

Designing with Children with Severe Motor Impairments

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ABSTRACT

Children with severe motor impairments such as with disabilities resulting from severe cerebral palsy benefit greatly from assistive technology, but very little guidance is available on how to collaborate with this population as partners in the design of such technology. To explore how to facilitate such collaborations, a field-based participant observation study, as well as structured and unstructured interviews, were conducted at a home for children with severe disabilities. Team-building collaborative design activities were pursued. Guidelines are proposed for how to collaborate with children with severe motor impairments.

Author Keywords

Accessibility, children, design, participant observation.

ACM Classification Keywords

H.5.2 User Interfaces – *user-centered design*. K.4.2 Social Issues – *assistive technologies for persons with disabilities*.

INTRODUCTION

One of the fundamental challenges when trying to build technology that truly helps people with their jobs and lives is the challenge of design—determining needs, generating viable solutions, and evaluating alternatives. In the field of human-computer interaction, integral activities in the process of design include communicating with the users to learn about the intended context of use, solicit ideas, and evaluate alternatives. When the potential users of a system have an extremely limited ability to communicate, such as with children with severe motor impairments, these fundamental design challenges are exacerbated. This paper discusses specific attempts that were made to develop meaningful collaborative relationships with two children with severe motor impairments, and to provide guidelines that may be useful when pursuing design activities with such children.

PREVIOUS LITERATURE

Designing for children without disabilities presents unique challenges—and opportunities—that has advanced the role of children from testers to design partners (Druin, [3]). To some extent, the work presented here attempts to emulate

the low-tech prototyping discussed by Druin except that our children do not have the motor skills to do the actual assembly themselves. The goal of the work presented here is largely to figure out how to move *into* the first six months of design exercises that are reported by Druin to be necessary for a child to unlearn the established power structure, as is necessary for true collaboration. Our goal is to instill a similar sense of partnership and agency in children with severe motor impairments.

Previous literature guides and inspires this work. Adults with aphasia, a cognitive disorder that impairs speech and language, have contributed to participatory design activities such as the evaluation of existing products, brainstorming, and prototyping [4]. The work shows value in designing with a mix of both target and advocate users, such as users with only mild disabilities. Technology interventions enabled children with autism to contribute to the authoring of life-size full-body virtual peers [5]. A process was developed to involve young adults with cognitive disabilities in the design of accessible communication systems to increase their independence [2].

Practical guidance is available for developing and deploying Augmentative & Alternative Communication (AAC) solutions for children with severe motor impairments. Beukelman & Mirenda [1] is perhaps the best practitioner's textbook on delivering AAC and supporting people with complex communication needs.

Previous literature provides guidance for engaging people with disabilities in the design of assistive technology, and for working with children with severe motor impairments, but little or no guidance on how to engage these particular children in a design process. This paper describes an extended study that was conducted to evaluate how to collaborate with such children.

METHOD

A participant observation study was conducted at a home for children with severe disabilities. The home is in the U.S. Pacific Northwest, adjoins a hospital, and provides extensive medical and life support to about sixty full-time resident children. None of the children are ambulatory, and 85% are fed with gastrostomy tubes, or g-tubes. The children have a wide range of capabilities and limitations in terms of purposeful movement and communication such as with AAC systems, devices, and strategies. None are verbal, though a few have a clear yes/no response.

The study was initiated by the author contacting the home and explaining that he was trying to build collaborative

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Figure 1. A collaborative design session with two girls, the speech language pathologist (center), and the author.

relationships with potential users of eye-controlled communication technology. The home eagerly welcomed him, and enlisted him in their community volunteer program. The author spent an initial eleven weeks (four days a week, three to four hours per day, for a total of forty-two visits) at the home in early 2007, primarily getting to know two teen-aged girls with severe cerebral palsy. He subsequently visited once a month specifically to pursue design activities with the same two girls. The girls will be referred to as Alex and Julie. The home specifically suggested that he interact with these two girls. The project obtained approval from the University of Oregon institutional review board, informed consent from parents and staff, and informed assent from the two girls.

Alex and Julie are both about seventeen years old, have severe cerebral palsy, are nonverbal, have very limited functional use of their arms and legs, and do not read. Both have some ability to press large button switches with their hands, or to hit switches by turning their head to one side or the other, though it is a slow process. Figure 1 shows such switches in place. Both girls have a reasonably clear yes/no response that caregivers can learn over time. For Alex, she smiles for “yes” and moves her head to the side for “no.” Julie vocalizes a quiet “uh” for “yes” and “uh-uh” for “no.” Once these yes/no responses are learned, a conversation can be had. The girls exhibit clear emotional responses, such as smiling, laughter, sadness, and anger.

Initial goals of the study were to get comfortable with the environment, build rapport with the two girls, learn how to communicate with them, and engage them in a range of meaningful activities, such as exchanging greetings upon the author’s arrival, watching videos together, reading to the girls, trying to teach letters and numbers, and setting up the switch-based AAC devices. Each activity was also accompanied by ongoing dialogue about the activity, such as what video to watch, what characters are doing, or how to use an AAC device. Subsequent project goals included engaging the girls in collaborative design sessions aimed at establishing a design process.

RESULTS

The primary data used for the study are field notes that were written by the author immediately following each visit, and formal and informal interviews that the author conducted at the site. Photographs were also taken during some of the visits. Parental permission was obtained to take and publish photographs of the girls.

Interacting with the Children

There are some general trends in the author’s field notes. One is that notes written after initial visits focus more on awkward and uncomfortable feelings that arose during the visit, whereas later field notes spend more time on specific logistical and communication challenges that came up. Feelings of social awkwardness largely subsided over time, but one feeling that continues to persist after each return visit, now roughly one per month, is a feeling of extreme physical exhaustion after the session. This exhaustion is not shared by the speech-language pathologist (SLP) who interacts with such children daily.

One of the most common sets of feelings that the author experienced himself and observed in others were feelings of unsureness, unknowing, and doubt when interacting with the girls. People demonstrated this unknowing and doubt in many different ways, and coped with the feelings in many different ways. For example, an experienced nurse who had been working at the home for quite some time told the author that, even with all her experience, she is still somewhat at a loss for how to interact with the children, and asked the author for ideas. Also, caregivers and volunteers would routinely ask Alex and Julie questions but, rather than waiting for an answer, fill in their own projected guesses of what the answers might be. The author was initially disturbed by this apparent impatience but over time realized that it was, in part, a coping mechanism for dealing with feelings of unknowing and doubt.

The author had a number of “breakthrough” moments in the initial rapport-building stage. Two stand out. The first was on the fourth day visiting the home when, during a group activity, Julie slowly moved her arm to initiate touching hands with the author. This was the author’s first physical

contact with either girl. Even though the staff had already specifically clarified that it was okay to touch the children's hands, he initially feared any physical interaction—even just moving a wheelchair—as he worried about the girls' well-being. The author discussed the interaction with staff members and was again reassured that this sort of human contact was appropriate and in fact good for the girls. At all times while at the site, the author carefully followed the volunteer requirements presented in the volunteer training, such as by washing his hands frequently and by never helping to lift a child.

It appears as if conscientious people interacting with children with severe disabilities tend to wonder, even from moment to moment, whether they and other people around them are doing the right thing, and behaving in the most helpful and appropriate manner with the children. Frequent discussions with other caregivers, and with the children themselves when possible, may help to build rapport and trust with the collaborators, and to put the designer at ease.

A second breakthrough occurred on the author's ninth visit to the home, when he finally broke through a social and perhaps motivational impasse with Alex that had frustrated the author since he started. He observed and learned that Alex particularly enjoyed somewhat ornery activities, as is customary among many teenagers. The author recorded a few slight insults on a manual switch device and pushed Alex around in her wheelchair so that she could playfully tease the staff. Each press of the switch would advance through "you have a big butt," "you have stinky feet," and "you think you're cool, but you're *not*" in the simulated voice of a teenager with an attitude.

Alex observed the initial insult recording process with great interest and a growing smile. When the author tried to add a few pleasant comments to the series, Alex scrunched up her face and kicked in protest, so he stopped. The author did explain that the insults were not completely socially acceptable. But he wanted to give her the voice that she clearly desired. The author was slightly reprimanded a couple days later for enabling "borderline" offensive comments and inappropriate behavior, and he felt bad. He did not repeat the activity, but he did not need to, as the rapport was established. It could also be argued that the author was enabling a healthy and age-appropriate activity.

Design Work

While the ultimate goal is to have the children contribute to the design of technology, it is clear that the girls first need to gain some experience and knowledge about the process of design itself, and how to contribute to design activities.

One particular design session proceeded as follows. The two girls, a speech-language pathologist, and the author sat around a table. Figure 1 shows the configuration. The SLP set up each of the girls with "yes" and "no" switches, each activated by a different head movement. The SLP had been refining the ideal switch positions for each of the two girls over the previous months, and appreciated another context in which to evaluate and reinforce their use. Her physical position between the two girls made it possible for her to

actively adjust the switch positions and provide physical assistance.

The girls were introduced to the concept of design as an activity in which we would work together to make something, deciding together how it would be made. The first design decision, which we made together, was *what* to make. The author and the SLP proposed a number of ideas such as jewelry, a song, a new dance, or a garbage can (wild ideas were offered to motivate creative thinking and calibrate responses). After each suggestion, the two adults would spend about thirty seconds listening for the "yes" and "no" responses from the girls' switch devices, repeating the question as necessary, and encouraging the girls to respond with the switches rather than their usual conversational yes/no responses. The responses were written down, including their number and order, to capture nuances such as consensus-building and level of excitement. For example, both girls offered many rapid "yes" responses to the suggestion of designing a dress.

Figure 1 shows the process of selecting a color for the dress, using color "swatches" torn from large rolls of poster paper. The SLP innovated in the color selection process by quickly reprogramming each of the girls' "no" switches with a recorded vocal series of the four colors. This way, she pointed out, she could reinforce the use of the "no" switch position for scanning and the "yes" for selecting, consistent with her other AAC efforts. The girls took turns scanning through the colors, and selecting their choices.

Figure 2 shows design artifacts that were iteratively developed with input from the girls across multiple sessions. They are dress models that illustrate the concepts of "hippy chick," "smart librarian," and "punker girl."

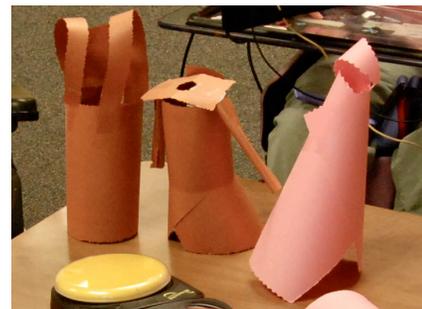


Figure 2. Design artifacts.

GUIDELINES FOR DESIGNING WITH THIS POPULATION

Based on observations and interactions, the following eight guidelines can be offered for collaborating in design activities with children with severe motor impairments.

1. Accept the awkwardness and nervousness.

Designing with children with severe motor impairments will likely require a designer not accustomed to working with this population to face uncomfortable feelings, especially at first. Communication moves at a pace roughly two orders of magnitude slower than with typically developing children, and with a great deal more ambiguity in both directions. This is initially unsettling and disorienting, but these feelings can be managed over time.

2. Advocate for the children's self-expression.

Designers must make special efforts to demonstrate to potential collaborators that the designer really wants to hear their voice in the social process. Promoting children with severe motor impairments to the status of "design partners" (Druin [4]) for building interactive systems is going to be very different if those children have not had the same opportunities as typically developing children to express their opinion. Designers should learn children's current communication techniques before introducing new techniques, and find novel opportunities for the children's voices and opinions to be heard.

3. Use low-tech interactions to design high-tech.

Caregivers and SLPs often establish an initial low-tech (or no-tech) means of communicating with a child, such as a yes/no response by looking up or to the side, and then build on this to develop technology-based communication, such as with switch-based devices that may permit a richer conversation. The design activities pursued here provided the SLP with a team-based opportunity to motivate the girls to learn to use their switches, but throughout the design process we also listened for the no-tech communications, even if just to encourage the girl to repeat their answer but with the switches.

4. Interact with as many different caregivers as you can.

Interacting with many caregivers who already knew these two girls accelerated the process of learning how to understand and communicate with the girls. One staff member demonstrated over time that she was a particularly gifted listener and was able to understand several of Julie's communications, including a vocal "no" that the author was mistaking for a "yes," and a throat sound that the author feared was a choking sound, but the staff member clarified was just Julie's way of saying she did not like something.

5. Specifically learn how to hear "I'm done."

It became clear that it is particularly important to learn how a child indicates that he or she is done with an activity. When Julie gives her "I'm done" signal during a design session, we take a break.

6. Join the other teams working around the child.

Following the team-based approach advocated by Beukelman and Mirenda [1] accelerated the process of getting to know the girls and provided great synergy in advancing multiple constructive agendas in parallel.

7. Decompose design activities into discrete subtasks.

Activities in the design process, such as generating alternatives and discussing the merits of each, need to be accomplished in a step-by-step deliberate manner. Since, at present, the girls are not able to introduce new ideas of their own, we do our best to offer many alternatives and closely monitor their emotional responses and level of interest in each new idea.

8. Work with multiple children in parallel for synergy.

Working on a regular basis with two children at the same time clearly provided many benefits. The two girls provided each other with motivation and camaraderie. When one girl was asked if the other should try an activity,

or if she thought the other would be able to do it, the answer was invariably "yes." Working with two together also enabled parallel activities, such as by posing a question to the two together, and then coaching each of them through their physical movement needed for a "yes" or "no."

CONCLUSION

Designing with children with severe motor impairments requires deliberate reconstruction of the many activities required for design in general, including building teams, establishing communication channels, and discussing alternatives. It appears as if providing enough support for each of the individual social and creative subtasks involved in a design process can start to give children with severe motor impairments a sense of ownership of the process. Future challenges include transitioning from the initial phase of low-tech prototyping and power restructuring, to the design of new AAC solutions.

If we have successfully formed a collaborative design team, then an open question might be how much of the time that the author spent (forty-two sessions across eleven weeks) was necessary to form this team. It appears as if a dozen or so sessions might have sufficed. The two rapport-building "breakthroughs" discussed earlier, for example, both occurred within the first dozen visits. Following the above guidelines right from the start would likely have moved things along more quickly, though challenges will persist, such as surmounting the structural barriers to finding and joining existing teams [1].

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