
Working with Children with Severe Motor Impairments as Design Partners

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Abstract

This paper discusses attempts that have been made to team with children with severe motor impairments in the design of technology to help those children express themselves. The project is still new, and the endeavor extremely challenging, but small successes as well as enormous challenges can be reported and discussed. Much can be learned from the literature and practice of alternative and augmentative communication, in which children are asked to assist in the design and implementation of a communication scheme for that child. The challenge is to integrate these approaches with what has been learned when collaborating with typically-developing children in the design of new technology.

Keywords

Accessibility, children, design, disabilities, technology.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Working with Children with Severe Motor Impairments and Their Caregivers.

There are two major activities that the author and his collaborators have pursued. The first is the development of eye-controlled software that runs on a commercial eye tracking device that enables children

with severe motor impairments such as severe cerebral palsy to draw pictures [2]. Figure 1 shows one of the users/collaborators with severe cerebral palsy as she uses her eye tracker to draw an outdoor scene with green grass and blue sky. The developers of the software, including the author, have not actually met this collaborator in person as she is about a day's travel away from the author's design studio.



Figure 1. A remote collaborator for developing EyeDraw.

The second major activity has been to develop collaborative relationships with children who are more local to the studio, such that more regular face-to-face design work can be done directly with children with severe motor impairments and their collaborators. Figure 2 shows the author meeting with two such children and an assistive technology specialist at a home for children with severe disabilities that is much closer to the author's home institution. This regional interaction facilitates more regular interaction. The

author spent eleven weeks of his sabbatical in 2007 visiting this home, and these two young women in particular. He visited for three hours a day, four days a week. Though no new technology was developed during those eleven weeks, the extended visit helped to create social bonds and lines of communication that need to be in place for collaboration to happen.



Figure 2. From left to right, a speech therapist, two potential design collaborators, and the author.

Best Practices for Understanding and Designing for These Children and Their Caregivers

Much guidance for understanding and designing for children with severe motor impairments can be gleaned from the literature on alternative and augmentative communication (AAC), such as Beukelman & Mirenda [1]. The literature offers advice such as on building a team around a child, and techniques for developing communication schemes. One specific technique, for example, is to continually provide feedback, letting a

child know what you are hearing them say to you, such as “I think you are saying ‘yes’” or “I am hearing a very clear ‘no!’”

Other literature such as Musselwhite [4] provide specific suggestions for fun play activities for children with severe motor impairments, which are also likely a great jumping-off point for engaging these children in design activities. Best practices for interacting with these children also demonstrate the need for the collaborators without disabilities to have a fun, creative, and playful demeanor if they wish to evoke the same from the children.

Perhaps the most important established approach for working with these children with the disabilities is to build a team around each child. Beukelman & Mirenda discuss this at length. The team should likely include the child, their parents and siblings, teachers, caregivers, nurses, augmentative communication specialists, recreational activity coordinators, physical therapists, speech therapists, technology developers, and possibly other people as well. Each team member brings unique skills and perspectives, all of which are necessary for success. This is well-established for developing alternative and augmentative communication schemes, and will clearly hold as well when working with the children as design partners to develop new technology for their use.

The author’s EyeDraw project was successful in part because of the cooperation of a distributed team of experts and collaborators. The teams included children who already use an eye tracker, their parents, eye tracking technical experts, a nurse, an assistive technology practitioner, software developers, and

designers. The downside was that the team was very geographically distributed and never assembled at the same location, though the author traveled to meet most team members face to face at least once.

Specific Challenges When Working with This Population, and Methods for Approaching These Challenges

There are many challenges in collaborating with children with severe motor impairments as design partners. These challenges parallel the difficulties in developing alternative communication schemes for such children. It is surprising to learn that, routinely, the greatest obstacles have little or nothing to do with the child’s disability but are instead structural, institutional, social, geographical, financial, legal, and attitudinal. For example, some communication devices that run on a standard computer are designed so that they cannot access the internet because the device would then no longer be considered a “communication device” and covered by medical insurance.

Different stakeholders will have different goals, interests, skills, abilities, and resources. For example, there will be a wide range of opinions as to what are “age-appropriate” activities for children who are teenagers and yet have severe motor impairments that will have limited their development in some areas. It takes a great deal of time, patience, persistence, and perhaps luck to build a successful team around a person with disabilities to deliver a successful alternative communication scheme, and the same will surely be true when collaborating on a design project.

Working with children with severe motor impairments will require a lot of patience, and the ability to tolerate

feelings of unknowing and awkwardness. In his time at the home for children with severe disabilities, the author experienced these feelings on a daily basis, and also observed numerous techniques that other caregivers used to cope with similar feelings. For example, after posing a question to a child who communicates largely with yes/no responses, a caregiver with time and patience will wait patiently for a reply and, if one does not come, decide when to either ask the question again, perhaps using different language, or when to just move on. Different caregivers handle these situations differently. Caregivers occupied primarily with the basic health needs of many children at the same time typically do not have the time required for conversations with these children, and will provide on the child's behalf the answer he or she imagines that the child would provide. Perhaps the biggest challenge in working with this population is the time required.

Spending a lot of time with a few children in a lot of different activities will enable a designer to get a rough sense of their likes and dislikes, what motivates them, and how they show interest, excitement, and dislike. One really important cue that the author learned when working with one of the two young women was that she would generate a sound in her throat and have a look of distress when she was completely tired of an activity and ready to do something else. It was initially alarming to see, as if something was seriously wrong, until another caregiver who knew the child well explained that she was simply saying "I'm done with this." If a designer intends to ask a young collaborator to contribute to a range of design activities, it will be important to pick up on a cue that the child is done.

New Directions for Research and Design

A major outstanding challenge is to try to integrate what has been learned by researchers and practitioners working with AAC with what has been learned about collaborating with children without disabilities as partners in the design of new technology. The work by Druin [2] and colleagues has particularly inspired the author with its shift of perspective from children as testers to children as collaborators. This more proactive approach is consistent with the potentially empowering attempts by AAC specialists to help children with profound physical impairments break out of the mindset of "learned helplessness." In both cases, the goal is to give a voice where one is not currently heard.

Example citations

[1] Beukelman, D. R., & Mirenda, P. (2005).

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