
Designing a Remote Communication Device with Young Adults with Cognitive Disabilities and Their Families

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Abstract

This research study uses a combination of interviews, participatory design, and a technology field trial to understand how remote communication technology plays a role in the independence, social connectedness, and safety for young adults with cognitive disabilities and their families.

Keywords

Cognitive disabilities, ethnography, mobile communication, participatory design, technological probes

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.

In particular, mobile communication has the potential to play a dramatic role in increasing the independence of young adults with cognitive disabilities [4]. My dissertation research explores applying user-centered design for mobile communication devices (customized cell phones on a hand-held platform) for this population.

Background

My research began with a round of interviews conducted in 2004 with 20 families and teachers in the Boulder and Denver areas. All of the families have young adults with cognitive disabilities who are living at home. This study looked broadly at assistive technology usage and adoption issues among young people with cognitive disabilities [2]. Remote communication emerged as playing a key role, or potential role, in increasing the independence and social inclusion for young people with cognitive disabilities (and an increased sense of safety for their parents). However, off-the-shelf cell phones generally had major usability flaws for this population, including complex menus, small buttons, and fragility.

Parents also described remote communication tasks that regular cell phones aren't designed for, such as controlling who is called, a panic button that would dial a configured phone number or series of numbers, and

more generally, the ability to check that a person is "okay" without necessarily talking with them.

These findings led me to focus on remote communication for my dissertation research. My current study involves some of the same participants from the initial interviews, and looks more deeply at the remote communication needs of these families, and potential technology designs.

There are at least three challenges for designers applying User Centered Design in this context. First, while we strive for universally-accessible design [5], each user will have a unique set of abilities and needs. A second challenge is that users are represented by a group of individuals, including themselves and a network of caregivers, among whom there is distributed knowledge about the user's abilities, interests, and needs. Third, designing technology for the home and mobile environments introduces dimensions of accessibility, privacy, and a more delicate environment that is changed with the presence of the researcher. A carefully crafted design methodology that considers these dimensions is crucial [1].

Method

The goal of this research is to deeply understand the tasks and context in which families use remote communication with their young adult with special needs. To gain this rich understanding, I use methods from ethnography including interviews, observations, and a newer method, technological probes, that combines a technology field trial with ethnographic data collection, in order to understand the focus population.

Interviews & Observations

I am currently conducting another interview study with local families who have an adult child with a cognitive disability. These interviews are focused on understanding how remote communication plays a role for these families in the areas of safety, coordination, and independence. The interviews are semi-structured (meaning I have a list of interview questions, but the interview is more conversational than a formal survey), and generally take place over two separate hour-long sessions. Unlike the previous interview study, the young adult with cognitive disabilities is asked to participate directly in the interview. I ask questions to both the parents and the son or daughter with cognitive disabilities.

This interview study includes 4 – 6 families. There are fewer families involved in this phase than the initial interview study because the interviews are more in-depth and require a higher level of commitment by the participant.

Representative User Tasks

The results of this round of interviews will be a small set of representative remote communication tasks for each family. These tasks will then be used to guide the participatory design process and technology field study.

Participatory Design Sessions

At the end of the interview study, I will meet with each family and review and refine their task descriptions. Then we will create simple, low-fidelity (paper-based) design mockups for the user interface of a remote communication device that matches the tasks.

Device Field Study (Technological Probe Study)

The largest study in my research is a device field study, which will provide rich, real-world usability data with a remote communication device with the target population. For a period of 8 weeks, the family members with cognitive disabilities will use the device to communicate remotely with their parents and others. Families will also be empowered to suggest design changes to the device during the course of the field trial.

For this field study I am planning to collaborate with a local software company that develops systems for people with cognitive disabilities, AbleLink (<http://www.ablelinktech.com>). AbleLink has recently developed a hand-held based cell phone tool that is picture-based, and has a simplified user interface, called the Pocket Ace. This collaboration is important in ensuring that my research findings will influence real product design in the near-term. My research will also benefit by having a much more stable platform to give to study participants than a typical research prototype.

This field trial will follow the lifespan of the remote communication device, from initial configuration, to a usage period of 8 weeks. In this way, I will be able to analyze both the caregiver interface for configuring and customizing the device, and the experience of the person with cognitive disabilities using the device for daily tasks.

The device will be instrumented to maintain a detailed log of usage, which can be uploaded to another computer and reviewed regularly. This will complement ethnographic data collected from the families via a traditional diary study through the course of the field

trial. In this way, the device will act as a technological probe [3], which is a technical artifact that collects real-world usage data about participant behavior in an area of interest, e.g. mobile communication, while also inspiring and evoking meaningful design ideas from its users in the course of use. Technological probes have been used in design environments where it is difficult to apply standard ethnographic methods, such as in the family home, and during highly mobile activities.

In this study, design meetings will be held every two weeks (4 total) with each family, during which the family will suggest improvements and modifications to the device based on usage experience. "Update" meetings will be held in alternate weeks during which the device is upgraded with recommended design changes, and any usage issues are discussed.

Anticipated Results

My research incorporates ethnographic methods and participatory design in order to fully include young adults with cognitive disabilities and their parents in the design of their own mobile communication device. This research also explores the role of a technology probe as a nexus between ethnography and design, in a sensitive research setting in which traditional user centered methods must be adapted. This project develops a rich understanding, grounded in empirical data, of the role of mobile communication in

independence, social connection and safety between parental caregivers and their children with cognitive disabilities; and will inform user interface guidelines as well as design methods for building assistive technology on mobile devices with this population.

Citations

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