

Immersion as a Strategy to Facilitate Participatory Design Involving People With Intellectual Disabilities and Caretakers as Proxies

Shaping spaces for participation through contextual insight

Åsmund Dæhlen

Department of Informatics, Faculty of Mathematics and
Natural Sciences, University of Oslo
Oslo, Norway
email: aasmunkd@ifi.uio.no

Suhas Govind Joshi

Department of Informatics, Faculty of Mathematics and
Natural Sciences, University of Oslo
Oslo, Norway
email: joshi@ifi.uio.no

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 domain-specific 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 activities (e.g., swimming and field trips).



Figure 1. Illustrations being used as an alternative form of communication

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 1. OVERVIEW OF THE RESEARCH METHODS

#	Research method	Participants
A	Participatory inquiry	30 users and 15 employees
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 Employees

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 experts 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 explorative 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.



Figure 2. 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 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 2. 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 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.

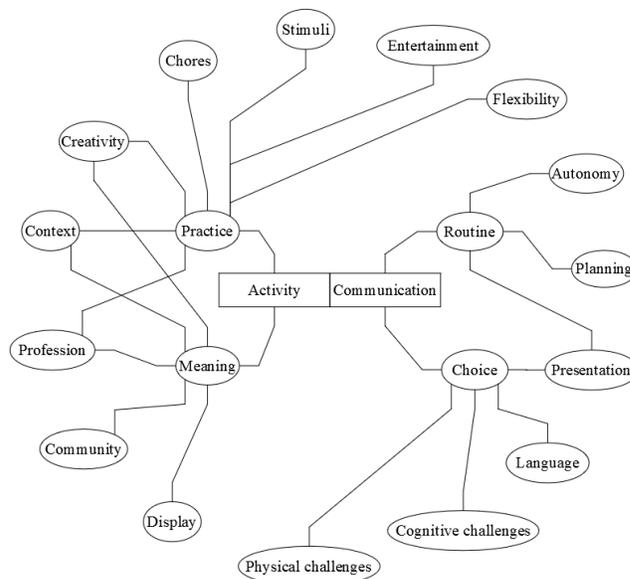


Figure 3. The result of the thematic analysis

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. 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.

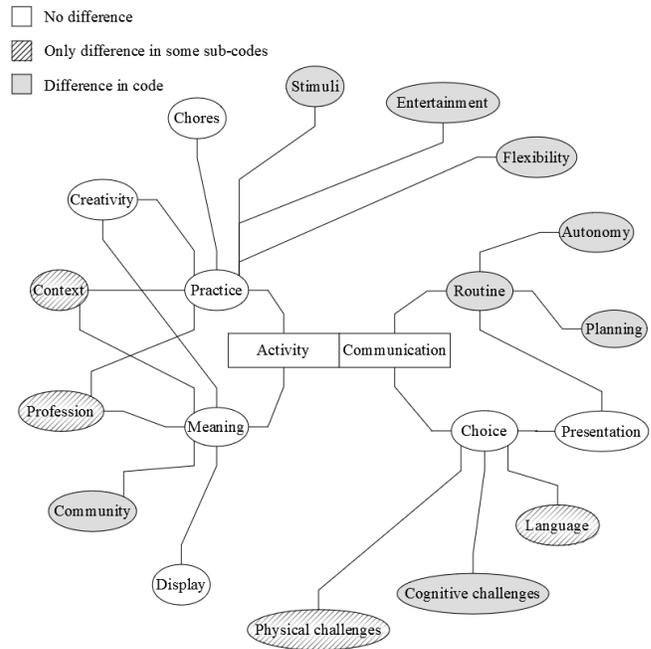


Figure 4. Distribution of difference in coding between the two researchers

TABLE 3. OVERVIEW OF THE FOUR THEMES AND MAIN FINDINGS

Theme	Main findings	Source	Key observations and quotes
Meaning (Activity)	<ul style="list-style-type: none"> Meaning emerges through the context in which the activities take place. The company of the caretaker can affect the way in which meaning emerges. 	[A], [C], [F]	<p>Users have individually tailored activities and contexts to situate specific kinds of meaning</p> <p><i>“Examples of meaning bearer are social relations, safety, predictability, well-being, change of environment, learning and acknowledgment.”</i> (caretaker, [F])</p>
Practice (Activity)	<ul style="list-style-type: none"> The practice involved in activities varies between users. Activities need to be flexible regarding duration. 	[A], [C], [E]	<p><i>“Some activities require 1-on-1 assistance depending on the individuals involved and the context in which it is carried out.”</i> (diary entry, [C])</p> <p><i>“During the first day, I had to end an activity with a user because I was requested to help with something else”</i> (diary entry, [C])</p>
Choices (Communication)	<ul style="list-style-type: none"> 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]	<p><i>“The user was presented with two alternatives, which I later discovered was a rather restricted choice considering the user’s capabilities”</i> (field note, [A])</p> <p>Representations of choices often require non-verbal forms of communication (see Figure 1, [B])</p>
Routines (Communication)	<ul style="list-style-type: none"> Structure and daily routines affect the users’ ability to participate. Routines promote autonomy by facilitating learning over time. 	[A], [C], [F]	<p><i>“For some users, it is a crisis to have a day off as it breaks routines”</i> (caretaker, [F])</p> <p><i>“One user was frustrated when I communicated that I had to leave early because it disturbed some of the users’ routines”</i> (diary entry, [C])</p>

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 us 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 has 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

[1] J. Perry and D. Felce, “Initial findings on the involvement of people with an intellectual disability in interviewing their

peers about quality of life,” *J. Intellect. Dev. Disabil.*, vol. 29, no. 2, pp. 164–171, Jun. 2004.

[2] J. L. Boyd-Graber *et al.*, “Participatory design with proxies: developing a desktop-PDA system to support people with aphasia,” in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 2006, pp. 151–160.

[3] T. Bratteteig, K. Bødker, Y. Dittrich, P. H. Mogensen, and J. Simonsen, “Organising principles and general guidelines for Participatory Design projects,” *Routledge Handb. Particip. Des.*, p. 117, 2012.

[4] M. K. Bahus, “bruker,” *Store norske leksikon*. [Online]. Available from: <https://snl.no/bruker> 2018.10.19

[5] M. Brereton, L. Sitbon, M. H. L. Abdullah, M. Vanderberg, and S. Koplick, “Design after design to bridge between people living with cognitive or sensory impairments, their friends and proxies,” *CoDesign*, vol. 11, no. 1, pp. 4–20, Jan. 2015.

[6] M. Dawe, “‘Let Me Show You What I Want’: Engaging Individuals with Cognitive Disabilities and Their Families in Design,” in *CHI ’07 Extended Abstracts on Human Factors in Computing Systems*, New York, NY, USA, 2007, pp. 2177–2182.

[7] C. Putnam and L. Chong, “Software and technologies designed for people with autism: what do users want?,” in *Proceedings of the 10th international ACM SIGACCESS conference on Computers and accessibility*, 2008, pp. 3–10.

[8] J. Blomberg and H. Karasti, “Positioning ethnography within participatory design,” *Routledge Int. Handb. Particip. Des.*, pp. 86–116, 2012.

[9] H. Holone and J. Herstad, “Three Tensions in Participatory Design for Inclusion,” in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, New York, NY, USA, 2013, pp. 2903–2906.

[10] F. Redhead and M. Brereton, “Growing local participation through long term design,” in *Proceedings of Participatory Innovation Conference 2012*, 2012, pp. 1–4.

[11] N. Moraveji, J. Li, J. Ding, P. O’Kelley, and S. Woolf, “Comicboarding: using comics as proxies for participatory design with children,” in *Proceedings of the SIGCHI conference on Human factors in computing systems*, 2007, pp. 1371–1374.

[12] P. Francis, S. Balbo, and L. Firth, “Towards co-design with users who have autism spectrum disorders,” *Univers. Access Inf. Soc.*, vol. 8, no. 3, pp. 123–135, Aug. 2009.

[13] N. Hendriks, L. Huybrechts, A. Wilkinson, and K. Slegers, “Challenges in doing participatory design with people with dementia,” presented at the Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - Volume 2, 2662196, 2014, pp. 33–36.

[14] M. Brosnan, S. Parsons, J. Good, and N. Yuill, “How can participatory design inform the design and development of innovative technologies for autistic communities?,” *J. Assist. Technol. Hove*, vol. 10, no. 2, pp. 115–120, 2016.

[15] M. Crang and I. Cook, *Doing ethnographies*. Sage, 2007.

[16] T. Robertson, T. W. Leong, J. Durick, and T. Koreshoff, “Mutual learning as a resource for research design,” in *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts - Volume 2*, 2014, pp. 25–28.

- [17] V. Braun and V. Clarke, "Using thematic analysis in psychology," *Qual. Res. Psychol.*, vol. 3, no. 2, pp. 77–101, 2006.
- [18] H. Hutchinson *et al.*, "Technology probes: inspiring design for and with families," in *Proceedings of the SIGCHI conference on Human factors in computing systems*, 2003, pp. 17–24.
- [19] P. Börjesson, W. Barendregt, E. Eriksson, and O. Torgersson, "Designing Technology for and with Developmentally Diverse Children: A Systematic Literature Review," in *Proceedings of the 14th International Conference on Interaction Design and Children*, New York, NY, USA, 2015, pp. 79–88.
- [20] J. Halse, Ed., *Rehearsing the future*. Copenhagen: The Danish Design School Press, 2010.
- [21] P. K. A. Havgar, "Designing for Intellectual Disability: Combining User-Centered Design and Research through Design," *Master Thesis Univ. Oslo 2016*, 2016.
- [22] S. G. Joshi, "Emerging ethical considerations from the perspectives of the elderly," presented at the CaTaC'14: Culture, Technology, Communication: Celebration, Transformation, New Directions, Oslo, Norway, 2014, pp. 186–203.
- [23] C. Bigby, P. Frawley, and P. Ramcharan, "Conceptualizing Inclusive Research with People with Intellectual Disability," *J. Appl. Res. Intellect. Disabil.*, vol. 27, no. 1, pp. 3–12, Jan. 2014.
- [24] L. C. L. de Faria Borges, L. V. L. Filgueiras, C. Maciel, and V. C. Pereira, "Customizing a Communication Device for a Child with Cerebral Palsy Using Participatory Design Practices: Contributions Towards the PD4CAT Method," in *Proceedings of the 11th Brazilian Symposium on Human Factors in Computing Systems*, Porto Alegre, Brazil, Brazil, 2012, pp. 57–66.