

# Enter the Cloud of Unknowing: Collaborating with Children with Severe Motor Impairments

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## ABSTRACT

Children with severe motor impairments such as disabilities resulting from severe cerebral palsy could benefit greatly from assistive technology devices such as eye tracking. However, there is very little guidance available on how to design for this population. As part of moving towards engaging children with severe motor impairments as design collaborators and partners, the author spent eleven weeks as a volunteer at a home for children with severe disabilities, and conducted an ethnographic study including structured and unstructured interviews, and participant observation with extensive field notes. Insights for working with this population have emerged. One theme that persisted was the tremendous amount of uncertainty, due to communication barriers, that persists when interacting with these children. Working with this population may require researchers and designers to enter a “cloud of unknowing,” in which they feel lost and unsure of what they are doing, while at the same time forging ahead with the project.

## Categories and Subject Descriptors

K.4.2 [Computers and Society]: Social Issues – *assistive technologies for persons with disabilities*; H.5.2 [Information Interfaces and Presentation]: User Interfaces – *user-centered design*.

## General Terms

Design, Human Factors.

## Keywords

Accessibility, children, children with disabilities, cerebral palsy, collaboration, design, ethnography, participant observation, participatory design.

## 1. INTRODUCTION

This project investigates the potential for the development and use of assistive technology (AT) for people with severe motor impairments. In the course of developing AT software for drawing pictures with eye movements [7], it became clear to the author that

the designers involved in the project (including he himself) needed more direct contact with the actual end users to truly understand their needs and the intended context of use of eye-controlled software. However, when developing systems for people with severe motor impairments, it is generally very difficult to interact with and thus understand the parameters, abilities, and expectations of the intended users, and the context of use. The goal of the project is to determine how children with severe disabilities can contribute as design partners in the development of new AT and AAC (augmentative and alternative communication) devices, and what is needed to collaborate directly with these children. The project also investigates the context of use of such technology.

The primary research questions are as follows:

- How can assistive technology designers work directly with children and adults with disabilities such that more and richer ideas and designs can evolve?
- What are the social and physical environments of people with severe disabilities, such that AT and AAC can fit into and potentially complement those environments?
- What are the difficulties when introducing children to AT and AAC? How can these difficulties be reduced?
- How can children with severe disabilities contribute as design partners in the development of new assistive technology intended for their use?

## 2. PREVIOUS LITERATURE

Other researchers have investigated designing with typically developing children, and have advanced the role that children without disabilities play in the design of computer interfaces, such as Druin [4]. The children’s role has evolved from user to tester to informant to design partner, with clear benefits to the design process. Druin explains that “over time, I found that the more I worked closely with children, the more I came to expect the unexpected when it came to ideas, technology directions and honest feedback from children.” (ibid., p.13) This previous work helped to inspired the author to also collaborate with children, but children with severe disabilities.

Participatory design has also been used with adults with aphasia, a cognitive disorder that impairs speech and language, to design and develop a portable electronic daily planner for these users (Moffatt et al. [8]). The individuals with aphasia contributed to brainstorming, evaluation of existing products, and several stages of prototyping. Reflection on this particular design process led to the following recommendations when conducting participatory design practices with special populations: Assess abilities through

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standardized tests, connect with existing groups and organizations, gain practical experience with the target population, and use a mix of advocate and target users. The “advocate user” in this case was a user with only mild disabilities. Davies et al. [3] presents a related participatory design project in which a group of researchers and designers, one with aphasia, collaborated to design a portable communication device. The project stressed egalitarian mutual relationships in the design process. A goal of the project presented here is to identify—or become—advocate users for the children with severe motor impairments, and to pursue similarly egalitarian relationships.

Technology interventions have been developed to enable children with autism to contribute to the authoring of life-size full-body virtual peers (Tartaro & Cassel [12]). Some of the design guidelines developed for this population will transfer to our intended population, such as how the system should (a) provide scaffolding for increasingly complex interactions and (b) support social contexts.

Much practical guidance is available on Augmentative & Alternative Communication (AAC), and on working with children with severe motor impairments. Beukelman & Mirenda [2] is a very highly-regarded textbook and reference on AAC, and provides extensive practical guidance and insight into the problems of communicating with people with severe disabilities. There is also a good body of work that specifically discusses the challenges of raising and interacting with children with severe cerebral palsy. Finnie [5] discusses the specific physical challenges of raising a child with cerebral palsy, and is in many ways a very practical guide written for parents and caregivers, and includes many suggestions for engaging activities. Hewett, Newson, & Newson [6] describes many of the social and physical situations that arise for children with disabilities, and for their families and caregivers. Musselwhite [8] provides a wealth of ideas for highly motivating play activities for children with severe disabilities, and scholarly support for the activities. The chapter on switch-based activities especially informed this project. As will be discussed later, the author successfully used such activities, with a slight twist, to help draw a teenager out of what Musselwhite and others describe as “learned helplessness,” which occurs when a child is nonresponsive because there is either insufficient motivation or understanding to respond.

Previous literature provides guidance for designing assistive technology and for working with children with severe motor impairments, but little or no specific guidance on how to collaborate with this population, or how to proceed with such collaborations despite the uncertainty that will surround the interactions.

## 3. METHOD

### 3.1 Methodological Approaches

The primary methodological approaches used in this paper are qualitative and quantitative methods in anthropology, including ethnographic techniques, participant observation, structured and unstructured interviews [1]. The approach is also consistent with the requirements analysis phase of scenario-based design [10], in which the goal is to be able to tell rich stories that exemplify the context of use.

The author conducted a participant observation study at a home for children with severe disabilities, and entered with a number of assumptions and biases. Assumptions include that there are a

variety of social networks at the home, that these networks evolve over time, and that they function (or disfunction) in a manner that produces regular patterns and results of behavior. It is assumed that there are hierarchies in place, with people in prescribed roles. The project aims to discover these roles. The home is partly a place of employment, and partly a residence, so there should be a mix of dynamics. Developing a deeper understanding will help to illuminate how software designers can open lines of communication with children with disabilities, help these children to be good collaborators, and fit AT into the social context.

### 3.2 The Site

The first task was to find a location that would be appropriate for learning about collaborating with children with severe motor impairments, a location at which the author could have extensive interactions with at least two children who could potentially benefit from eye tracking; that is, children with cognitive ability and eye control, but little other motor ability. Staff at several care facilities for children with severe disabilities were contacted, and collaborations proposed. It was surprisingly challenging to find an institution that was appropriate and welcoming. One institution, for example, exhibited what appeared to be distrust and suspicion of an outside AT researcher approaching the group. Eventually one facility expressed a strong interest, and an extensive collaboration was initiated.

The primary research site is a home for children with severe disabilities in the northwestern United States. The home will be referred to as the “center” in this paper. For eleven weeks in early 2007 (January 11 through March 31), the author spent an average of three hours per day, four days a week at this center. The center eagerly agreed to collaborate in research pertaining to the development of assistive technology based on eye tracking. The author’s formal role at the center started off as that of a volunteer in the center’s volunteer program because this enabled him to assimilate into the center through routine methods, and to demonstrate his intention to collaborate such that both sides in the collaboration received clear benefits, as volunteers are greatly valued for their time spent with the children.

The center is home to about sixty children with profound physical and/or mental disabilities. None of the children are ambulatory. Eighty-five percent are fed through gastrostomy tubes, or g-tubes, that put liquid food directly into the stomach. Only one child is verbal, and only a few others respond to “yes or no” questions, so a relatively small number of the children use augmentative communication devices. The well-being of the children is provided by an interdisciplinary team of doctors, nurses, augmentative communication specialists, recreational activity coordinators, physical and occupational therapists, certified therapeutic recreation specialists, speech therapists, assistive technology specialists, nutritionists, and volunteers, which is how the author formally entered the community.

The children are cared for around the clock by certified nurses assistants and an extended staff of caregivers and activity coordinators who provide the children with a fun and respectful childhood, with many programs, activities and field trips. There has been some but not extensive use of AT at the center. This makes the center a good site for investigating the introduction of AT to children with severe disabilities, and exploring how these novice participants might assist in design but, as was learned, perhaps a suboptimal site for collaborating with staff who are experienced with the introduction of AT.

### 3.3 Activities Pursued

Specific activities that the author pursued included:

- Established a rapport with two teenaged girls with severe motor impairments (such as severe cerebral palsy), and interacted with these girls extensively over the eleven-week period. The two girls will be referred to as “Alex” and “Julie.”
- Developed a rapport with caregivers and activity coordinators at the same facility, and collaborated in many activities with the two teenagers and staff.
- Informally assessed the cognitive and motor abilities of these two teenagers, and assessed their ability to use current AT and AAC devices.
- Interacted with these two teenagers enough to determine what sorts of activities the girls do and do not enjoy engaging in, both passive activities (such as being read to or watching TV) and interactive activities (such as programming voice buttons or designing jewelry).
- Conducted structured and unstructured interviews with staff at the center, discussing myriad topics pertaining to interacting and communicating with the children at the center, and how assistive technology might be introduced and deployed at the center.

### 3.4 Types of Interactions

The author engaged the children in many activities, including social, entertainment, educational, enabling, and design. All of these activities would seem to be useful for collaborative participatory design of AT and AAC devices.

#### 3.4.1 Social

This included various forms of greetings, responses to children’s attempts to get attention, holding hands (which was initiated, remarkably, by one of the children), and having simple connecting conversations such as asking the child about their day at school. This activity also gave the children and author opportunities to practice asking and answering easy yes/no questions.

#### 3.4.2 Entertainment

This includes activities in which the child somewhat passively enjoys an activity such as having a book or the newspaper read to them, or watching a TV show or DVD. Reading to the children is the most common activity done by volunteers at the center.

#### 3.4.3 Educational

The author comfortably fell into the role of teacher or tutor, and engaged the children in numerous educational activities such as teaching them numbers and letters, and continual instruction in working with AAC.

#### 3.4.4 Enabling

The author teamed up with the AAC specialist at the center, and together with the children worked on the introduction and adoption of AAC devices. This included designing and programming the contents of speech-generating devices, and extensive time spent with the children physically training them to use the devices, and numerous approaches to helping the children understand that the devices provide a means for the children to first think of something to say, and then use the device to say it. Figure 1 shows the four collaborators working together on such tasks.



**Figure 1. The center’s AAC specialist, the author and the two teenaged girls, setting up an AAC device and playing a game.**

#### 3.4.5 Design

Collaborative design occurred in many settings, such as discussing what sorts of verbal comments to put onto manual switches (such as the AbleNet BIGmack) for the girls to “say”. Figure 2 shows the same team collaborating simultaneously on the design of Easter eggs and the content of an AAC device so that one of the girls could communicate her egg design choices.



**Figure 2. The same team, collaborating on the design of Easter eggs. The girls are laughing because the AAC specialist is making fun of how difficult it is to program an AAC device.**

Collaborative participatory design projects with children with severe disabilities are likely to involve these activities: social, entertainment, playing, educational, enabling, and design. Clearly there are opportunities for creativity on the part of both the designer and the children at every step of the way. Through it all, the designers are faced with helping the children express themselves as well as continual ongoing assessment of what the child understands.

## 4. DATA

Field notes that integrate observation with interpretation were written up immediately following each visit to the center, typically taking one hour to record the observations for a three-hour visit. Other data included personal recollections beyond the field notes,

impressions formed based on notes and experiences, a coded textual analysis of some of field notes, and structured and unstructured interviews. Some observations are more concrete than others, such as when a clear communication, or a clear positive or negative response from the girls, is observed. Other observations are more speculative, such as when trying to interpret a person's intentions or motivations, or what a child is feeling or trying to communicate. The speculative comments are typically distinguished by phrases such as "It seemed as if...." One of the goals of the analysis is to find concrete support for the subjective impressions.

## 4.1 Coded Field Notes

A coding scheme was developed to analyze the field notes, to analyze the data for trends and themes, and to learn contexts of use of potential eye-controlled communication devices. Four of the codes that were used are shown in Table 1. These four relate to ideas that were forming, in the context of the research study, regarding aspects of the girls' lives and how the center operates.

**Table 1. Some codes used to analyze field notes.**

AWK	Awkward situation of some kind or another, or reference to awkwardness.
POS COM	Evidence of a positive communication experience for the children.
RUL	Some kind of rule is discussed or enforced.
UNK	Unknowing - A situation arises that points to the "cloud of unknowing."

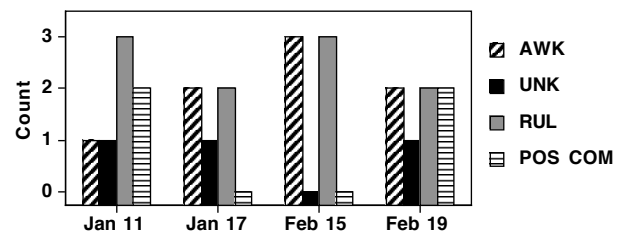
What follows are abbreviated excerpts of coded field notes from two days at the center. The first excerpt is from one of the author's first days at the center; the second is from a visit a month later. Each event in the day was described in one or two brief sentences. Each event was then coded based on roughly twenty possible encodings, including the four listed above. Only four of the twenty codes are actually included here, primarily to just give a sense of the data collected and analyses performed.

17 January 2007: I read from *The Babysitter's Club* and brought Alex up to date [POS COM]. The girls seemed zoned out. I felt ignored and at a loss [AWK]. I walked away, at a loss for activities to do with the girls [UNK]. An activities staff member offered to suggest some things. The coordinator intervened and explained a lot, as follows. The "conversations" with the girls will often feel uncomfortable [AWK]; it takes time and patience to have these conversations [AWK]; Alex is a little tough and they want to see how she deals with me; the attention is good for the girls; Julie likes reading comprehension questions; I can move them to a quieter space but not leave them alone [RUL]; I could just read them the newspaper. I suggested that Alex doesn't seem to like me. The coordinator said give her time.

19 February 2007: Julie seemed very ill at ease today. Nobody truly asked what was wrong. Other volunteers do not wait for Julie to answer, and do not converse. Another volunteer admired the way I spend time with and interact with the girls. Julie struggled with her Dynavox. Staff feeding kids watched me patiently interact with Alex. A staff encouraged Alex with a task I gave her. Switch parts are missing or broken. Alex helped troubleshoot through Y/N questions [POS COM]. Alex uses her switch to repeatedly ask me to play a video. The staff needs to learn

about AT. Three adults are talking around Julie but not listening to her. When I left for the day, Alex shook hands goodbye, as I have been trying to get her to do [POS COM].

The occurrence of the four codes were counted for each of four days at the center. Figure 3 shows the number of events that received each of the codes. As can be seen in the graph, even after a month of visits, the author continued to either observe or experience awkward situations and the "cloud of unknowing"—a feeling that one is in a fog and has no idea where they are or what they are doing—on a daily basis.



**Figure 3. The variations in experiencing or observing awkward situations, the cloud of unknowing, rules discussed or imposed, and positive communications for four days.**

## 4.2 Other Observations

A great many other observations were made. Two relate to the the use of existing AAC devices. Julie was extremely motivated to use her Dynavox AAC device. Once the author was instructed on how to set up the device, Julie would maintain a very high level of attention-getting activity from the moment the author arrived each day until he asked her if she wanted to use her Dynavox, at which point she would consistently give her loudest, clearest, most physically engaged YES!!! response of the day. This is despite the fact that Julie would also, consistently, by the end of an hour-long practice session grow very frustrated with the device, confirm "Yes" that the device is very hard to use, and indicate that she "Yes" she wanted to end the activity. The "I'm done" communication started with a particular throat sound combined with an upward motion of her body in her chair. A staff member explained early on that this is Julie how Julie says that something is wrong. The author would follow it with yes/no questions to find out what is wrong. "I'm done" is an important communication to learn how to hear, and to listen for.

It was particularly difficult developing a rapport with Alex in the first weeks at the site. She would not respond favorably to many attempts to engage her. One interpretation of the behavior would be that she was trying to express lack of approval and social removal from a lot of situations—consistent with many U.S. teenagers. It was very challenging to make an initial social connection. A breakthrough occurred when the author recorded some mild insults such as "You have stinky feet!" into one of the hand-activated voice-players, and wheeling the young woman around so she could issue insults to different staff members throughout the center. The teenager loved it. The staff members seemed okay with it, and glad to see Alex so engaged, though the author was subsequently asked to not repeat this particular activity. But it provided a first major opportunity to bond with the young woman, a very strong motivator for the young woman to finally start using the AAC devices that the author was setting up

for her, and a particular voice that she clearly desired, but was not readily available.

## 5. ANALYSIS

The use of written field notes, personal recollections, impressions based on the notes and experiences, structured and unstructured interviews, and a coded textual analysis of four days' field notes provide a rich cross-sectional view of what is involved in the lives of these children and their caregivers, communicating with two girls, and ultimately the context of use of assistive technology for this population.

One of the biggest surprises was that the caregivers who interact with these children on a daily basis have as many questions as the author about the right way to interact with the children. Some have become comfortable enough to express, usually in private, that they regularly wonder about what is going on inside these girls' minds, and how they should be trying to reach them. One nurse even solicited the author's advice, which came as quite a surprise! Regardless, this is in some ways reassuring. Evidently, one piece of advice that can already be offered to people who want to collaborate with children in the design of assistive technology is that designers must be able to embrace, and be comfortable with, huge mysteries and the cloud of unknowing.

As can be seen in Figure 3, awkward situations did not substantially decline during the first month. At least for the four days chosen, positive communication also did not appear to rise substantially. These trends result in part because sensitivity shifted over time. For example, indications that the girls recognized the author upon his arrival at the center were initially very positive experiences, but eventually became routine.

Many children with severe disabilities establish "learned helplessness" in which they rely on caregivers to provide them with everything they need to stay alive comfortably. There is no need to learn how to say "I'm hungry" because if they just wait an hour or so, they know they will be fed. At the center, learned helplessness exists and is perhaps to some extent unavoidably reinforced through some caregiver actions. Many questions to Alex, for example, were met with no response at all, suggesting a removal from the situation, though a carefully selected question that tapped into her rebellious nature would often evoke a response even in those situations, demonstrating that she was still present, just not communicating. Observing how some caregivers and volunteers interacted with the children, it became clear that there was not always time to wait for a child's response if there are fifty-seven other children to be fed, and the caregiver's primary role is to keep the children physically healthy, not advance their intellect. It also appeared as if a nonresponse created awkwardness that discouraged a person without disabilities from continuing to try to interact with someone with disabilities.

The primary research questions relate to opening lines of communication with children with severe disabilities, identify potential collaborators with disabilities for the design of AT, and how to design software that fits a child's needs and interests. Not only does the process move very slowly, but collaborators without disabilities will need to let go of social conventions and accept that silence and feelings of being ignored will be a normal and perhaps even healthy part of the design process.

Over time, and through a great deal of interaction, the interests and needs of two children became clear. This was accomplished

through extensive paced conversations in which questions are asked such as "You look sad. Are you sad?" and by following up with other yes/no questions to confirm an understanding, such as by asking the same question in the opposite direction, such as "Are you happy?"

## 6. IMPLICATIONS FOR COLLABORATION

Working with children with severe disabilities on a daily basis for three months helps to reveal what is needed to collaborate with these children. Perhaps the most important observations are as follows:

- Trying to engage children with severe motor impairments in a meaningful way is very rewarding, but socially, intellectually, physically exhausting.
- The obstacles are innumerable. It is clear why few researchers may have tried this before. Many of the obstacles are in fact well-known and articulated by Beukelman & Mirenda [2] (p. 116).
- A very positive and supportive team is needed. Beukelman & Mirenda also discuss this at length.
- It is helpful to first engage the children in situations that are familiar to them, with people who already have deep relationships with the them.
- It helps to first get to know the children via low-tech communication, though this will take a long time.
- Working with two or more children with disabilities at the same time is very useful. Given the opportunity, for example, they cheer each other on.

The next two subsections cover a range of suggestions for collaborating with children with severe motor impairments, first the basic needs, and then the more advanced needs.

### 6.1 Basic Needs for Collaboration

It goes without saying that there are a number of basic needs that must be met for children with severe motor impairments to contribute to design processes, and for designers without disabilities to work with these children. Basic needs will be discussed first, and then more advanced needs for collaboration.

#### 6.1.1 Children's Basic Well-Being Must Be Met

For children to contribute to a collaborative design process, their physical well-being must be taken care of. Interleaved with the activities discussed here, for example, the center's nursing staff was continually attending to the basic needs to survive such as with feeding and other personal needs.

#### 6.1.2 Designers Must Be Comfortable with the Setting

Designers without disabilities working with children with severe disabilities will need to be largely comfortable with the children and their environment. Many people who work with these children report that the experience is extremely rewarding, but also express uncomfortable feelings in more private moments. As well, there are some physical aspects of the setting, especially if the site has many such children, that may at first be unsettling for people who are not accustomed to such an environment. For example, caregivers routinely set up gastrostomy feeding tubes and sometimes children have seizures. It might be wise to ease into a project, such as by starting with a few short visits.

Designers may experience sadness as they contemplate the limitations and shortcomings that these children will face in life, and feelings of helplessness as well as unrealistic expectations of “saving” these children either through personal interaction or technological breakthroughs. Feeling helpless, depressed, and the need to *do something!* is perhaps much better documented in literature on ethnographic research (see [1], p. 372) than in the literature on working with people with disabilities, though the two experiences have a lot in common. Staff at the center discuss a wide range of emotions that they experience working with the children, including the joy of being with the children but frustration at not having the time to engage the children in the ways they would like.

### 6.1.3 Interest in the Children, and Rich Discussions

A designer will need have a genuine interest in working with these children. The designer will also need to work to figure out what sorts of activities that the children enjoy, and wholeheartedly engage the children in these activities. The staff report that the children are very perceptive and know when a volunteer is genuinely engaged. Multiple staff at the center pointed out, in interviews, that the author succeeded at developing a strong rapport with the teenagers, and was able to have rich discussions, such as the following:

I arrived at the center at 3:50 PM and everyone was in their chairs and centrally located, which was a bit unusual. The team leader told me that they were probably going to have a fire drill. I mentioned that Julie would probably have a hard time with that, because she is a very careful listener and sensitive to loud noises. We talked to Julie and explained to her that it was going to happen. Julie immediately got worried and stressed, which she indicated by jumping up in her chair, making very distressed facial expressions, and issuing a quiet crying wail. The team leader explained to her that it would only be a pretend fire, that no one would be hurt, that Julie would be okay, and so she had nothing to worry about. I asked Julie what was worse, the (extremely) loud noise of the fire alarm or the people running around as they follow procedures during the drill. First I asked the entire question, and then I broke it up into a series of yes/no questions. Julie said that it was the loud noise that bothered her the most. I then asked Julie if she wanted me to put my hands over her ears during the fire alarm. She said yes. We practiced it. She then calmed down quite a bit, and was much better about the possible fire drill. (Field notes, 2007, edited for clarity and brevity.)

### 6.1.4 Practiced Communication Techniques

Constant and continual assessment of a child’s communicative, cognitive, and other abilities is a central requirement of working with children with severe disabilities. For example, if a child does not respond to a yes/no question, the designer needs to assess whether the child understands the words, the child is attending to another conversation, or other possible explanations. Beukelman & Mirenda [2] discuss at length the need and procedures for such ongoing assessments.

### 6.1.5 It Takes a Team

Some requirements for collaborating with children with severe disabilities is well-documented in the literature on augmentative communication. Multiple AAC specialists pointed to Beukelman and Mirenda [2] as an important reference on AAC. Many of the challenges that were encountered in this project, and many of the

things that clearly needed to happen for AAC to work for the children, are well-documented. For example, Beukelman & Mirenda [2] discuss (a) a team-based approach to the introduction and daily use of AAC and (b) common structural difficulties for AAC delivery programs, such as no staff development plan to teach the care staff how to set up, use, and troubleshoot AAC devices.

A researcher or practitioner collaborating with children in the design of new technology must recognize his or her role in a much bigger team that is supporting the use of existing protocols and technology. Cooperation with current efforts demonstrates motivation in exactly what the designer hopes to accomplish, which itself requires a team of caregivers and others who are supporting the *designer’s* activities. For example, the designer or researcher should attempt to (a) learn, actively practice, and reinforce existing communication protocols and technologies in a manner consistent with the rest of the team, and (b) obtain permission from parents and actively attend team meetings such as individualized education program meetings and team meetings that pertain to AAC.

### 6.1.6 Time and Patience

Collaborating with children with severe disabilities requires a lot of time and patience. A team leader at the center commented favorably on how the author would “slow down and break things into little bitty pieces” that the children could understand, but also expressed frustration that the staff, charged with the physical care and health of the children, did not have enough time to do the same.

### 6.1.7 Structural Support

The social aspects and organization of a group of people working to deliver AAC dramatically affect the success or failure. Beukelman and Mirenda [2] (p.116) enumerate routine structural challenges. In the study discussed here, a number of structural components contribute to the success of the project. For example, the center provided (a) a quiet place to work with the children on a regular basis and (b) regularly scheduled access to the children in wheelchairs as opposed to the three other physical setups in which the children are routinely placed (standard, prone, and lying) for a range of health benefits. The wheelchair arrangement was best suited for moving the child to a quiet place to work and for attaching AAC devices that the children could access. Provided that there were no conflicting physical health needs, the staff were extremely amenable to having the children available in wheelchairs, including coordinating via phone calls in advance. These particular needs may sound mundane and obvious but could easily make or break a project. What follows are findings that move beyond the basic needs to start a collaboration.

## 6.2 Advanced Needs for Collaboration

Numerous social, physical, and structural components contribute to this project’s progress towards collaborating with children with severe motor impairments. This section discusses components that go beyond the basic needs for collaboration, to more complex needs.

### 6.2.1 Raw Creative Materials

When working with these children, it is very useful to have ready at hand lots of arts and crafts materials, music, and props for spontaneous activities. These can help with both communication as well as collaborative activities such as designing jewelry. One of the quiet places to work with the children on a regular basis at



the center is a large room called the “learning center” which is stocked with abundant supplies.

### 6.2.2 Personal Creativity and Silliness

Personal creativity and willingness to do anything (sing, dance, talk like a robot, etc.) helps foster successful interactions with the youths. One staff member said that the girls grew to enjoy interacting with the author largely because of the respect that he showed them, while at the same time willing to be very “silly” at a moment’s notice, such as by asking one of the girls to judge his various styles of dance (salsa, disco, breakdancing, etc.) as part of getting past a communication impasse.

### 6.2.3 Lots of People Who Know the Children

Being able to observe and interact with dozens of different staff and volunteers interacting with the children in lots of different ways enhanced an ability to explore a personal style for creative interactions with the children. Seeing the range of styles also provided implicit community permission to explore various types of interactions. Various staff members engaged in singing, dancing, joke-telling, harmless pranks, and pseudo “gossip” about other children and staff members. These activities also served to integrate the children into the broader social fabric. Working with one child away from such a community might not give a researcher the same exposure.

### 6.2.4 Multiple Children With Disabilities in Parallel

Working on a regular basis with two children rather than just one at a time clearly provided many great benefits. The two girls provided each other with both explicit and implicit motivation, incentive, encouragement, and sometimes competition, all of which contributed to motivation and communication. Sometimes one girl would explicitly tell the author (via yes or no questions) either that she did not want to try an activity (such as trying a device) or that she did not think she could do it. An effective strategy at this point, it was learned over time, was to ask the *other* girl if she thought the first girl should give it a try. Invariably, the answer was “Yes.” Each girl encouraged the other.

Working with two children also creates a situation in which the researcher can get one child started on an activity or a yes/no question, and then work with the other child while periodically just reminding the first child of their task or the question they had been asked. This way, the time spent waiting for a response (which can last from 10 seconds to a minute to an eternity) can be used even more productively, in parallel, with another child. There are benefits, though it may be challenging to find two children who are roughly the same age with the same level of ability, as was found at the center. It is also very much to the staff’s credit that they specifically suggested working with these two girls.

### 6.2.5 Acceptance of the Awkwardness and Unknowing

There will be a great deal of awkwardness and unknowing when working with these children. It comes with the territory. The designers and researchers must be mentally and physically prepared for this. This unknowing and awkwardness is clearly evident in experienced caregivers, but that is not to say that they are completely comfortable with it. Some appear to develop coping strategies to deal with it, and some of these strategies may help the caregivers to focus on the children’s more basic needs, perhaps at the slight expense of the children’s higher needs.

The unknowing and awkwardness may come as a surprise to people who interact with these children for the first time, and it may take some time and effort to get used to it. The AAC literature does not seem to adequately discuss this awkwardness. Perhaps the best evidence of it can be derived from primary sources such as Strohm [11] in which siblings of children with severe disabilities discuss their feelings as they cope with how their lives are affected by their siblings with disabilities.

## 7. DESIGN SESSIONS

Moving towards the goal of a design team in which Alex and Julie would be active collaborators, a few design sessions were conducted that specifically focused on the goal of engaging the two teenagers in a collaborative design process. The sessions are currently ongoing, roughly one per month. While the ultimate goal is to have the children contribute to the design of AT and AAC devices, we are not there yet. Design sessions currently focus on much simpler objects, such as jewelry or dresses, as the teenagers have chosen, and not yet on the design of interactive software.

One particular design session in Spring, 2008, proceeded as follows. The two teenagers, a speech-language pathologist (SLP), and the author sat around a table. Figure 4 shows the configuration. The SLP set up each of the teenagers 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 teenagers over the previous months, and appreciated another context in which to evaluate and reinforce their use. Her physical position between the two teenagers made it possible for her to actively adjust the switch positions and provide physical assistance to remind the girls of the “yes” and “no” positions during the session.

During the design exercise, the author and the the SLP generated ideas and then either the two teenagers, or all four collaborators, would express their level of interest in each idea. The first question was “What should we make?” Alternatives were proposed one at a time, and the teenagers’ yes/no responses were recorded on paper. This is actually a bit harder than it sounds because some head movements are not necessarily intended to communicate but still hit the switches, in which case we ask followup questions for clarification and practice with the head switches, such as by having “Everyone please say ‘Yes!’” and then “Everyone please say ‘No!’” As well, sometimes one of the



Figure 4. A collaborative design session.

teenagers would make her quiet “yes” or “no” vocal sound while hitting the opposite switch, in which case we would stop and talk her through issuing the same response with the switches. Another interesting challenge that arose when recording their responses was that sometimes answers changed, such as after hearing what the other teenager said. An effort was made to record this ordering as it might be meaningful.

After proposing a number of items that we could design together, including jewelry, a garbage can, a new dance, and others, there was a very clear and repeated “Yes!” response to the suggestion of a dress. So we proceeded to design a dress. Figure 4 shows the first step in the design exercise of designing the dress, which was to select 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 young collaborators’ “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” switch position for selecting, consistent with her other AAC efforts. The teenagers each took turns scanning through the colors, and selecting their choice. The SLP and the author also weighed in on their color choices. The SLP pointed out, as the author started considering his choice, that Alex started scanning through the colors again, evidently to assist the author in his selection; so he waited until his choice came around to say “Yes.” These sorts of interactions represent how the design session can and should be used to simultaneously support the goals of multiple team efforts around the children.

## 8. CONCLUSION

The purpose of the project is to determine how children with severe motor impairments can contribute as design partners in the development of new assistive technology and augmentative and alternative communication solutions, and what is needed for designers to collaborate directly with such children. Through the use of extensive participant observation as well as structured and unstructured interviews, substantial progress has been made towards identifying what is needed for such collaborative partnerships, and towards such a partnership.

Working with children with severe motor impairments provides an opportunity to have very meaningful discussions with intellects and minds that are largely inaccessible to most people, and to open new doors to new minds. But there are also many documented and undocumented challenges, and the designers should be prepared to deal with these. Unknowing and awkwardness, for example, were observed and experienced. New challenges are being explored such as, in collaborative design sessions, finding ways for the teenagers to not just respond but also generate ideas, and ways to improve the clarity of their responses and contributions, which would also reduce the designers’ unknowing.

Lest a reader be intimidated from working with children with severe disabilities based on a fear of these potentially uncomfortable feelings, it must also be stated that working with these two teenaged girls continues to be a very exciting, intellectually engaging, socially uplifting, and spiritually rewarding activity. There is a lot that a designer will need to do to

engage in participatory design with this population, but the real and potential benefits are enormous.

It is very important that nothing written here be construed in any way as a criticism of the center or caregivers. The site is an amazing place. The staff provide these children with a rich, wonderful, and healthy life. This paper focuses not on the children’s perhaps more basic needs, but on the challenges and opportunities in advancing children’s intellectual and creative development, specifically as is needed for design collaboration.

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