Using Participatory Design with Proxies with Children with Limited Communication

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ABSTRACT
Including children with communication disorders in the participatory design and evaluation of digital technologies is challenging, as communication between designers and users — an important part of this approach — can be impacted. Using *Participatory Design with Proxies* (PDwP) supports the inclusion of input from different stakeholders, such as parents, teachers and *Speech-Language Pathologists* (SLPs), who can provide valuable insight and feedback to augment direct input from users, which may be severely limited. We describe how we used PDwP to design a digital living media system that motivates children with disabilities to use digital therapeutic and learning applications and supports communication and collaboration between users. We employed an iterative design process to fabricate three functional prototypes and used them as design probes in participants' home and school settings. We present lessons learned in the form of the strengths and shortcomings of using PDwP for designing systems for children with limited communication abilities.

Author Keywords
Participatory Design with Proxies; Children with Disabilities; Digital Living Media Systems

ACM Classification Keywords
H.5.2. User Interfaces: User-centered Design

INTRODUCTION
A challenge for conducting *Participatory Design* (PD) with users with disabilities is that some disorders severely limit users' communication abilities, making it difficult to gather, interpret and incorporate feedback directly from them [47]. Given the importance of including users with disabilities in the design process of assistive technologies, it is important to explore and refine methodologies that support inclusion despite difficulties [34, 38]. Many such tools and methods are being developed to address these difficulties, including alternative communication tools and techniques for design that are not solely focused on verbal or written mediums [47], and methods for the "designerly" re-interpretation of data gathered from participants [13]. One such approach, *Participatory Design with Proxies* (PDwP), is a variation of PD in which proxies are also included in the early stages of design to gather domain knowledge about a particular design [8, 23]. Proxies are individuals who are very familiar with the target users or who resemble them closely. This approach has been used successfully in the past to design systems with both adults with disabilities [8] and children with disabilities [23].

In this paper, we explore the strengths and weaknesses of PDwP, in the design of an ambient digital living media display that motivates children with disabilities that limit communication abilities to use *target applications* (i.e., digital applications with therapeutic and/or learning outcomes) and communicate more with others. *Digital living media systems* are systems that combine living organisms and electronic components [18, 19]. In this paper, we focus on describing how, when designing one such system, we applied PDwP to gather and interpret useful insights that might otherwise have been impossible to access. We describe the formal evaluation of the system elsewhere [19].

In the next section, we present a review of the research literature on the use of PD with children with and without disabilities. Next, we describe our design process in which we designed and used 3 functional prototypes to gather input from various stakeholders, including *Speech-Language Pathologists* (SLPs), teachers, parents and children. We describe how we used the PDwP method to combine our observations of the children's behavior and feedback from their adult communication partners to interpret the data and address research questions. We conclude with a series of lessons learned.

BACKGROUND
Participatory Design (PD) [40, 42] is a design methodology that emphasizes the incorporation of user domain knowledge and recognizes the importance of collaborating and co-creating technology with users and their community. An essential technique of PD is to actively engage users of technology in its design. Originally, PD was used to develop technologies for the workplace; however, it became apparent that it also offers great value to many other areas

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of design and development including designing for users with disabilities [29] and specifically designing with children with disabilities [1, 14, 26]. *Participatory Design with Proxies* (PDwP) is a variation of PD in which proxies, people who are familiar with the target users or who resemble them, are included in the early stages of design to gather domain knowledge about use scenarios [8, 23].

Several PD methodologies have been developed specifically for including children in the design process. *Cooperative Inquiry* is specifically developed to allow children to be design partners and collaborate with adults to come up with novel design ideas [11]. The method views children as potential designers and aims to facilitate their abilities to be design partners through accessible and intuitive methods. It is typically used with small groups of children over long periods of time. Guha et al. are developing an inclusive version of Cooperative Inquiry that provides provisions for involving children with disabilities [17]. Other related approaches view children as co-designers, and include Bonded Design [31] and Informant Design [41]. Moraveji et al. used comics and storyboards as tools to engage children in PD [35].

Participatory Design with Children with Disabilities

Frauenberger et al. have argued strongly for engaging children with disabilities and their community in the participatory design and evaluation of computational interfaces, arguing that the three identified benefits of using PD, namely 1) better understanding of requirements, 2) building realistic expectations in target groups and 3) empowerment of marginalized groups, are amplified in this context [14].

Several projects have used PD to work with children with disabilities to develop new technologies. In the ECHOES project, Frauenberger et al. worked with two high-functioning children on the Autism spectrum and one child with an undiagnosed language disorder, and 30 typically developing 6-years-old children, on the design of a technologically-enhanced learning environment to scaffold the social skill development of both typically-developing children and children on the high functioning end of the Autism spectrum disorder [13, 15]. The researchers found that working with children provided information that otherwise would have been difficult to obtain. Additionally, they found the importance of finding a balance between the benefits of participation and the risks of causing stress or pressure. Finally, they found it essential to interpret and translate children's feedback and ideas into realistic and practical design choices using a "designerly" approach in such a way that the interpretations stay true to the core messages of the children's ideas [13].

The ECHOES project was inspired by the *Reactive Colours* project*,* which included children on the Autism spectrum as key informants in the design of an interactive software system, *ReacTikles* that provides users with engaging and relaxing activities [28]. The researchers used surveys and interviews with the children's parents to gather feedback about prototypes that they then incorporated into the next iterations of their system. Similarly, Piper et al. included children on the Autism spectrum, in the development of SIDES, a cooperative tabletop computer game for social skills development [36]. They found that interviewing children one-on-one put a lot of pressure on the child and decided instead to conduct interviews in groups.

Brederode et al. involved children with different physical and learning disabilities as design informants in the development and evaluation of *pOwerball*, an augmented reality tabletop tangible game to encourage collaboration and social interaction for children with mixed abilities [9]. This entailed a combination of interviews and observation sessions with children to gather insights that they incorporated into the system. They further evaluated the system with children with and without disabilities. The researchers argued that the child design informants' involvement provided useful insider information about their likes and dislikes about the game and created empathy and understanding between the researchers and the children without creating much stress or pressure.

Several research projects have developed new methods and tools to involve children with different disabilities in the participatory design of new digital systems. These tools and methods include the use of templates and personas [33], low-tech mockups [5], group interaction with prototypes [2], and peer interviews [40].

Including individuals with significant communication and language disabilities in PD can be challenging because of their limited expression when expressing their needs and desires [10, 23, 30]. In the case of children, this is compounded because it can be harder for them than for adults to participate in abstract or hypothetical discussions and scenarios. For these reasons, some researchers have also employed caregivers as "proxy users" to explore the needs of individuals with disabilities [8]. In the case of children, proxy users can include the children's parents, teachers and other individuals who are familiar with them. However, it is clear that working with proxies is not the same as working directly with the users of technology [42] and it should only be used when working directly is impossible because of barriers such as very limited communication or access [42].

Several recent projects have explored using PDwP to design various systems, including serious games and intervention systems. Hirano et al. used a PDwP method to design and evaluate, *vSked*, a visual scheduling tool to support classroom activities for children on the Autism spectrum [23]. To inform their design, they identified and included adult stakeholders (10 teachers and 3 SLPs) as design partners and conducted interviews with them and observed their classrooms and sessions over nine months. They incorporated the results into a working prototype that they co-examined with their design partners. Using stakeholder feedback, they refined the working prototype which they then evaluated with student users in the classroom. The researchers found that incorporating adult stakeholders in the design process was helpful in building a relevant product. In another similar project, Kientz et al. described the major social and behavioral difficulties of working directly with children with disabilities as design partners, and mitigated this using the help of adult proxies (caregivers, parents and teachers of children on the Autism spectrum) to inform the design of a wearable interface to detect self-stimulatory behavior in the children [30].

In another project, Dawe used a “technology probe” (i.e., an early prototype) to develop a communication application for individuals with cognitive disabilities [10]. The probe was developed based on qualitative data (interviews with 20 families of children with cognitive disabilities). It was used to elicit suggestions and ideas from two individuals with cognitive disabilities and their families. Dawe argued that using a technology probe could be an effective tool for the inclusion of individuals with significant cognitive disabilities in the design process as it facilitates dialogue. The concrete instantiation helped overcome difficulties in engaging in abstract or hypothetical discussions. Additionally, Dawe observed that having a concrete object (even in early versions) that can be modified in response to users’ suggestion and requests can create ownership and empowerment in users [10].

Thus, previous research show that 1) by including a variety of users and stakeholders in the design process, valuable domain expertise can be uncovered [45], and 2) an important aspect of including users with limited communication in the design process is identifying appropriate communication tools and protocols (i.e., alternatives to spoken or written language) that allow for the expression and integration of their input [38]. We take these results into account by including a diverse group of stakeholders, and by using functional prototypes or probes [26] to elicit feedback. While PDwP has been employed as a methodology in the past, none of the previous projects, to our knowledge, have explored the impact of using it for facilitating access to context-dependent data, such as results that emerge from observing the spontaneous use of a system in the home setting, and in interpreting the impact of interactions beyond the immediate context of use.

DESIGNING A DIGITAL LIVING MEDIA SYSTEM FOR MOTIVATING CHILDREN

Rafigh is a digital system that uses the growth of a living media interface, a living mushroom colony, as a component of its interface. Its purpose is motivate children with disabilities, in a home or school setting, to (1) use digital target applications with positive outcomes, and (2) encourage collaboration and communication between children and their adult communication partners (i.e., teachers, caregivers). It consists of a physical enclosure that houses the mushroom colony and an irrigation system controlled by an embedded computer. Rafigh is designed for use in the home or school setting.

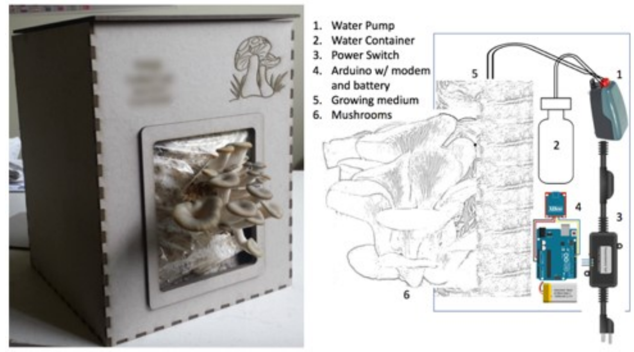

Figure 1. Rafigh (Prototype 3): the physical prototype (left), schematic with component names (right)

Rafigh (Figure 1, left) consists of a physical enclosure that houses a mushroom colony and an irrigation system controlled by an embedded computer. It is designed to be used in conjunction with a customizable suite of 3rd-party digital applications, which we term “target” applications due to their desired therapeutic and/or learning-based anticipated benefits. The choice of target digital applications is a parameter of the system; it is delegated to the child's parents, teachers, SLPs, or other stakeholders who determine the desired therapeutic and/or learning outcomes. Rafigh monitors the use of target digital applications; the more the children use them, the better the adherence to an optimal watering schedule resulting in faster growth. Figure 1 (right) shows the system schematic.

The mushrooms take between 10-16 days to completely grow. For the first few days, there is little change in the visual appearance of Rafigh but in the last 4-5 days of growth the appearance of the mushrooms is more dynamic and visibly changes every few hours. Figure 2 shows the growth of Rafigh over time.

Figure 2. Rafigh's growth over time

Designing Rafigh using PDwP

The current project aimed to study how digital living media systems can (1) better motivate children to use therapeutic and/or learning applications, and (2) support more collaboration and communication between them and their adult communication partners. Work on this initial question lead to another research question: What is an appropriate participatory methodology to design engaging technologies for children with limited communication capabilities? In this paper, we focus on this methodological question.

We decided to frame the research project using the *Research through Design* (RtD) methodology. RtD is used in HCI research to conduct experiential inquiry into a design space through the iterative design and evaluation of artifacts [48, 50]. In this approach, the design and deployment of prototypes, as well as, critical analysis of their affordances and implications, are the primary modes of inquiry [4, 48]. RtD supports the inclusion of multiple stakeholders and multiple points of views and encourages participatory methods [48].

The first phases of RtD, prior to iterative design and reflection phases, involve defining the focus of a project and collecting and synthesizing data to inform it. We conducted a literature review and a series of interviews and focus groups sessions with SLPs. We have reported the results of the review and SLP interviews elsewhere [21] and here briefly summarize their results.

The literature review identified the potential of *Tangible and Embedded Interfaces* (TEIs) for engaging children in the context of communication and behavior intervention, with diverse projects supporting artistic expression [6], collaboration [12] and speech language therapy [18], emerging in recent years. TEIs, also known as *physical* or *digital manipulatives* [50], are characterized by electronic microcontrollers, sensors and actuators that are embedded in either existing or newly designed physical objects [27]. They go beyond the traditional computer screen to engage movement and make the user experience more engaging and accessible. TEIs can be physically more expressive and flexible than traditional desktop interfaces, allowing for the development of novel interfaces that incorporate emotional and ludic cues to the child [50]. *Automatic Speech Recognition* (ASR) has also been previously used to engage children's speech but is found to present challenges in the automatic creation and presentation of meaningful and accurate feedback [3, 21, 44].

SLP interviews consisted of one-on-one, open-ended interviews with 5 SLPs who work with children. Each interview lasted between 45 minutes and an hour. Additionally, we conducted two focus group sessions with SLPs. Three SLPs attended the first meeting and four SLPs attended the second. These sessions lasted between one and a half to two hours. During the interviews and focus group discussions, we asked the SLPs about a possible computational software or hardware solution that could support their practice. We categorized the data into the following 5 design themes:

Intervention-focused Activities: The SLPs believed that a digital system to complement therapy and support communication and collaboration in settings outside of the clinic (e.g., home or school) would be useful. They identified technology's potential to capture children's attention, stating that an interactive toy can be useful if it motivates children to complete complementary speech language exercises at home. Additionally, they stated that it is important that automatic feedback, if provided, be accurate and consistent.

Engagement: The SLPs stated their desire for a digital toy that can sustain the children's speech exercises in the absence of SLPs. They stated that a challenge they often faced was the children's lack of engagement with therapeutic and learning exercises.

Customization: The SLPs identified the need for making the system customizable for each user. They stated that in their practice they customize exercises and intervention activities for each client.

Context of Use: The data indicated a strong need for increased practice of speech and language skills in the home, as well as, school settings. The SLPs emphasized the key role of close family members (e.g., caregivers, parents, siblings), as well as, peers and teachers as communication partners with whom the children can practice language and speech skills. This result points to the importance of considering both *how* and *where* the system is used.

Technological Instantiation: Three of the SLPs already use props such as dolls and physical toys, as well as, images and flash cards to engage children. These toys allow for the development of narrative and the engagement of the children's attention. They stressed that it is useful to have physical toys that children can touch and grasp and are also durable. Two of the SLPs used therapeutic iPad applications regularly to engage their clients.

Based on these results, we developed a general design concept that we used in subsequent PDwP sessions as a communication and discussions tool and consisted of the following description:

Rafigh is an interactive digital system in the form of a digital physical system to support communication and collaboration for children with language and communication disorders in the home setting.

The following series of PDwP sessions were conducted *in situ*. These contexts included the children's school and home settings (as opposed to the lab or clinic settings). In previous research, the importance of using *in situ* evaluations for assistive technology [25] and ubiquitous systems [37] is emphasized. This approach provides higher internal validity and can uncover factors that might go undetected otherwise.

Design Iteration 1

The first series of collaborative design sessions consisted of four one-hour sessions over 4 weeks, with a participating special education teacher (A1) and a 4-year-old boy with speech delay (P1) at a local special education school. At the time of the sessions, A1 had administered speech and language exercises to P1 for close to three months.

During the first 2 sessions, we used the design concept developed above to brainstorm with A1 and also observed the intervention activities and exercises she was using with P1. The exercises consisted of speech drills with animal names and numbers that P1 responded to with vocalizations that sometimes resembled the words but were not clear. A1 used low-tech toys and pictures to emphasize target words and phrases. She suggested that we develop a system to prompt P1 with similar words and provide rewards when they are repeated.

Figure 3. Prototype 1 with LED lights and enclosure (left) and with internal electronics exposed (right)

We incorporated observations from these sessions, input from A1 and results from the literature review and SLP interviews (presented above) into a first prototype, Prototype 1 (shown in Figure 3). Prototype 1 was a tangible cardboard box that housed a microcontroller, LED lights and a bubble blower. The user could activate the lights and bubble blower by repeating after audio and image prompts from a laptop computer that the prototype was placed next to. The software for Prototype 1 consisted of a graphical user interface that prompted the user with a series of animal names. When the child user repeated the words correctly (as determined by an ASR module), the LED lights and bubble blower were activated.

In the next two sessions, we brought Prototype 1 to the school and showed it to A1 and P1. P1 initially showed signs of interest in the water and bubble blower and was happy when bubbles were produced. However, the system did not motivate him to use his speech more: he did not respond to the speech prompts and did not show interest in the software interface. He kept touching different parts of the system and eventually pulled out several of the LED lights. He showed particular interest in the physical box and the electronics inside. He lost interest in the system after about 10-15 minutes.

A1 made several comments and suggestions about the prototype. First, she identified making the system more engaging for P1 as a key requirement. She suggested that an engaging mechanism should be employed that can keep P1's attention over longer periods of time. Additionally, she suggested that the limited software component of the system could not adequately keep P1 interested.

"Both the application and toy have to use brighter colors, more exaggerated sounds, maybe it should be a game they can play. Children this age get distracted easily, you need to make the playing more fun!"

Second, she suggested that if two or more children could use the toy, its appeal might increase. She emphasized that the system should support intervention in the home with complementary exercises. She suggested the family of the child user should be engaged in the intervention. Finally, she observed that P1 liked to touch the system and pull and push on its components. She stated it is important that the system be more robust and have a stronger structure that makes it possible to leave it with the child user over time.

Design Iteration 2

Based on results from sessions with Prototype 1, we decided to design a more engaging and robust prototype. A key outcome of our sessions with prototype 1 was the need to implement an effective means of engagement. We reviewed both the research literature on developing engaging applications for children and the space of existing commercial toys and applications for children. We were inspired by popular toys that simulate living pets, such as *Tamagotchi*, *AIBO* and *Furby*, to explore the idea of using changes in the appearance of living media to engage children. User studies with the *Paro* system, which consists of a responsive physical seal robot, has shown that it can successfully engage and relax both children on the Autism spectrum and elderly users [41, 48]. While simulated toys are easy to control algorithmically, there has also been concern about the possibility of them confusing or disappointing child users when they realize that the system is not alive [43]. We decided to experiment with real living media, to avoid causing these negative emotions in our users and also to study the possibility of combining living media and digital technology in this domain. In this paper, we focus on the design methodology of the system and provide a detailed discussion of previous work on digital living media systems elsewhere [19].

Prototype 2 consisted of a physical housing made from repurposed iPad covers that contained the living media, a living mushroom colony with an initial spore-based state, connected to a micro-controlled irrigation system. The growth rate of the mushrooms was controlled via the watering strategy, which is mostly linearly correlated to growth (but should not involve overwatering, which is detrimental). We also developed an iPad software application for use in conjunction with the system. The application consisted of a story reading activity for the children. The amount of time that the software application was used correlated positively with the amount of water that was administered to the mushrooms. Figure 4 shows Prototype 2 with grown mushrooms.

Our motivation for incorporating the living media was the conjecture that the children would be curious to use the application to see the mushrooms grow faster. The children would have a chance to care for the mushrooms during interaction, possibly being engaged through dynamics of empathy and responsibility. Additionally, we had designed the system to be used collaboratively by the children and be left at their home, a feature that could potentially support increased collaboration and communication between them.

Figure 4. Prototype 2 with mushrooms and iPad

When selecting the specific living medium, we considered potential risks and made provisions to address them. First, we considered the possibility that interacting with living media might pose a physical health risk for the children. Living media, and organic materials in general, if not treated properly can become toxic. Given this possibility, we decided against using plants, such as pea shoots or lentils that need to be planted in soil and compost. We instead chose to use mushroom kits specifically designed and tested for use by children. The kits consist of a growing medium, typically composed from used coffee grounds and inoculated by oyster mushroom spores (the *P. ostreatus* species). Both the mushrooms and the organic material in which they are housed are non-toxic.

Second, we considered the possibility of emotional risks. During interaction with living media, the life forms might die. This situation can pose emotional stress, especially to children, who might hold themselves responsible for the death. Given this possibility, we decided against using sentient animals such as gold fish or sea monkeys as living media because their deaths might have caused emotional distress to the children. Using non-animal life forms, such as mushrooms, in applications that benefit human users is in accord with ethical recommendations by Harvey et al. [18]. Additionally, in the design we provisioned for a scenario when the children do not use the applications, in which case, we would still provide a small amount of water to the mushrooms. Conversely, we would avoid overwatering the mushrooms by limiting the maximum amount of water that can be administered. These provisions mean that the mushrooms cannot be killed through the interaction and only their growth rate can be influenced.

We tested Prototype 2 in the lab for several weeks to verify that we can use it to grow mushroom colonies successfully. We identified several structural problems with the prototype, including a need to separate the electronic and organic components, and to place a lock to avoid tempering by child users. Additionally, our initial experiments with the iPad software application showed that having one application severely limits the usefulness of the system. Thus, we decided to restructure the microcontroller software such that it can be remotely controlled and input with the usage information of a suite of target applications. We incorporated the above insights into Prototype 3.

Design Iteration 3

Prototype 3 (Figure 1, left) consists of a custom-made laser-cut box with separate partitions for a living mushroom colony and a remotely controlled irrigation system that dispenses water based on the child users' usage of target digital applications.

We used Prototype 3 in two separate series of design sessions conducted over 2 weeks in home and school contexts. In each series of design sessions, two children with limited communication and one adult proxy participated. We describe the sessions next.

Prototype 3 in the Home

In the first series of design sessions with Prototype 3, two siblings, a 13-year old boy (P2) and a 10-year old boy (P3), and the children's mother (A2) participated. The siblings, both P2 and P3, both were on the Autism spectrum (P2 on the severe end and P3 on the mild end). A2 is a full-time caregiver and takes care of the children at home.

After contacting A2 and learning about her interest in the project, we started the design sessions with two 1-hour conversations with her. During these sessions, we introduced the project to A2 and asked her to tell us more about P2 and P3. She stated that P2 and P3 rarely communicate with people they are not familiar with (including us). She wanted them to try using learning and therapeutic digital applications expand their vocabulary, improve their communication skills, and to collaborate and communicate more with each other and with her. When we showed her a series of target applications we had identified, she wanted to try to see which ones P2 and P3 would be interested to use. She stated that it is often hard to predict which applications P2 and P3 would like or not. In the past, P2 and P3 had occasionally used some applications (mainly on the family computer before) but they were not using any application on a regular basis.

After the initial sessions, we left Prototype 3 at the participants' house for two weeks. We visited the participants' home approximately every 4 days during this time to collect observations and input from A2. Each visit would last between half an hour to an hour. During this time, we did not talk directly with P2 and twice talked briefly with P3 in A2's presence. We asked A2 to describe how the system worked to the child participants. When we first brought Prototype 3 to the participants' home, A2 placed it on an easy-to-see counter in the kitchen and said that this would make it easy for P2 and P3 to see the mushrooms grow.

In our subsequent visits, A2 stated that P3 had become very interested in the mushrooms' growth and checked them regularly. P2, however, was not interested in them and was more interested in the digital applications. A2 also stated that, together with P2 and P3, she had found several learning applications that the children liked and she had decided that they could use those as target applications. She observed that including the children in the application selection was important.

During the second week, when the mushrooms' growth was more visible, A2 reported that P3 had asked several times about how large the mushrooms would get and had told P2 to use more digital application so the mushrooms would grow more. During this week, P2 and P3 had spent more time together using digital applications. P2 had mentioned the prototype at school and had also shown it to some relatives who were visiting. At the end of the two weeks, once the mushrooms were harvested by A2, she said that P2 had expressed interest in using the prototype to grow mushrooms again.

Prototype 3 in the School

In the next and final series of design sessions, we used Prototype 3 in a school context with two children with Cerebral Palsy and an adult school psychologist (A3). The child participants (P5 and P6) were both 13-year girls who were non-verbal and experienced severe motor impairment arising from Cerebral Palsy; P5 and P6 use alternative communication protocols, including picture books and idiosyncratic systems of head gestures, but not sign-based communication systems/languages. They did not use assistive technologies or alternative means for computer access. A2, P5, and P6 had been working together for about 2 years. However, their communication was limited and they did not use sign language.

During 3 collaborative sessions, each lasting between 20-40 minutes, together with A3, we discussed how Prototype 3 should be adapted for use by the child participants. A3 described that a key task for both P5 and P6 would be to try to learn to use new computer-based *augmentative and alternative communication* (AAC) systems. Prior, both children had tried unsuccessfully to use computers for communication. A3 stated that the most promising options had been single-switch scanning software. *Scanning* refers to a widely-used computer access method in which choices (e.g., letters, words, phrases) are periodically highlighted on a computer screen and the user can select them using a variety of alternative input techniques, including single physical switches or puff switches [7]. According to A3, the children's attempt to use scanning software and a variety of input devices (i.e., puff switches and single switches) had been unsuccessful because (i) using them was difficult and required a lot of practice and effort and, (ii) it was hard for the children to stay interested in performing repetitive tasks such as selecting letters to type their names.

Figure 5. Prototype 3 in the school setting, with custom made switch and projected computer display.

Given this background, A3 suggested that we use Prototype 3 to motivate the children to use the scanning software. With her help, we prepared a setup with a single switch used to control a desktop scanning application, *JClic Fressa* (http://jclic.softonic.com) that helps children practice scanning selection and supports vocabulary development by requiring users to select words that correspond to colors and articles of clothing. Figure 5 shows the set up at the school.

Following the setup, we conducted a series of 6 observation sessions (each between 30-60 minutes) over 20 days with P5 and P6. During the first 2 sessions, each child participant used the target application on its own, and for the next 4 sessions they used Prototype 3 in conjunction with the target. A3 described how the prototype worked to P5 and P6 when it was introduced in the third session. During the sessions, the children could decide how long they wanted to use the prototype, with continuous monitoring by the school psychologist (checking with them every 3-5 minutes to see if they wanted to continue).

We recorded application use times for each child during the sessions. Additionally, A3 took note of any comments the children made about using the application or Prototype 3. Since the child participants were non-verbal, A3 used a small number of questions that the children could reply to using gestures, non-speech vocalization and low-tech communication protocols.

The use-time data showed that, on average, both child participants used the target application longer when used in conjunction with Prototype 3 than on its own (by almost twice as much for P5 and three times as much for P6). A3 stated that, in the presence of Prototype 3, she observed signs of curiosity and interest in both children, especially when they saw the mushrooms growing:

"*She (P5) was interested from the beginning but P6 became interested only when she could see the mushrooms growing. They both mentioned the system in between the sessions.*"

A3 observed that having the physical prototype in the space helped stimulate conversation among other teachers, staff and students who were not directly involved in the project. She stated that given that P5 and P6 are non-verbal, including them in conversations with other students has been challenging. She indicated that several students and teachers commented about Rafigh upon seeing the mushrooms growing and talked to her and P5 and P6 about the project. She believed that placing the prototype in a public visible location was important for this result.

A3 believed working with living media, especially over a long period of time, has the potential to create positive feelings of empathy and responsibility in the children. She suggested that maybe several instances of the system could be set up in a garden that children could grow together by completing therapeutic activities over an extended period. She stated that the children did not clearly know how their collaborating with each other helped grow the mushrooms.

Summary of Design Iteration 3

The feedback from the final series of design sessions was promising and provided evidence that Rafigh motivated children to use the target applications more often and to create more communication and collaboration in home and school contexts. It also revealed several considerations including 1) the importance of involving users in choosing target applications, and 2) the impact of the location where the system is placed. We will include these insights in Rafigh's usage instructions. The design process also revealed several important features of the PDwP approach that we will discuss in the next section.

LESSONS LEARNED

Overcoming logistic and privacy barriers: Given that Rafigh is an ambient system for use in the home or school settings, gathering ecologically valid data about its reception in its context of use poses challenges which were mitigated by the PDwP approach. For instance, we needed the ongoing observations of the adult participants to understand the impact of having Prototype 3 in the children's home and school settings. Using other data-collection schemes, such as video recording or frequent researcher visits, can be disruptive to the family and school staff and can affect the way the children interacted with the system. Thus, using PDwP helped us overcome logistical and privacy barriers. This feature is especially useful for the evaluation of ambient systems in their context of use.

Understanding system impact beyond the individual: Similar to results from previous research [10, 23, 30], we found that working with proxies can provide insight into the impact of the interaction beyond an individual user and outside of the immediate context of use. One of the goals of Rafigh is to increase its users' communication with others. When conducting design sessions with Prototype 3, the proxies provided data about how the prototype had increased child participants' communication with others in both home and school settings. It would have been difficult to find this result without input from the proxies who were observing the children's interaction with others at times other than when the prototype was present.

Overcoming communication barriers: In accordance with previous research [8, 10], we found that using the PDwP approach can successfully overcame communication barriers. In our experience, when conducting the design and evaluation sessions with children, we relied on the adult participants who were familiar with the children to interpret and to communicate insights about the interaction to us. Developing alternative communication protocols and learning to interpret them successfully takes a long time and sometimes requires special expertise (e.g., when using communication protocols). Without the help of proxies, we could not gather input about the prototypes easily.

Indirect representation: When using PDwP, it is important to be aware that the input from the proxies might not necessarily be representative of actual users [42]. Researchers and designers must be aware that while helpful, input from proxy users is not the same as that from actual users. Data reported and interpreted by stakeholders might be impacted by their biases. PDwP should only be used when researchers cannot work directly with the user population and input from proxy users should be verified whenever possible and frequently with members of the target user population. Another related challenge with using PDwP is that data reported and interpreted by stakeholders might be impacted by their biases. When evaluating Prototype 3, we used both qualitative and quantitative data to investigate the interaction.

CONCLUSION

Including participants with limited communication in the participatory design of technology is challenging. We used an iterative *Participatory Design with Proxies* (PDwP) process to better identify the potential of this approach for designing new systems with children with limited communication. We found that using PDwP can provide flexible ways to include and interpret input from users, with whom researchers cannot directly communicate. Additionally, it supports the development of context-dependent systems that need to be designed and evaluated *in situ* and with input from multiple stakeholders. We also found that with this approach it is important to verify data from multiple sources.

In this study, we focused on input from adult participants to interpret children's behaviour or communications. In the future, it would be interesting to explore dynamics that arise when children with and without disabilities interact with each other when using a system. What are some techniques to help combine input from both populations effectively to inform design? How would such a study be different from our current approach?

Another longitudinal study can examine whether the type of suggestions and insights provided by adult and child participants change over time: Would they be more about the form factor and functionality of systems or their underlying design concepts? Finally, a user study can evaluate Rafigh with different user populations and examine the impact of the current design decisions on the interaction.

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