Design Methods to Engage Individuals with Cognitive Disabilities and their Families

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ABSTRACT
In this position paper, I describe the process of adapting and combining traditional design methods to design assistive technology *with* and *for* individuals with cognitive disabilities and their family caregivers. First, I will present a research project to design a remote communication system with families with a young adult with cognitive disabilities. I will then discuss design methods that contributed to this research.

BACKGROUND
Today, many individuals with moderate cognitive disabilities live with their parents as children and young adults. When these individuals graduate from the school system, parents find themselves with the added responsibilities of acting as their grown child's primary caregiver and social coordinator, managing their child's schedule as well as their own [5]. New supports are needed for this family-based care model, such that parents feel secure and confident letting their adult children go out into the community, and know they are safely reaching their potential as active community members.

Remote communication can potentially play a dramatic role in increasing the independence of young adults with cognitive disabilities [10]. Yet there are significant HCI problems for this population with off-the-shelf mobile phones, and there is little research to understand the requirements for a remote communication system for individuals with cognitive disabilities.

RESEARCH GOAL
In this research, I co-designed a picture-based, handheld remote communication system with young adults with cognitive disabilities and their family caregivers. The system has simple mobile phone capabilities. The user sends and receives calls through a picture and audio-based interface (see Figure 1). The system also supports remote communication tasks specific to the needs of the families, and the system interface and functionality is customized for the needs of each user. The platform is a Windows Mobile 5.0 handheld phone. The goal of this research was to design an effective remote communication system for each family, and to understand the dimensions of customization that the system would need to support to become a meta-design environment, to evolve with users' needs and abilities.

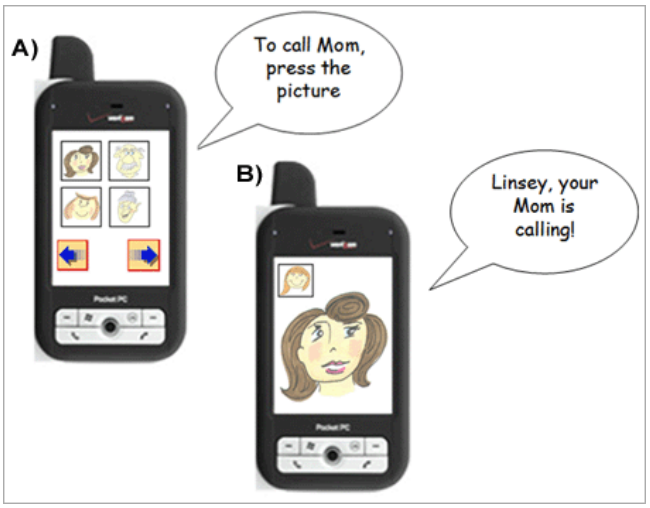

Figure 1: Remote communication system for the care recipient. A) Making a call; B) Receiving a call.

DESIGN APPROACH
This research project had three phases, with each phase progressively grounded in and building on the previous phase. I first developed an understanding of *how things are* by studying existing practices and technology in use, and then moved to exploring *how things can be* by introducing new technologies into the environment. I combined design methods including ethnography[11] , participatory design [14], and evolving technology probes [8].

The first phase was a semi-structured interview study (n=20) with parents and teachers of students with cognitive disabilities [4]. The purpose of this phase was to gain a broad understanding of the role that assistive technology

plays today for these groups, and the benefits and barriers to assistive technology adoption and use. I learned about current technology that caregivers are using to provide care, and technology young adults with cognitive disabilities are using (including assistive technology, and general technology like video games and portable music players). I explored issues and barriers in assistive technology adoption that parents and teachers have experienced. Finally, I asked parents and teachers to share their hopes and dreams about assistive technology, so that my research could be guided and inspired by the visions of my user population.

In the second phase, I took a closer look at a few themes that emerged in Phase 1: remote communication, independence, and social connectedness. Phase 2 was a more in-depth semi-structured interview study with fewer participants (n=5). The research setting was the family home, and I interviewed parents and their young adult children with cognitive disabilities. I learned about ways that caregivers and care recipients achieve remote communication today, and the role that it plays in increasing independence and safety. I also explored perceptions of independence and safety, among parental caregivers as well as among young adults with cognitive disabilities. Although some of the young adults with cognitive disabilities used mobile phones and some did not, I learned about common themes in requirements and desires for an accessible mobile-phone based remote communication system.

In the third phase, I conducted an evolving technology probe study [8] with two of the participant families from Phase 2. The purpose of this phase was to understand how a handheld remote communication system can support the remote communication tasks specific to each family, and how each family's needs and requirements change over time through realistic use. In this phase I co-designed the technology probe through participatory design activities with each family. The functionality and user interface reflected the needs and abilities of the child with cognitive disabilities and the goals and practices of the families. The technology probe simultaneously supported remote communication and unobtrusively "observed" the user in communication tasks. In *probe fashion*, we also added features to the system meant to inspire and provoke families to reflect on ideas about future technology During this phase data was collected through the probe usage logging, a nightly voice-mail diary, semi-structured interviews and observations. We conducted participatory design activities during the probe study to modify and evolve the probe, and then I implemented the modifications. Evolution was based on usability problems as well as new ideas that emerged through use.

UNIQUE DESIGN ENVIRONMENT

There are three ways in which this design environment differs from a typical software design project. First, we are designing for individuals with a wide range of cognitive and physical abilities. While we strive for universal design, we must also recognize that each user represents a "universe of one" with unique needs and abilities. As a result, designers can make fewer assumptions about users' abilities and ways of interacting with technology [12]. Typical user-centered design methods like single interviews and brief observations are not sufficient to develop a good understanding of a person's skills and practices. Basic user models used for evaluating an interface must be reconsidered for users with disabilities [9]. This is complicated by the fact that these users are more challenged in describing their own situation and motivations. Often, the skills central to abstract conceptualization and reasoning are very limited, and users may be unable to conceptualize and verbalize their individual needs and preferences.

A second way in which this environment differs from a typical user-centered design scenario is that each user is represented by him or herself as well as through a network of caregivers, among whom there is distributed knowledge about the user's abilities, interests, and behaviors [2]. Caregivers also have hopes and goals for the individual with cognitive disabilities, and the motivations of the caregivers must be understood and balanced with the individual's motivations during the design process.

A third consideration for this project is that it takes place in family homes and communities, rather than the workplace. Conducting design in the home environment introduces dimensions of accessibility, privacy, dynamic and ad-hoc organization, and a more delicate environment that changes with the presence of the researcher [3, 8].

REFLECTING ON DESIGN METHODS

A carefully crafted research methodology that considered the unique aspects of the design environment was needed in this research. I will now discuss the strengths and limitations of the design methods I incorporated in the project.

Ethnography

Ethnographic methods such as in-depth semi-structured interviews, participant observation, and diary studies [1] provide the designer with rich real-world data about the user's social and cultural environment. These activities are extremely valuable to ground a design project in rich user data. Yet there are challenges using ethnographic methods in a private setting such as a family home, where a researcher can't unobtrusively observe family activities in the home for extended periods of time. Also, ethnographers frequently spend years collecting sufficient data to describe a social situation, during which time they dedicate their lives to the project and immerse themselves in the culture of study. Technology designers almost never have the time nor the inclination for such an undertaking.

Participatory Design

Participatory design empowers users as co-designers of their own technology. In my design environment, caregivers and individuals with cognitive disabilities are both vested stakeholders in the design, and have very different ways of contributing to the design process. I found that caregivers were able to contribute to typical participatory design activities (such as sketching and evaluating low-fidelity mockups) much more than individuals with cognitive disabilities. Another limitation of participatory design is that it only considers the technology system during the design phase, and doesn't address how the system must change and evolve during use time [6].

Meta-Design

Meta-design is relevant for this design environment because it can potentially help address the following issues:

- **Wide variations in user ability**. Due to the variance in individual users' abilities (for a device to be used by people with a range of cognitive disabilities), the user interface and functionality of the device will need to be customized (most likely by the family caregiver).
- **Frequent changes in communication needs**. Parents frequently update their children's augmentative communication devices based on current activities (e.g. to talk about what the individual did last weekend, etc.), and so there is reason to believe that the remote communication device may need to be frequently updated.
- **Changing usage environment**. The environment in which the communication device system will be used is far more dynamic than a workplace environment, and changes in users' abilities and environment will introduce new communication needs.

The meta-design approach recognizes that a technology system will need to change and evolve during use time according to the unique needs of different users.

When designing new technology, there is a bootstrapping problem in anticipating the nature of evolution [15] before the user has begun to use the technology. Designers need to anticipate which system modifications should be possible, and which should be easy. Since every configuration option and user interface element adds complexity, each dimension of customization must be considered judiciously. Easy modifications should be in areas of the system where the desired behavior and or appearance of the system are very likely to differ between users, and should be supported as customizations before or during use time. Possible (but less easy) modifications can be in areas where the behavior or appearance of the system are likely to be the same for most users, and so can be treated as more advanced capabilities. Some aspects of the system need to be made intentionally difficult to modify, in order to prevent accidental breakage of core functionality.

Before use, new envisioned technology will have limited meaningfulness for users, and users will thus have limited motivation to participate in design. Even when users are highly motivated, most are unable to predict and articulate their own contextual behavior before they have incorporated the technology into their lives. Figure 2 and Figure 3 illustrate these two challenges.

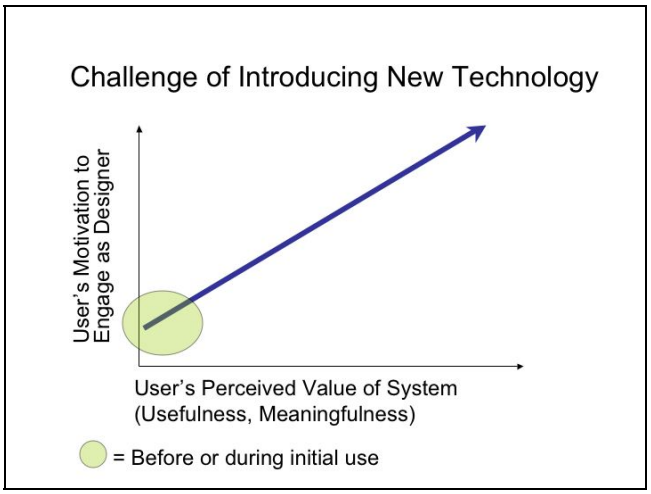

Figure 2: Risk of assuming user motivation before user has experienced value from the system

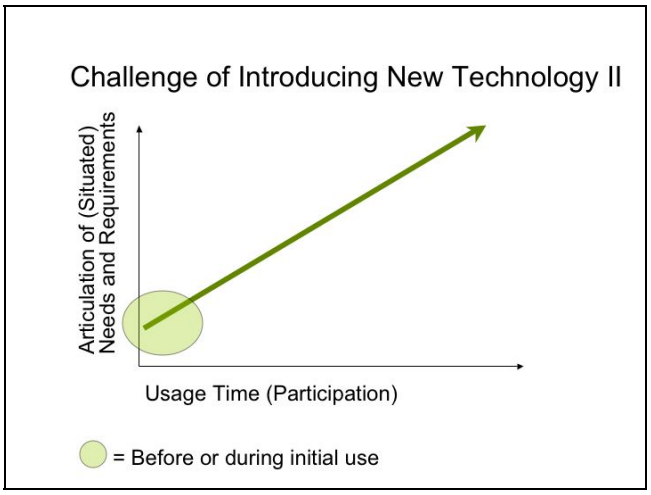

Figure 3: Challenge of anticipating situated action, and dimensions of evolution

These figures illustrate the challenge of designing a meta-design environment for new technology. In my design approach I found I could mediate these challenges by combining participatory design with technology probes, which incorporate *technology usage as part of the design process*.

Technology Probes

Technology probes [7, 8] explore a domain of human behavior by providing simple, useful functionality, inspiring users to consider how technology can enhance their environment, and collecting extensive usage data through realistic use.

Insights into Requirements for a Meta-Design Environment

Traditionally, the functionality of a technology probe does not change over the course of a study. To explore emergent customization needs, I actively modify the technology probe through participatory design activities throughout the usage study. I found that supporting an *evolving* technology probe gave insight into how users' needs change over time, and how our system could be designed as a meta-design environment.

Engaging with Individuals with Cognitive Disabilities

During the probe study, the participants with cognitive disabilities moved from passive onlookers to active participants in the design process. I hypothesize that there are at least two reasons for this: technology probes support *knowing-in-action* and *reflection-in-action* [13]; and the probe provides affordances that connect emotionally with the participants with cognitive disabilities.

Individuals with cognitive disabilities, like everyone, have a great deal of knowledge that is tacit and embedded in their actions, which makes self-reporting difficult [13]. For these individuals, this is compounded by a limited language ability and difficulty with abstract thought. Rather than asking users to describe previous usage scenarios or imagine future ones, technology probes allow users to interact directly with technology and effectively "show you" what they want and need.

Challenges

Challenges of conducting an evolving technology probe study include the intensive time requirement of a researcher during the probe study, to maintain and evolve the technology in rapid iterations. Researchers must be committed to address technology problems and requested changes rapidly in order to maintain a high level of trust and confidence by the participants. Another challenge with a technology probe is that it introduces technology into the environment fairly early, and may narrow the design space prematurely. Researchers can present various versions of modifications, or even various versions of the probe, to actively encourage participants to consider diverse design ideas.

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