Exploring the Communication Needs of People with Disabilities Through Participatory Design

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Abstract
Communication is among the most intimate and important activities in human life. Design for people with physical and cognitive disabilities often overemphasizes the practical aspects of communication and underemphasizes the social and emotional aspects. This project aims to increase our empathy and understanding of the social and emotional aspects of communication to aid in the design of assistive technology that better supports this population of users. We describe our approach to participatory design with people with limited speech including the challenges and iterative modifications to the methodology.

Author Keywords
Empathy, Communication, Assistive Technology, Participatory Design

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction
Goals: Augmentative Alternative Communication (AAC) has transformed the lives of people with speech disorders by providing alternatives to and enhancing spoken communication. However, available technologies often overemphasize the most functional aspects of speech such as requesting and information

transfer, while underemphasizing the more social and emotional aspects of communication [1]. While it is of tremendous importance for designers of these technologies to develop deep understanding and empathy for the user group in order to address these vital and more intimate aspects of communication and social life, this approach presents many challenges. The goal of this project is to develop methods for understanding the most important aspects of communication for people with significant speech impairments, and for responding to these needs with design.

Challenges: The primary challenge of conducting participatory design with this user population is difficulty with speech-based methods. While it is generally understood that questions in ethnographic interview should be open ended, this is a significant challenge with this population, because their ability to produce long or complex answers to questions is limited and they are accustomed to answering yes/no questions or completing partial sentences. Here, it is possible that despite the obvious developmental differences from children, methods that have been developed to elicit responses from children could be adapted for this population. Booth and Booth [2] suggest it is acceptable to use leading questions as long as a participant demonstrates a willingness and ability to say no. We remain concerned about how best to approach this very significant challenge. In particular, the validity and reliability of responses can be questionable for users of assistive technology with limited vocabulary [3].

One of the arguments for engaging in participatory design with children despite their communication challenges and limited skills is their creativity and divergent thinking [4]. A challenge working with users who have spent their lives in institutional settings is that they may have a high degree of learned helplessness, and be unaccustomed to having choice and agency [5]. This can make it difficult for participants to buy into and believe in their agency in the design process. In addition, people with disabilities have a long history of being exploited and abused by researchers and professionals, which can make it even more important, and challenging, to build the kind of trust that is necessary for participants to feel optimistic and engaged in the work.

In addition, it can be real challenge for designers when they do not know how to engage or understand. We hope this project will lead to new insights into the information, emotional supports, tools and methods designers working with this population need to thrive.

Methods

Participants: The 9 initial participants in this project (which is ongoing with additional participants) are adults with physical disabilities ranging in age from 40-80 years old. All participants are part of a therapeutic day program for people with cerebral palsy and related disabilities, where they spend every day participating in a mixture of vocational, recreational and rehabilitation related activities. All participants use wheelchairs for mobility and have some degree of upper extremity impairment as well. While all participants have some form of significant speech disorder, they have a variety of abilities when it comes to communication. While the participants do have some cognitive and social differences, they have a generally high level of cognitive ability.

Fig. 1: Image Boards

Ethnographic Observation of Social Skills Group: Participants are engaged in a weekly discussion group about social skills and relationships. The group consists of a mix of facilitated discussion about social issues participants' experiences, as well as more structured activities and exercises. Observing the group is an excellent opportunity to learn more about what is important to participants in the realm of social interaction. Another advantage of the group is the opportunity to leverage the group knowledge and familiarity [6]. We attend the weekly meetings, collect audio-recordings and create detailed field notes. To date we have attended 9 meetings of the social skills group and an additional 8 hours interviewing and conducting design activities. We will perform content analysis to uncover themes and insights from these sessions.

Interviews With the Use of Visual Aids: Cue Cards [7] and Talking Mats [8] are tools that can be used to scaffold interviews by providing visual cues. While these tools are somewhat constraining considering the high level of cognitive ability among participants, they served as a model for the technique we developed. During the interviews each participant has a paper in front of them where each individual answer they give is written on a sticky note, as well as some quotes from their discussions during the social skills group. As the interview progresses a note is added every time the user answers a question and both the interviewer and interviewee periodically reflect together on the full picture created by the notes. This is especially helpful since the slow nature of communication causes the interviews to be broken up over multiple sessions. By making the notes transparent to the participant, we establish a greater level of trust in the reliability and validity of the insights we gather.

Image Boards: Within design education Mood/Image Boards are commonly used for providing inspiration and cohesion to design projects. Image Boards are usually collages of images that together help give the impression or overall aesthetic or affective idea for a specific design. Usually, the designer creates the board for themselves and then uses it to inform their understanding of the problem or their design of a solution for a particular project. For this project, the idea of Image Boards was borrowed, but the participants created the boards to represent their perspective on the design. To accomplish this each participant is offered a variety of magazines to choose from and they go through the magazines of their choice selecting images they are attracted to or they feel represent them. Once they have selected enough images, each user works with the researcher to compose a collage incorporating all of the images. The image boards are the first step in a participatory design process of iteration

Participatory Design of Custom Low-Tech Assistive Devices (work in progress): A predominant theme in the social skills discussions was the difficulty participants experience when interacting with people they do not already know. To address this need, in the next phase, participants and designers will work together to design low-tech wearable tools that introduce the wearer and how to communicate with them best. Because of the challenges these users have demonstrated with open ended conversations, this process will be iterative and take advantage of technology probes [4], [9]. The process will begin with the presentation of a series of prototypes and/or

sketches of different ideas based on the interview findings and image boards. The designer will ask the participant to respond with ideas and feedback, and then create a more refined set of technology probes for them to respond to. This cycle will continue until the participant is satisfied with the design and feels they are excited enough about it that they want to wear it and use it on a regular basis.

Preliminary Insights

While formal analysis is incomplete, several themes and issues have emerged. One important insight from the creation of the collages was that very distinct personalities and styles were apparent. While a one size fits all design might meet the practical needs of users, it fails to reflect the variation between individual personalities and emotional experiences. Another important insight is that participants within this community have in many cases known each other for their entire lives, and people have very strong feelings about others, positive and negative. In addition to some of this emotional build up, participants are adept at understanding each other's speech even though they are relatively unintelligible to unfamiliar individuals including the researchers. This collective knowledge and experience is an important asset to harness in the design process.

Ongoing Work

At the time of this submission the design process of the low-tech wearable devices is incomplete, but expected to be complete by Spring 2014. Additionally, content analysis to look for more detailed and robust themes and areas of opportunity of the social skills group discussions is ongoing. The most important contribution of the work will be achieved when and if the insights and methods developed here lead to the empathic relationships between designers and people with disabilities necessary for the development of novel assistive technology by.

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