Desperately Seeking Simplicity:

How Young Adults with Cognitive Disabilities and Their Families Adopt Assistive Technologies

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ABSTRACT
A surprisingly high percentage of assistive technology devices (35% or more) are purchased, but not successfully adopted. Through semi-structured interviews with a dozen families, we have come to understand the role technology plays in the lives of families who have a young adult with cognitive disabilities, and how families find, acquire, and use these technologies. This study addresses gaps in existing research and informs future efforts in assistive technology design. Design implications include the importance of simplicity not only in technology function but in configuration, documentation, maintenance, and upgrade or replacement; as well as the need for designers to use methods that consider the multiple individuals and stages involved in the technology adoption process.

Author Keywords
Cognitive disabilities; ethnography; design; technology adoption; assistive technology

ACM Classification Keywords
H.5.2 [Information Interfaces and Presentation]: User Interfaces - User-centered design; K.4.2 [Computers and Society]: Social Issues – Assistive technologies for persons with disabilities)

INTRODUCTION

Personal technologies have transformed the way we work, stay in touch with our family and friends, collect and share music and other media, and in general how we spend our free time. For families with a child with cognitive disabilities there is widespread hope, though not always fulfilled, that personal technologies can bring a dramatic increase in their level of safety, independence, and social connectedness, and assist in the difficult life transitions often experienced by people with special needs [4]. Unfortunately, research has shown that a high percentage of assistive technology devices that are purchased, 35% or more, end up sitting around unused and abandoned [8] [11] [15].

Assistive technology (AT) is the term used to describe technological devices or software that have been designed to assist people with disabilities. AT includes wheelchairs, hearing aids, screen readers for the blind, and special educational software for people with learning disabilities. One weakness in the existing literature is that studies of technology adoption tend to group together all types of disabilities, from motor and sensory to cognitive (e.g. [11] [15]). The types of AT devices in use for different disabilities vary widely. A single abandonment rate for all AT does not provide a very useful picture for anyone, given the large differences among the devices and the populations that use them.

Another shortcoming with studies in this area is that analyses tend to focus purely on successful adoption vs. abandonment. This simplistic, binary approach fails to reveal the ways and contexts in which technology is used [18], user satisfaction, and whether the technology is effectively addressing the impairment; issues which are paramount for designers creating new AT. This approach also fails to reflect the processual nature of technology adoption: the adoption process has multiple stages that take place over time [16].

A third gap in previous research is related to the way assistive technology is defined and identified. I will argue that the category of assistive technology is problematic, because it ignores "regular" technology that has been re-purposed or appropriated [3] to compensate for a disability. By starting out with a preconception of what is and isn't assistive technology, these studies are only providing a

CHI 2006, April 22–27, 2006, Montréal, Québec, Canada.

partial picture of the role technology is playing in the lives of people with disabilities.

To address these three gaps in the existing literature, I conducted semi-structured interviews with parents and teachers of young people with cognitive disabilities. My core research questions were: What role does technology play today in the lives of families who have a child with cognitive disabilities? How do families find, acquire, and use these technologies? What are the key factors that increase or decrease adoption of technology?

The paper begins with a description of the methods and setting of this study. I then discuss three major themes that emerged in the findings: the role of multiple individuals in the adoption process; the critical importance of simplicity of AT, particularly in configuration and support; and the perceived potential benefits of assistive technology. I provide design implications for each of these issues and conclude with a discussion of the broader impacts of this research in identifying direction for further assistive technology adoption and usage research.

THE COGNITIVE LEVERS RESEARCH PROJECT

This research is part of a larger project at the University of Colorado called the Cognitive Levers research project. The Cognitive Levers (CLever) research project is a collection of projects that explore the application of new technology to increase independence for individuals with cognitive disabilities, and to aid the support community who provide care for them.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [1] defines a person with cognitive disabilities as one who is "significantly limited in at least two of the following areas: self-care, communication, home living social/interpersonal skills, self-direction, use of community resources, functional academic skills, work, leisure, health and safety". It classifies four different degrees of cognitive disability: mild, moderate, severe, and profound. Approximately 80% of people in this population have mild disabilities. Another 14% have moderate to severe delays. In total, 20 million Americans are living with cognitive disabilities [2], which result from a variety of developmental etiologies including Down syndrome, certain genetic disorders, birth defects, and in some cases cerebral palsy and autistic spectrum disorder. Other cognitive disabilities result from acquired disorders such as Alzheimer's, and dementia.

Creating effective technological tools to assist individuals in this population is a challenging task. Previous studies have shown that although individuals with cognitive impairments have greater functional disability than individuals with other types of impairments, they use the fewest number of technological aids [10]. Studies suggest that this is due at least in part to the absence of technology designed for this population [15]. The goal of augmenting cognition [5] is less concrete than augmenting other types of disabilities, such as vision or mobility, because the cognitive mechanisms people use to achieve their goals vary between individuals and over time. It is not as simple to determine where the cognition ends and the "cognitive prosthetic" should begin [13]. Cognitive abilities vary widely even among individuals diagnosed with the same type of disability such as autism or cerebral palsy. Each individual has a unique set of abilities, and an effective technological tool must match the individual's needs in order to augment his or her abilities.

For these reasons, assistive technology design, particularly when focused on assisting individuals with cognitive disabilities, can benefit from an ethnographic approach that illuminates the needs and abilities, goals and motivations of these individuals. Ethnographic methods include on-site interviews, which are used in this study, as well as observations, diary studies, and other types of data collection that support rich qualitative analysis. In this research, an ethnographic approach has provided a deeper understanding of the network of caregivers that typically surround an individual with cognitive disabilities. This network, often including parents, doctors, case workers, teachers, doctors, physical therapists, will greatly influence how technology is perceived and used.

METHODS AND SETTING

The goal of this study is to gain a broad understanding of the types of assistive technologies used today by young individuals with cognitive disabilities, the purpose and usage contexts of these technologies, and how these technologies are adopted. Since young people spend half their day in the school system, it was important to include both teachers and parents as interview respondents. Where possible, I interviewed the teacher and parent of the same child.

Interview questions followed these general themes:

- Current assistive technology devices in use, and their role and impact in the life of the student/child
- Assistive technology devices that the respondents used in the past, and why the devices are no longer used
- Other technology (PCs, Walkman devices, video games) used by the student or child
- Wishes for future assistive technology
- Initial response to, and recommendations for, two CLever projects (MAPS, a handheld prompting system, and Mobility for All, a public transportation guidance system).

The interviews were deliberately conversational in nature rather than formal surveys, in order to let themes around these topics emerge naturally. Interviews were conducted in the family homes or the teachers' classrooms. This setting allowed the respondents to show and demonstrate many of the devices described, as well as the physical contexts in which they are used.

As with many studies of minority populations, there are only a small number of potential participants in the local area. As such, the participant sample was non-random and identified through snowball sampling, where current participants identify other potential participants. The inclusion criteria were deliberately functional rather than clinical, and describe an upper and lower bound of ability. Specifically, participants were chosen who have a student or child with the following characteristics. The student or child:

- has moderate to severe developmental/cognitive disabilities
- is physically capable of independently operating very simple technology (e.g. a switch, which is an input device that consists of one large button)
- is pre-adolescent or older, and is socially capable of performing tasks away from a caregiver
- may or may not have used, or be using, an AT device

Functional descriptions have been found to be more effective than clinical or condition-based descriptions to indicate whether an individual can use and benefit from assistive technology [13]. Using simple, functional criteria also allows caregivers to make their own assessment about whether or not their child or student fit the criteria, and they do not require access to medical records.

In total, twenty interviews were conducted with twelve families and eight teachers in the Boulder and Denver area. Interviews lasted from 30 to 90 minutes (the family interviews were somewhat longer and teacher interviews shorter due to teachers' constrained schedules). Among the families, I interviewed four mothers (the rest of the family was not at home), and eight mother-father pairs. The child with a cognitive disability was present for eight of the family interviews. All of the families were broadly middle class, held a variety of occupations, and their children attended public school.

The individuals with cognitive disabilities ranged in type of disability, age, and gender. Four of the individuals have autism, five have Down Syndrome, and twelve have other or unspecified developmental disabilities. Many of these individuals are multiply handicapped, meaning they have a physical, visual, or other disability in addition to cognitive impairment. The ages of the children ranged from 13 to 23, with the majority between 18 – 23 years old. All children lived at home with their parents at the time of the interview (one has recently moved and is now living with assistance in her own apartment).

A variety of technologies were discussed, ranging from communication aids to alternate computer input devices to video games and Walkman devices. Table 1 summarizes the different types of assistive technologies that were either tried or are currently in use by the participants. This table does not include technology used purely for recreation (such as GameBoys and Walkman music players).

AT Category	Examples	# of Devices
Communication	Augmentative communication device, picture symbols	21
Writing	Word prediction and spelling software, word processor e.g. AlphaSmart	10
Prompting/ Scheduling	Picture schedules, timers, watches	
Reading	Screen reading software	9
Educational Software	Software & web-based educational games	8
Alternative Input	Special keyboard (e.g. IntelliKeys), switch	6
Math	Large-button calculator	3
Remote Communication	Cell phone, memo recorder	3

Table 1. Types of Assistive Technologies and Number of Devices Discussed in each Category in the Interviews

Interviews were audio-taped and transcribed, and analyzed qualitatively using methods from grounded theory [17]. Grounded theory is a structured approach to qualitative data analysis that allows concepts to "emerge" from the data (in this case, interview transcriptions), rather than an analysis based on a pre-determined set of categories. For this study, researchers coded concepts observed in the data, which were iteratively reviewed, revised, and similar concepts combined, until a few key "theories" emerged. Throughout this process the researchers sought to stay "close" to the data by continuously revisiting the transcriptions. Key themes emerged around the complexity of the adoption process, the need for simplicity in technology configuration and maintenance, and the common hopeful optimism towards technology.

UNDERSTANDING THE ADOPTION PROCESS

As mentioned earlier, studies have shown that there is a high rate of unsuccessful adoption of assistive technology. Through these interviews it became apparent that technology adoption is a process with multiple stages, and cannot be understood by only looking at a single point in time. It became clear that breakdowns in adoption can occur 1) due to the conflicting perspectives of the many individuals involved; and 2) due to the length of the adoption process.

Role of Different Individuals at Adoption Stages

Rogers [16] presents an adoption process model with five stages: knowledge or awareness of the innovation, persuasion (internal or external) to adopt, deciding to adopt, implementing the innovation by incorporating it into one's situated context, and confirming that the innovation is appropriate or not. The earlier stages are based on the intended or predicted uses of the technology, while the incorporation and confirming stages are based on the actual needs of the users in the context of their existing practices.

However, Rogers' model and many adoption studies assume that a single individual, or the same group of individuals, are making the decisions at each adoption stage. Among the interview participants this was actually often not the case, but rather different individuals or groups were involved in the adoption process at different stages.

One illustrative example is Erin (all names used in this paper are pseudonyms), who is a high school student with moderate to severe cognitive disabilities and moderate visual and hearing impairments. Erin's mother Paula feels that a touchscreen provides the best interface to the computer for her daughter. However, the family doesn't have a touchscreen at home, so the daughter uses the mouse which is more difficult for her. Meanwhile, Erin's teacher stopped using a touchscreen with Erin because the teacher was aware that Erin had become accustomed to using a mouse at home; the teacher reported that Erin reached for the mouse instead of touched the touchscreen.

In this case the teacher felt like it was important to give the daughter a consistent experience at school and home; the parent wanted a touchscreen to be used at school because it was easier for her daughter. At first glance it may seem like the teacher and parents simply weren't communicating with each other. However this example illustrates a common theme in the interviews: parents wanted the *best* technology available for their child and wanted it to be introduced and supported by the school system, which they felt had the expertise and support to do so. Busy teachers, on the other hand, gave a preference to technology that a student is already familiar with either from home or from previous school years. Teachers are also encouraged to give their students the most available and least costly technology options, give that there is a limited resource pool of AT in the school district.

This example demonstrates how the priorities of the parents and teachers that affect technology choice in the decision-making stage may be in conflict with one another. In other examples, such as the case described below, teachers and parents played prominent roles at different stages of the adoption process, which also created unintended challenges to adoption.

Length of Adoption Process

For a number of families the acquisition of AT is a lengthy process, in some part due to working with external agencies such as insurance companies and Medicaid. In the case of Kate and Nick, the acquisition of an AT device took over a year, during which time the potential user graduated high school and developed a lifestyle in which the device no longer added much value.

Nick's mother Kate had the school system's support while locating and choosing assistive technology for her son, but lost support at the incorporation stage. Kate wanted a portable device that would help her son Nick, who has autism and is almost completely nonverbal, to communicate. Nick recently turned 18 and so Medicaid would pay for a device. Kate describes how the school and the family worked together to identify a high functionality, expensive communication device for Nick called a LightWriter.

> Yeah those guys [the AT specialists], they came out. And we looked at all sorts of things together, and we tried all sorts of things, and it was the whole team. And Nick was there too ... and he tried them all too. And [the LightWriter] was ... the most portable, it had the most functions. People didn't have to stand looking over his shoulder to read what he was saying, so that, it had that comfort factor, too.

But things broke down in the incorporation stage, when Kate thought she would have the support of the school but did not. Acquiring the device through Medicaid took over a year, and by then Nick was close to finishing school. Kate explained:

> When it finally came there wasn't much time left in his school career to actually make it be functional. Because we all agreed that he needed to use it at school, in the school setting, to make sure that it wasn't a toy. Because if he came home, you know how can you force it, at home. When you don't really have to talk at home anyways. You know what I mean? So we all agreed that it had to happen at school. That school had to be the forcing agent here to use it, to make sure that it wasn't a toy. And there just wasn't time.

Kate goes on to describe how she feels stuck with what she has, and indicates that she questioned the appropriateness of the device in the first place:

> And once it was bought it was pretty much, this is it. It's yours now. And you're never getting another one. I kept saying, there has to be something more portable, there has to be something more portable. And I wasn't shown anything. From all the catalogs that they had ... I don't know how different it would have been if the timing had been better. It might have turned out to be really, more productive, if we could have actually had, like the school really working on it. As opposed to not. So, I don't know. Who knows.

Since acquiring the LightWriter, which cost over $3,500 and still sits in Kate's closet, Kate found and purchased a small device called a "hip talker" on her own, which is much more portable, cost a few hundred dollars, and which Nick uses regularly.

Schools frequently work with families to acquire a device near the end of the child's school career, because a school will often lend devices to students that it must take back when the child graduates, and because when students turn 18 they have additional financial support for technology through Medicaid. However this can create a situation where technology is chosen that is too complex and/or expensive than the family would have otherwise chosen; and the family is relying on the school for help incorporating the device into the student's life.

Design Implications

Among the interview respondents it was common for multiple groups to be involved in the adoption of assistive technology, and for these groups to play a different role at various stages of the process. Specifically, AT specialists or speech therapists often identified a potential technology; teachers were often involved in the trial period and decision-making stage; and parents were expected to incorporate the device into the student's life (or maintain it after the student leaves the school system). Each of these caregivers has a unique set of motives and beliefs about the purpose and appropriate usage of technology, and about a student's abilities, needs, and interests. This can create conflicts in the AT adoption process. These findings are consistent with Orlikowski [14] and others who have demonstrated that when there are conflicting perspectives or framings of the situation by different stakeholders -- in this case, between AT specialists, teachers, and parents -- it can lead to deep misunderstandings and unsuccessful adoption of technology.

To further understand adoption in this context, designers should consider the different stages of the adoption process and the network of caregivers involved. When collecting requirements for new assistive technology, designers must make the effort to understand and gather input from the various individuals who will be involved in the adoption process at different stages, including the often overlooked stages of incorporation and maintenance. For example, a designer might analyze the current practices and patterns of usage of existing technology in different physical contexts, such as while an individual is at her job or volunteer position, or community activity; and interview the individual's caregivers in those environments to understand the different caregivers' perspectives on the individual and the technology. The design process should include bringing awareness to, and perhaps even reconciling some of the divergent expectations, perceptions, and goals among the network of caregivers.

KEEP IT SMALL AND SIMPLE, PLEASE!

Parents and teachers identified three major desirable features for increasing simplicity of assistive technology: portability, simple yet evolving functionality, and ease of upgrade and replacement.

Portability

Nearly every parent and teacher cited small size and portability as a benefit of a current tool they use, or as an improvement on a bulky device. Some families also described the lack of portability as a reason for abandonment. One mother, Vivian, explained why her daughter Laura never moved her communication device from the kitchen table, and how this ultimately contributed to abandonment:

> It was cumbersome, that's a cumbersome thing to haul around for a kid, and then the motivation has to be there. If you want to communicate, it has to work. It has to coordinate with what you want, what you are able to do, and try to get that message out there. Well, she could just as easily go over to that cabinet and grab a cookie, as try to come over here, and try to press on this super hock [Laura's communication device] cookie button and it would say, "I want a cookie." And we tried to do different things, to make it even more motivational, but this is a kid who pretty much gets her needs met without language.

This is a case, representative of other parents' and teachers' descriptions, in which a cumbersome, heavy AT device is not used when the user is in a mobile environment. This example also illustrates the challenges parents have in motivating their children to use assistive technology when the children can get their needs met in a more direct way, although it may be less socially appropriate. This was particularly an issue with augmentative communication devices such as the device Vivian wanted her daughter to use. Vivian wants Laura to learn to communicate with strangers in a socially acceptable way, and sees technology as a way to facilitate that; but Laura sees the device as unnecessary and an annoyance while at home where she can communicate more directly through action. Vivian felt that motivation may have increased if the device was something Laura could have easily carried around with her.

Simple to Use and Able to Evolve with Child's Abilities

While it is a platitude to say that anything is better if it is "easier to use," parents and teachers strongly emphasized ease of use as an important property of assistive technology, referring specifically to the need for a very simple interface and a low learning curve. A few respondents explained that because of his/her disabilities, if their child had initial difficulty using the technology they were very unlikely to ever go back to it. Parents also suggested that the device could increase in complexity over time to grow with its user, as long as it started out very easy. When asked to give

the most important factor in successful use of assistive technology for her son, one mother explained:

> I think it would have to have ease of use, it would have to be easy to use … I mean, at first obviously it would take him a while to learn it, but definitely I think the biggest factor has to be ease of use

She went on to explain that the technology functionality should grow with the child:

> ... the device would have to also have the capability of becoming more complex as they get more and more used to the computer so that they're still advancing with the system, not something that's outlived its use. It has to be able to be expanded upon.

Parents' perception of technology complexity also had to do with understanding its functionality, documentation, getting it set up, and recovering from failures. Complexity did not always refer to the device interface itself being too complex for the child to use. For example, Kate explained why the LightWriter never got used by describing three areas of complexity: in configuration, in the interface, and in the documentation. When explaining the configuration process, she describes, "it's too complex, too many steps and too much work to just say his name and address."

Kate also explains her impression of the technical documentation that came with the device, and why she never even bothered calling technical support:

> The book was so confusing that I couldn't even figure out which version of Light Writer I had. I mean, so it was like, and you know if you call somebody, they're going to ask you a question, and you're going to sound stupid because you don't even know what machine you have sitting in front of you! … I mean, it took me a long time to figure out that I don't have the one that does this, I have the one that just does this. So that's why I can't get it to do what I've been trying to get it to do. So, while there probably was technical support, I never used it because – it was just too hard.

Finally, Kate explains why she was afraid of too many buttons on the complex user interface, and how this added complexity would make it harder to troubleshoot:

> "[I need] something without as many buttons, because he wouldn't know how to use all the buttons, and he'll jam it, and I would have to come home and figure out how to fix it."

Perceived complexity of configuration also affected AT adoption in the case of Karen and Fred, who recently purchased a few expensive devices for their daughter Angie through Medicaid. Angie is in her early-twenties and has Down syndrome. All of the recently purchased expensive devices require initial configuration, which Karen has not gotten around to doing. The assistive devices that the family does use with Angie are a simple memo recorder that records a single 30-second message, and a kitchen timer that prompts Angie when she needs to leave the house. Karen explains why the more expensive, complex devices have not been used:

> This is very complex. And I think the issue is, getting the time to set it up and work all the bugs out … And the thing about the Voyager [an assistive technology for browsing the web], or any of these, is just sticking with it, getting really good at operating it. If we had a computer set up … I mean, this is on a laptop right now. And with time con [sic] ... space limitations, and pulling it out, and setting it up, and this and that right now, it just hasn't been a priority in getting that mastered. And I'm really the only computer nerd in the house, so to speak.

Karen contrasts this with the simple memo recorder that she uses every day with Angie to prepare her for that day's activities:

> And what I like about this … is the simplicity of it. The ease of use, the, in the hurried world that we all live, it's just real, there. She pushes a button, she gets a message, she knows what the day will include

In Karen and Fred's case, the time investment of figuring out how to set up the more expensive devices they picked out for Angie is too high, given that the AT has not yet shown any value.

Karen's desire for technology that is "just there" and reliable was echoed by other parents who struggled with maintaining technology at home. Another mother explained how her son's simple communication device would periodically "zero itself out," and she would have to re-program everything in from scratch, each time having to call technical support because the programming process was so difficult and complex. Over time the communication device was abandoned because of this painful process, and her son instead uses paper-based picture cards to communicate.

An interesting observation that adds nuance, if not contradiction, to this description is that while simplicity was repeatedly emphasized, many of the children discussed in the interviews were rather technically savvy, and are already skilled users of everyday technology, including video games, computers, Walkmen, and VCRs and stereos. In fact, many parents explained that their children were drawn to technology because of its predictability and consistent behavior, and some parents and teachers even felt they had to limit the time their child spent playing video games or at the computer. A teacher described a case where a student quickly learned how to reprogram his communication device and would intentionally erase its contents, requiring the teacher to reconfigure it all over

again. The teacher lamented that the technology designers underestimated the technical ability of the users.

Simple to Upgrade and Replace

Simplicity also arose as an important feature when the technology was being upgraded or replaced. The importance of being able to update or replace a system arose more among families than teachers, probably because school systems have a better process in place for updating or replacing broken technology. Parents recognize that a fundamental property of technology is that it will break or "wear out," and will need to be replaced. A mother describes this in the context of her daughter's large button calculator:

> She has a large number calculator. So both the keypad is large, and the display is large, and it's tilted so it cuts down on the glare. And we got that at Walgreens! They're not hard to find. We've gotten them from Radio Shack too. And when they wear out, they wear out, but they're not very expensive ... plus she has one for home and one for school.

Another mother explained why she decided to buy an inexpensive communication device for her son:

> It was under 200 dollars. So when it breaks, it will be easy – it will be replaceable. It won't be like a big, 'oh my goodness. now what do we do?'

The same mother described how she found a simple memo device at Radio Shack that worked effectively for her son, and bought every single unit in the store (!):

> I know in middle school we had a cool little thing that we used. Again, I found a $69 talking memo thing, at Radio Shack, that was the coolest thing, we used it in middle school. But when I found it it was already on clearance. So I bought up every one I could find. And when they broke, they just broke, nobody would fix them. So we used that, and that was in middle school a lot.

The ability to replace technology also relates to issues of cost. Cost of technology played a different role at school and at home. As mentioned earlier, at school high cost devices actually seem to be abandoned more often because of the "limited resource pool" of assistive technology in the school district. For example, the school district may have five communication devices, and must decide which five students will benefit the most from having the device. If a device is not making an impact for a student, the teacher has pressure to return the device, rather than invest time helping the student learn and use it, because the impact the device is having with the student must justify it not being available for other students. One parent explained it like this:

> There's usually kind of a friendly inertia working against you in the sense that yeah, they want to be nice to you but they really don't want to do anything special because they have a limited dollar pool.

Teachers also described how they work within the paradigm of a limited resource pool:

> I was the one who terminated the use of the Dynavox, because I felt like the district was tying up a $7,000 piece of equipment and it wasn't fair to other people. So that was my ultimate decision. Could he use it? Probably, two or three years, but, I didn't know if, weighing the need for it in the district, if that was fair.

Another teacher described how she stopped using a touch screen with a student, and how the cost of the device was a consideration:

> And that's a pretty expensive piece of equipment, and rather than have it getting broken in the classroom, I just said, she's not using this anyway, so let's send it back.

At home, although many parents have some AT costs covered through insurance or Medicaid, cost is still an issue largely because parents didn't want to spend a lot of money on a device that would break or get lost, which most parents took for granted would happen. One mother explained why she didn't buy her autistic son a PDA, even though he would probably benefit from it:

> And you know, he is pretty reckless, we didn't want to have a piece of $300 equipment that he was carrying around, either. So expense became an issue.

Design Implications

The various aspects of simplicity described here: portability, ease-of-learning, ease of configuration, and replaceability span the hardware and software of a system. Portability is largely dependent on the hardware choice; ease-of-learning and ease of configuration are mainly dependent on the software design; and reliability and replaceability really depend on both. On the hardware side, replaceability is tied to cost and availability.

These observations suggest two important implications for assistive technology design. First, devices that do not have direct usefulness out-of-the-box, before configuration or customization, are less likely to be adopted. Parents are generally very busy people, and few enjoy "tinkering" with technology. Technology that can demonstrate value before requiring a major investment in time and effort to learn how to configure the device appear to have a better chance at successful adoption, because parents will be more willing to invest time once the value is proven. One design approach for this may be to support incremental configuration or

customization rather than assuming it will happen all at once before initial use.

Second, the importance of supporting configuration, updating, and replacing through the software means that the system should support backing-up, exporting, and restoring a system configuration, including any customizations. Usability must include not only the functionality and user interface of the device during normal use, but also consider the documentation and support materials, and the lifecycle of the technology from configuration to replacement. This issue has been raised elsewhere [7], in a call to expand the lens of usability to look not only at initial use, but also at the "end of life" of hardware or new versions of software, when the software needs to be moved or upgraded.

HOPES, DREAMS, AND TECHNOLOGY

Parents and teachers described desired outcomes of assistive technology in broad terms, including increased independence and safety, and increased and more appropriate social interaction. These desired outcomes reflect the role of technology, beyond merely facilitating a task, in altering the emotional and social context in which it is used.

Increased Independence

Both parents and teachers cited increased independence as a major benefit to using technology, and one of the potentials that technology holds. For example, Donna is a senior in high school who is multiply handicapped and has cognitive, visual and physical disabilities. Donna can walk, with the assistance of ankle splints. Cognitively, she has difficulty remembering multiple steps of a task. She has a work-study job at the high school in the cafeteria serving food, and her mother Emma created a low-tech memory aid for her: she took pictures of Donna at her job, and created a poster-sized chart with the pictures and single word reminders of Donna's different tasks on the job. Emma describes the benefit of the chart:

> She was able to be more independent, and knew, I have a chart, I don't have to ask … it's an independence thing.

Parents also discussed the challenge of finding the right technology for their children that would increase independence. Bobby is 20 years old, has autism, and lives at home with his parents. He loves computers and calculators, but he doesn't use any technology that addresses his disabilities. His mother Mary expresses the difficulty of finding the right kind of assistive technology to bring Bobby more independence:

> We've never gotten a handle on what would fit. We know that he could certainly use some support in a lot of different areas and could be more independent, I think, with support, but we don't really know what that is.

Parents often combined independence with the need for social interaction. In the following example, a father explains that technology should increase his daughter's independence as well as community involvement. Annie lives at home with her parents Jim and Sandy. She is 23, and has Down Syndrome. Annie used to use more technology when she was in school, but now she just uses her cell phone and occasionally a computer. She is active in the community, and holds two part time jobs. When asked how to measure the success of technology, Jim explained:

> what's the definition of success ... if it's used, and if it keeps her on task, and enables her to be more independent, and out in the community, then it has value.

Jim describes the important role Annie's cellular phone plays in bringing her independence:

> Well, when she first started going to work, I mean, she'd call from the bus stop, she'd call from the bus itself, she'd call when she got to Middletown, she'd call when she got to work. I mean, it's part of the process. Without the cell phone, she wouldn't have a job. And now, I don't know Sandy, does she call a couple times a week, maybe?"

Annie's mother goes on to connect the importance of the social connection, and how it increases her sense of safety:

> Yeah it's just, I know I can contact her, find her you know, and she can call us, or she can call ... she knows a lot of numbers, she knows a lot of people she can call if she needs help.

Emma describes the potential role a cell phone could play in her daughter Donna's independence:

> It's almost like an intermediary to being independent. I'm not with you, but I can follow where you are and I can contact you immediately and you can contact me immediately.

In this example Emma articulates how the cell phone can potentially increase social connectedness as well as her perception of safety, because the mother and daughter are only a phone call away. Unfortunately her daughter Donna doesn't currently use a cell phone because the buttons of a standard cell phone are too small, and so this potential is yet unrealized.

Increased Social Interaction and More Appropriate Social Behavior

Most of the assistive technology that families used played a role in increasing social interaction. Another important corollary to this is that parents didn't just want increased social interaction, but also appropriate social interaction mediated through the technology. For example Kate has found or devised a few simple technology devices for her non-verbal son Nick, all of which are directed at increasing

his social interaction. Nick uses an inexpensive communication device that has 8 buttons, each of which cause a voice recording to play; Kate has programmed "hungry," "hello," "goodbye," and other single word messages that he can use "out in the community". Kate also makes sure that Nick writes and sends an email every day, using a small laptop that she purchased inexpensively. Kate has also "appropriated" a talking photo album for Nick, which has recorded messages about Nick, along with pictures, so that he can introduce himself to others.

Parents also described how the right technology could guide their children to behave in ways that are more socially appropriate, and become more socially accepted. Laura, a freshman in high school, sometimes uses a computer at school and at home, and likes to visit musical web sites (with the help of her Mom, Vivian), and look at photographs on the screen. Vivian explains how technology might help Laura to have more socially appropriate behavior:

> Appropriateness instead of maybe going up and trying to hug you, which she would be prone to do. You know, which a lot of people with disabilities do. And we try to teach her, okay, what would be more appropriate is high five, or what's up. I see technology as maybe a way to make a friend. You know, just in the limited sense, but to just say hi, what's up, how are you.

Vivian is hopeful that technology could play a potential role in helping her daughter overcome existing social barriers and become more socially accepted.

Design Implications

Communication devices that not only support communication but also mediate it according to social norms are found in assistive technology as well as mainstream technology. One example is the Aware Chair [12], an assistive device used by people who are "locked in," meaning that they have very little physical ability to communicate, yet have a lot of brain activity. The Aware Chair has a simple biosensor input, and a smart interface that recommends communication options according to the time of day, who is in the room, and history of interaction with conversation partners. In another example, a "persuasive" cellular phone called the KITphone (keep-in-touch) reminds phone owners periodically to call people in their contact list who they haven't been in touch with recently [6].

Assistive technology designers should consider the role that technology will play in caregivers' goals around independence, social connection, and safety. Research in cellular phone usage has identified different roles that the cell phone plays among different age groups: for young people it is primary for social expressiveness and social interaction; for families it is primarily for coordination; and for the elderly it is adopted primarily for safety, and "remote caregiving" [9]. It is important to study what types of communication tasks are involved in caregiver-client communication, and design technology that supports those tasks. A follow-up study of this research might be to look at what specific role mobile communication plays in addressing the desired effects outlined by parents, and what technology might look like to support these tasks.

CONCLUSION

This research study focused on understanding technology usage among a population with a specific type of disability, in order to provide a more accurate picture than what is given in studies that group together all people with disabilities. This research also focused on the people using the technology, rather than starting with a problematic pre-determined definition of assistive technology, in order to understand how technology is used. This approach led to the observation that much of what families are using is re-purposed or appropriated technology that was not intended to be AT, but has been found to functionally assist with the impairment. These off-the-shelf solutions tend to be simple, inexpensive and replaced without hardship.

Technology adoption must be studied as a process, consisting of multiple stages, and involving a variety of caregiver stakeholders, who jointly form a caregiver network. This research has demonstrated that decisions made at each stage are based on different aspects of the environmental and social context. For example during the evaluation and decision-to-adopt phases, perhaps functionality takes the highest priority; during incorporation, maintenance, and upgrade/replacement, simplicity becomes paramount. Each caregiver has goals and expectations around assistive technology, and more studies should be focused on clarifying those goals, and exploring how existing assistive technology does or does not address these goals. Furthermore, the goals of each caregiver group in the network need to be understood when technology is chosen, and an "adoption plan" should consider each stakeholder's expectations at each stage of the process.

Studying the adoption process of existing assistive technology among real families has uncovered important design implications for future technology. These implications apply not only to assistive technology but are relevant more broadly to technology design in general. For example, studying the adoption process has reinforced the claim that user-centered design must focus on the entire life cycle of the technology, from configuration, to maintenance, to upgrade and replacement. In addition, usability analyses must incorporate not only the normal usage of the device, but also the supporting materials for configuration and maintenance (which may be done by a different person), including documentation and troubleshooting aids. This study also found that technologies that required a lot of initial configuration before they could be used were often still sitting on the

shelf; whereas technologies that provided simple, immediate usefulness were prevalent. This study lends evidence to the importance of carefully crafting a positive "out of the box" experience. Finally, this research highlights the value of incorporating ethnographic methods in the design process by demonstrating that although these findings come out of deeply studying the *specific*, they add to our knowledge of the *general* by contributing to our understanding of technology usage and design.

ACKNOWLEDGMENTS

I would like to thank Claudia and Bill Coleman whose generosity and concern for people with cognitive disabilities have made this research effort possible; as well as the members of my dissertation committee who have made substantial contributions to the method and data analysis described in this paper. This research was funded by a grant from the Coleman Institute for Cognitive Disabilities. Most of all, I would like to thank the participants of this study, who shared their valuable time and lives to make this study possible. All participant names have been changed to protect individual identity.

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