and 1 design expert
E	Interviews	Manager
F	Explorative workshop II	6 social workers

A. Phase 1 – Research Methods

1) Participatory inquiry

One of the authors of this paper immersed himself into the context by taking on the role of a volunteer social worker, receiving formal training and introduction similar to the training provided to all other social workers. The data presented here 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 a first-hand experience of the context and the users we are designing for and with in the second phase of our study. The methods of inquiry included observations and shadowing of social workers 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 the 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 authors' presence did not disrupt or interfere with the users' activities. We observed several relevant contextual concerns that included technologies (e.g., audio systems, massage chairs, and light projectors), objects used in activities (e.g., instruments, games, and drawings), places of interest (e.g., sensory rooms, resting places, and creative spaces), and different workshops (e.g., woodworking workshop, pottery and textile). Figure 2 depicts some specific examples: the top left image shows a knitting station; the top right image shows the multipurpose workshop; the bottom left shows the ball pit; the bottom right shows some of the paper shredders.

Figure 2. Examples of contextual concerns

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 the first four months, 18 journal entries were written down, ranging from a couple of sentences to several 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 two fellow researchers 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 using the activity center. One of the main sources of information was ten semi-structured interviews with the manager of the activity center. The interviews revolved around practical and organizational issues that were relevant to our facilitation of a PD process, including both the users and their social workers. These interviews revealed opportunities and limitations for participation, e.g., insight into the working schedule of the social workers, as well as suggestions on suitable social workers who could fit the role of participating proxy designers in later stages of our PD process. Each interview lasted between 30 to 60 minutes, and the interviews were scheduled throughout the first 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 social workers at the activity center during a morning meeting. The goal of this workshop was to compare how the social workers 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. Another result was the surfacing of what the social workers perceived as meaning makers for the users.

B. Phase 1 – Results

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 more in-depth insight to help facilitate the future activities of our PD process.

1) Activity

As our empirical context was an activity center, there was an intrinsic emphasis on activities. Both the social workers employed at the activity center and the users rendering the services shared an activity-centric focus. Already during the first participatory inquiry, we registered that the social workers' training revolved heavily around daily routines and how different users engaged in activities. Concerning how to engage the social workers as proxy designers in our PD process, the manager who was interviewed explained that the availability of these social workers 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 the social workers and the users if the PD process was 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 for 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 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., [23]. 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 social workers 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 social worker. The social worker who participated in the second exploratory workshop also described how being seen and heard 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 social workers. 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 relied entirely on the social workers' ability to interpret their language, or lack thereof, as well as the social workers' ability to reduce the dialogue to questions that the user could answer with a simple yes or no by using their bodies.

C. Phase 1 – 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 depends on our ability to facilitate communication between participants. As such, we used these two topics to structure our analysis. Figure 3 illustrates how the analysis included multiple people and different types of data.

1) Inter-rater reliability analysis

During the first analysis, we wanted to examine 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. A thorough description of the analysis procedure we followed has been reported in [1].

Figure 3. Examples of raw data (top row) used in the analysis (bottom row)

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 author 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 III, where Researcher A represents the immersed author, while Researcher B represents the researcher without any contextual knowledge.

TABLE III. ANALYSIS OF INTER-RATER RELIABILITY

		Researcher B		
		Communication	Activity	Total
Researcher A	Communication	21	7	28
	Activity	12	24	36
	Total	33	31	64

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 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 [31] 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 4 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.

D. Phase 1 – Findings

1) Contextual insight gained through immersion

Table IV 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. P*ractice* 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.

2) The distribution of a 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. In other cases, the differences in interpretation of first-order codes did not propagate as the clusters of codes were identified and collated. 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. 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

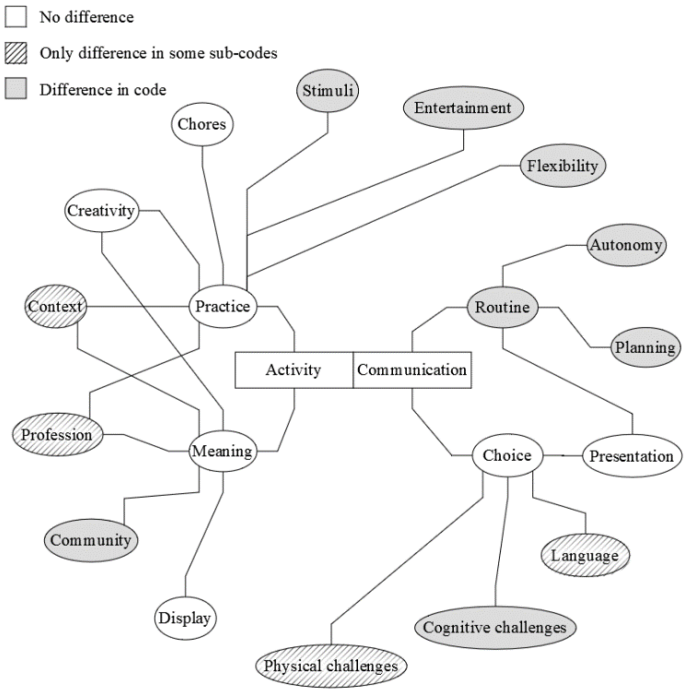

Figure 4. Distribution of difference in coding between the two researchers

TABLE IV. OVERVIEW OF THE FOUR THEMES AND MAIN FINDINGS

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

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 social workers as proxy designers.

V. CONVERGING ON INTERMEDIATE LEARNING OUTCOMES

This section links the two phases. As reported in [1], we summarized our findings from Phase 1 as three broader learning outcomes to guide future work: (1) build on established forms of mutual learning; (2) facilitate for social workers as proxies; (3) organize long-term.

During the planning of Phase 2, the three learning outcomes directed the overarching methodological necessities, while the contextual knowledge about the activity center and its users directed pragmatic action-oriented planning of tools and techniques. One requirement that emerged from Phase 1 was that the social workers still needed to be able to fulfill their roles as social workers. As a result, the process required that the users were engaged in design activities as though any other activity at the center. One of the main challenges would thus be to correctly manage the design process so that the social workers were enabled to both facilitate the inclusion of users, as well as conducting design workshops. As such, the social workers had to engage in two parallel design sessions: they needed to facilitate their own participation while simultaneously facilitating for the users to engage in the design process.

In Phase 1, we explored the social workers' potential for working *with* the capabilities of the users to facilitate everyday activities. This is present in the understanding of the themes *choice* and *routines*, which mainly reflects the supporting role of the social workers in day-to-day communication. We also explored *practice* and how *meaning* emerged. The four themes, in combination with the three learning outcomes, created a baseline for making six action-oriented guidelines to the upcoming PD process in Phase 2. The three former aimed at enabling the users' participation, while the three latter focused on proxies' participation where established forms of mutual learning and general knowledge about the practice were utilized:

1. Include a social component.
2. Appear similar to existing activities.
3. Offer flexibility through contextual adaption per the users' needs.
4. Introduce social workers to their roles.
5. Utilize tools and techniques that enable reflection on the role of participants.
6. Utilize tools and techniques that enable reflection on the role of facilitator for user participation.

These guidelines helped us plan Phase 2 by facilitating participation for both the users and proxies. We utilized the guidelines to help us shape the use of tools and techniques applicable in future PD generative sessions. In Figure 5, we illustrate this move between the two phases. The use of social workers as proxies in the design process was vital in enabling the users to participate, hence the vertical orange arrow between users and proxies.

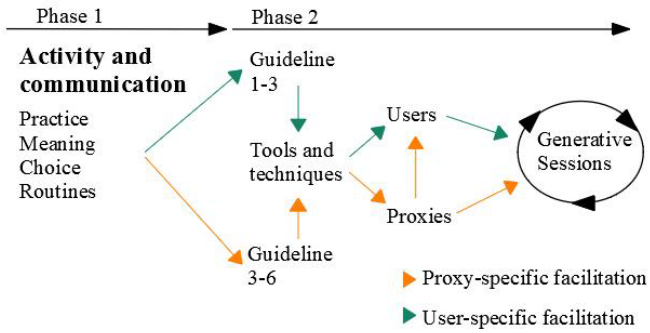

Figure 5. Moving between the two phases using the six guidelines

VI. PHASE 2 – FACILITATION

With the help of the six guidelines, we engaged 20 participants in three generative workshops where tools and techniques were informed by the contextual knowledge gained during Phase 1. To help us organize and reflect upon the workshops, we conducted an initial preliminary interview with the manager, as well as one concluding set of participant interviews. In total, Phase 2 included 26 participants and involved approximately 80 hours of in-situ presence. Table V outlines the main components of Phase 2.

TABLE V. OVERVIEW OF RESEARCH METHODS

#	Research method	Techniques	Participants
A	Preliminary interview	1on1 interview	Manager
B	Three generative workshops	Polaroid, collaging, and drawing.	12 social workers and 8 users
C	Participant interview	Group and single	5 social workers

Initiating a new dialogue between researcher and participants was carried out by targeting some of the already established routines and tools to organize meetings. We also had to spend time in context to recruit and introduce those who were unable to join. The main objective of the introduction was to sensitize the social workers to their role as facilitators and participants. A secondary motivation was to create a common goal, as emphasized by [12] and [13].

A. Research Methods

1) Preliminary Interview

We conducted a preliminary interview with the manager that guided most of the practical concerns of conducting our long-term PD process. One specific issue we wanted to overcome was the challenge of social workers participating without being aware of the goal and progress. Tailoring the design activities around their work schedules allowed us to maximize their opportunities for participation and mutual learning throughout the duration of the whole PD process. In addition, avoiding scheduling conflicts would help us circumvent fragmented participation from the social workers where we could risk them rejecting participation due to short burst facilitation [3]. It was also helpful to anchor a shared vision with the manager on how and what we wanted to achieve with the design process.

2) Three Generative Workshops

We utilized the three techniques outlined by Visser et al. [10]: sensitization, collaging, and drawing. There is a limitless number of tools and techniques available [9], as exemplified by [10, 12, 15, 32]. Generative techniques utilize tools that ideally are fitted to suit the context. Brandt et al. describe the role of such tools: "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." [9, p. 159]. The generative workshops were organized in common spaces within the activity center, familiar to both the users and their social workers (see Figure 6).

Figure 6. Examples of shared spaces where the workshops were organized

a) Sensitization

"In the sensitizing phase, participants perform exercises designed to let them think about past experiences, and make them 'reflective practitioners (Schön, 1983) of their present experience" [10, p. 126]. The goal of the sensitization was to introduce the social workers to their roles as both proxies and facilitators for the inclusion of users. Attempting to create an engaging workshop, we crafted a toolkit, composed of different creative tools (Figure 7), a small booklet with directions and questions as well as an Instax Polaroid camera. We sought to utilize tools in completing simple tasks that both introduced the proxies to their roles, and also let them reflect on those.

The sensitization was conducted by handing out the toolkit with a 20-minute introduction and discussion, as well as a small instructional chart answering questions they might have. We then left the toolkit at the center and did follow-up interviews in the coming days. Three introductory sessions were conducted with six participants over two workdays.

Figure 7. Sensitization toolkit

b) Picture Collaging

Similarly to [33], the recruiting of participants depended on recruiting for single sessions, as the activities needed to be timed according to schedules, existing practice, and depended on the day-to-day health, wellbeing, and needs of the users.

For the collaging session, one of the main goals was to co-create something intriguing for different people. The toolkit crafted consisted mainly of imagery targeted towards specific individuals as well as more generic imagery. The toolkit consisted of around 120 images, 40 words, and a large toolkit of creative artifacts (see Figure 8).

Figure 8. A large toolkit of creative artifacts

The images were chosen in several themes related to the design of technology, more specifically technologic

possibilities, interfaces, emotions, contextual, accessibility, and individual and diverse iconography. The sessions were conducted by handing out the different tools, then instructing and continually guiding the participants through the creative process. A total of five sessions were organized with 20 participants in a span of eight workdays.

c) Drawing

The drawing workshop was initially intended to be as extensive as the collaging workshop. However, due to time constraints, as well as an extended amount of time spent conducting the collaging session, only one participant conducted the drawing session. In [10], the drawing session is integrated into the collaging, but we chose to separate them to accommodate the experienced need for flexibility in conducting any activity.

3) Participant Interviews

The participant interviews were conducted to follow up on the generative sessions. The reason for conducting follow-up interviews was two-fold. First, they were conducted to make sure the social workers did not dismiss or reject the value of the workshops to innovate and design future solutions. Second, it was a reaction to the social workers not always being able to finish the sessions. We saw this as an opportunity for the social workers to discuss their thoughts surrounding the themes explored, even if they were unable to finish their participation.

B. Phase 2 – Results and Analysis

The data gathered through the three different activities in Phase 2 consisted of transcribed interviews, observation notes, discussion summaries, individual coding from workshops, photographs, resulting workshop artifacts, and Polaroid diaries. The analysis involved a coding process around two themes. First, *social workers' facilitation* emerged as a cluster of all concerns related to whether the social workers had been able to implement the design activities of workshops. This also included its tools and techniques, and to what degree they could facilitate the inclusion of people with ID into the activities. Second, *social workers' exploration,* gathered all observations of how the social workers utilized the presence and participation of the users to enact and explore ideas and assumptions about the capabilities of the users.

1) Results

A total of ten different generative sessions were conducted, along with seven follow-up interviews held in the span of ten workdays. 12 social workers actively participated in the generative workshops in collaboration with eight users. Without presuming to know the people with ID's health conditions, we consider user participants to be within profound to severe ID [34]. The users' age ranged from circa 35 to 60 years old with physical disabilities ranging from profound to negligible.

a) Social workers' facilitation

Throughout the generative workshops, the social workers included the users in the workshops as active participants, using the different generative tools as well as their knowledge about users' general capabilities. In discussions and interviews, the social workers focused almost exclusively on communicational aspects on how to include the users into the workshops, emphasizing their physical, cognitive, and language capabilities.

The social workers often described how they accommodated the user's cognitive capabilities. They also reflected on how to present choices. One such example was during the early stages, where one social worker reflected on asking leading questions and changing the wording after conducting the sensitization. In a group discussion following the sensitization, two social workers discussed how they had to change the wording of the sensitization kit.

In another workshop, two social workers used the morning meetings and introductory talks to discuss the possibilities for one particular user's participation. This user had had "a bad week", and the social workers who had been working with the user previously were apprehensive about how they could adequately include the user. In the introductory talks, one social worker explained and reflected on this user's need for social interaction to generate meaning. When they later worked with facilitating the user's participation, they specifically focused on how to make the activity social, using both the tools available and their knowledge of the user's capabilities. While they initially were apprehensive to include the user, they managed to co-ideate a paper prototype for a planning and communication tool.

b) Social workers' exploration

During the three generative sessions, we discovered how the social workers developed their understanding of the design problem through the users' participation in the same workshops. One main reason was that the social workers could exploit the presence of the users to explore assumptions about their capabilities and help navigate their own design ideas. To achieve this variant of mutual learning, the social workers would often use pre-existing contextual tools, the toolkits, or even co-crafted new tools to explore.

The social workers would also use the presence of the users to scaffold their understanding of how the users made choices and understood abstractions. In one instance, a social worker tested whether the user could make informed decisions on a screen-based interface by co-assembling two prototypes, one tangible and one screen-based (see Figure 9), based on a selection of activities that the user enjoyed. The two prototypes helped the social worker further explore

to what degree the user understood abstractions on the screen-based interface. This offered the social worker an even more in-depth understanding of the user's ability to make an informed decision.

Figure 9. Exploring how users understand abstraction with different interfaces

In another session, a social worker explored how the user would perceive and understand different examples of iconography and pictures by using the toolkit to create non-verbal means of communication based on their previous knowledge of the user's capabilities and familiarity with symbols (see Figure 10). By engaging in such activities, the social workers matured their understanding of the user's ability to comprehend different representations.

Figure 10. Symbols used to explore the user's ability to comprehend representations

Learning about such opportunities in the user's ability to participate offered great help in knowing how and when to involve the user in future proxy activities. The presence of users continuously confronted the social workers about their understanding of the user's capabilities, which sometimes turned out to be incorrect, or in need of adjustment. By participating in co-design activities, the social workers gradually matured their ability to give the people with ID a voice in a PD process. More comprehensive descriptions of how these situations of mutual learning unfolded can be found in [34].

C. *Phase 2 – Findings*

We summarize our findings around the two themes identified in the data during the analysis: *social workers' facilitation* and s*ocial workers' exploration*. The two themes highlight the observed case-specific discoveries relating to the overarching research question. The two themes are examples of how social workers acted as proxies in both facilitating the inclusion of people with ID into the design-making stages, and in turn, how this influenced the decision-making processes and explorations of possibilities that these generative techniques allowed.

1) *Social workers' facilitation*

This theme outlines our understanding of how the social workers utilized their knowledge about their users' capabilities to include them in the workshop using the tools that different techniques offered to facilitate for engaging user participation.

Initially, we intended the activities to engage the users passively in similar, albeit arbitrary, activities such as board games, artistic activities, or any activity that resembled the generative sessions. The results, however, uncovered that the social workers utilized their understanding of the users, their communicational capabilities, and understanding of practice and meaning, to include the users into the generative design sessions. This effectively made the users more directly involved in the design activities than initially intended.

2) *Social workers' exploration*

Throughout all stages of Phase 2, the social workers actively engaged the users in mutual learning. They explored their assumptions about users' capabilities and concrete ideas utilizing both existing and new tools to engage the users. The inclusion of the users also opened up possibilities for the social workers to explore through discussion with peers and researchers by sharing ideas and furthering their understanding of capabilities and technology. Finally, they also matured their understanding of how they could involve people with ID into generative design activities when serving as proxies. Table VI summarizes the two themes and related main findings.

TABLE VI. THE TWO THEMES AND RELATED MAIN FINDINGS

Themes	Main findings
Social workers facilitation	• Social workers can facilitate for engagement of user participation • Tools and techniques enable social workers to engage user participation
Social workers' exploration	• User participation let social workers inform themselves and the researchers about the users' capabilities • Social workers utilized and created tools to facilitate exploration • The social workers' exploration opened possibilities for discussing with peers and researchers

VII. USING SOCIAL WORKERS AS PROXIES TO FACILITATE PARTICIPATION

In the immersive nature of our PD process, taking on the role of a volunteer social worker gave us a possibility to create and embed mutual learning in the context on the premise of the users and social workers. In Phase 2, the basis for further exploring possibilities for participation of people with ID was built on an understanding of the context through the four themes presented as our intermediate learning outcomes. We operationalized these themes as six guidelines that helped us inform the use of tools and techniques as a means to enable participation from the user through the inclusion of social workers as proxies. Having engaged with users and their proxies in generative workshops now allow us to structure a discussion around our overarching research question: "h*ow can we facilitate design with people with different intellectual capabilities using Participatory Design?".* We have divided the discussion into two main arguments that reflect the core idea of the strategy we advocate for facilitating PD involving users with ID.

A. Enabling appropriate proxies can facilitate the inclusion of people with ID into all design stages

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 [24]. However, we argue that the social workers specifically constitute appropriate proxies due to their ability to break down language barriers (as seen in [23]) that may prevent equalized power relations. Both throughout the immersive process of Phase 1 and the generative sessions in Phase 2, the proxies were vital in bridging communicational gaps. This point is best exemplified by cases where the users relied on mixed forms of communication, e.g., hand signs, body language, and words, to express themselves. In such situations, both contextual knowledge and having the social workers explicitly tell you what they think the users were communicating, enabled participation from the users.

While conducting the different generative sessions in Phase 2, the social workers actively engaged the users in all stages, utilizing their knowledge about physical, communicational, and general cognitive capabilities to activate and engage them in design-making using both existing and new tools [35].

Balancing power relations is a common challenge found within PD [3, 5]. During both phases, the social workers' presence during activities increased the researchers' chances to successfully facilitate a space for mutual learning by supporting non-verbal and contextual forms of communication. Users were able 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 [2]. Facilitating sessions in a larger arena that allowed the users to practice collaborative working skills was seen as highly dependent on the presence of the social workers in our study, and other studies have suggested that this factor is often overlooked [25]. We also want to shed light on considerations related to the management of the design process [5] and advocate the use of social workers to help lower the threshold for participation as they know how to initiate design discussions without disrupting ongoing everyday activities. One such instance was during Phase 1 where the social workers approached us to discuss topics of interest. Another more prominent occurrence was in Phase 2, where the social workers actively engaged in planning when, where, and how we would conduct the different sessions, considering daily routines and needs of the users.

To engage the participants differently, we used contextual probes [22, 36], both as a way to circumvent users finding themselves in a "passive role" [30] due to communication barriers, and as means of sensitizing the proxies, forcing reflections on their roles as design-proxies and facilitators for user-participation [10].

B. The inclusion of people with ID by proxies lets proxies explore assumptions about user capabilities

The people with ID participating in the generative sessions could inform the proxies about their different capabilities *during* the decision-making stages of design. In the field PD, it is mutually agreed that the heart of the tradition is participation [9, 37]. Brandt et al. [9, p. 147] point to Wenger [38, p. 56] and their definition of participation in a community of practice as a "complex process that combines doing, talking, thinking, feeling and belonging. It involves our whole person including bodies, minds, emotions, and social relations". In our study, the bodily presence of people with ID helped enrich the design sessions, effectively giving the end-users another means of communicating needs [21].

While proxies constitute a vital part of bridging potential communication gaps and leveling power relations, we argue that generative tools and techniques, such as those described by [10], can open up the design space for the users by permitting different means of expressing wants and needs by utilizing channels of *telling, making and enacting* [9].

In Phase 2, we observed that despite substantial limitations due to physical and cognitive capabilities, people with ID contributed to decision-making, through the presence of either mind or body. This expands on earlier studies that focus on the inclusion of people with ID, and other cognitive limitations, into initial inquiries and later testing stages [6, 7, 19, 20]. In their respective studies, [6, 7], made it possible for users to "show, share and interact" in later testing stages by utilizing prototypes. Here, we enabled the proxies to "show, share and interact" during earlier stages, which granted the proxies a greater understanding of capabilities when ideating. We postulate that the inclusion of people with ID into the design-making makes it possible to fail fast and find solutions that better resonate with the end-users earlier in the design process.

Through different generative sessions in Phase 2, proxies utilized the tools available, both existing and new, to generate or verify knowledge about the users' capabilities. In their work, Brandt et al. emphasize enacting as an important component in any PD process, where we utilize the physicality and accessibility of the end-users to explore possibilities for future use: "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" [9, p. 164]. In the case of people with ID, who might be unable to express wants, needs, likes, or dislikes through traditional communicational means, we argue that the embodied means of communication becomes particularly important in exploring future use. In our study, the physical presence of the people with ID, and the possibility for proxies to enact scenarios of use by utilizing their knowledge about users' physical and communicational capabilities let them explore future possibilities of use.

VIII. Enabling People With ID to Participate

We consider the main contribution of this paper to be our proposed immersive strategy on how to include people with ID in PD processes by engaging social workers as facilitators. We have put forward and discussed the two overarching arguments of our approach: that the process can (1) enable appropriate proxies as the facilitators of the inclusion of people with ID in all design stages, and (2) let proxies explore assumptions about users' capabilities as they facilitate the inclusion of people with ID. Our findings demonstrate different ways the presence of social workers enabled dialogue in ways that supported non-traditional forms of communication, strengthened core principles of PD such as mutual learning, and allowed people with ID to engage in decision-making. As such, we consider our findings to contribute to ongoing discussions on a method level of how to engage people with ID in specific PD activities, as well as relevant to methodological discussions where we suggest using immersion as a strategy to facilitate long-term PD collaborations. We end the paper by positioning our propose strategy into two central discussions with the PD community, namely how our strategy builds on top of established forms of mutual learning and practice, and that it should be organized as a long-term commitment.

A. *The PD process should be built on top of already established forms of mutual learning and practice*

One core concept of PD is to enable participants to take control of their futures by affecting the technology that will help shape it [2]. 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. Havgar [39] 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 [40]. We argue that one of the essential reasons we have been able to include people with ID into decision-making processes has been based on utilizing established forms of mutual learning and practice.

However, in order to get to a 'starting line' [7] where inclusion into ideation is possible, we argue that immersion offers a chance to learn about everyday activities where people with ID and their social workers already have established mutual learning through their everyday activities. We have demonstrated how building on top of established means of communication may contribute to the participants accessing a sensation of mutual learning quicker [24], as well as taking more ownership of the design process and its outcomes [41]. Scaffolding the PD process around existing routines and habits allows for easier participation for social workers who find themselves in a busy work environment. This may also reduce misunderstanding as social workers are more familiar with the individual users and can assist the researchers in their interpretation of non-verbal forms of communication [42]. Lastly, we argue that building on top of already established practice, routines, and mutual learning has let us shape a PD process that omits problems such as described by Redhead & Brereton [3], that academic practice can be resisted by the local community.

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 [7]. 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 social workers' intimate knowledge of the situations. As such, we argue that long-term engagement is a way to converge on the uniqueness of each situation [6], as well as a way to avoid communities rejecting opportunities for collaboration due to short-burst facilitation [3].

Furthermore, we saw from our empirical context that committing to long-term engagement also contributed to both respect and trust [7], and the development of social relationships and skills [24]. This gave the activity center more time to familiarize themselves with our academic practice.

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."* [43, p. 15]. In these situations, the active engagement of social workers as proxies contributed significantly to adapting the process to both user needs and daily routines and practices. The long-term presence also meant that the social workers and researchers developed an understanding of how to work around issues such as the need for flexibility due to specific needs or physical and mental fatigue, a point also raised by [6, 19].

IX. CONCLUSION

This paper has reported from the exploration and facilitation phase of a long-term PD process involving people with ID and social workers as proxies. We have proposed using immersion as a strategy to elicit contextual concerns that can later shape tools and techniques applied in PD activities. Concrete experiences were used to demonstrate how we built a PD process on top of daily activities and routines of the people with ID at the activity center. The results from our empirical work highlight examples of how we have managed to enable long-term participation by finding new ways to achieve mutual learning and decision-making. Our proposed strategy emphasizes the vital role of the social workers as the enablers of participation from people with ID.

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