4-1-2008

Mobile Communication and Data Gathering Software for Autistic Children and Their Caregivers

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Position Statement

Positive design leads to positive change in our society. In most cases, discussions focus on those who *receive* the design. However, positive design may also have a positive, but often over-looked, effect on the designers themselves. Learning about difficulties others face and developing solutions is a benefit that can contribute to individual designers' education and general sense of well-being. Having a broader understanding of alternative views and lifestyles makes one a better person. In addition, positive design may benefit the entire field of information science by improving its ability to renew itself and attract new, young talent.

Today, there is a pronounced lack of student interest, especially from female students, in entering any of the STEM (science, technology, education and math) fields. Computer and information science suffer in particular. This lack of interest is often due to a misperception of the field. Students believe that pursuing studies in information or computer science leads to a job performed in a small cubicle without human interaction for the rest of their lives. They often see information technology jobs as limited to writing code all day for large projects where they play an insignificant role and about which they do not care. This perception may be strengthened when design and programming of software algorithms and systems is taught only by means of small, artificial class exercises. Although such work allows students to focus on and practice the mechanics of programming, it may stifle creativity and interest. Positive design can help bring students back into computer and information science. To do this design well requires an interdisciplinary approach and a focus on the positive outcome for a specific user group. We organized workshops for high school girls and found that they were very excited about information technology when they could see it as part of a toolkit to accomplish a larger goal. For example, jewelry designs that included information technology to improve women's safety was a very popular topic. Working on applied, high-impact, high-touch projects motivates students who normally shy away from information technology. We do not advocate that basic computer science is unnecessary, but that an additional group of students may be attracted to the field if they knew they could work on applied projects and have a positive impact.

We are working on a project that brings out both sides of positive design: a positive impact for designers as well as a positive outcome for the users of the design. We are developing communication software to enable and improve communication between autistic children and the people in their environment. We are starting collaborations with high schools to involve students in the design process. We work with K-12 teachers and therapists who teach children with autism. These caregivers help design and serve as proxy-users to represent the interest of the

autistic children. This is necessary because our focus group consists of severely autistic children. Autism spectrum disorder (ASD) has become one of the most prevalent mental disorders over the last few years and its prevalence is growing. ASD is a developmental disorder characterized by a wide variety of possible symptoms such as developmental disabilities, extreme withdrawal, lack of social behavior, severe language and attention deficits, and repetitive behaviors. One of the primary impairments is difficulty with communication: between one-third to one-half of people with autism do not have functional verbal communication skills [1]. Bondy and Frost estimated that as many as 80% of children with autism below the age of 5 do not speak [2]. Developing spontaneous, functional communication is one of the most important steps in development [1, 3].

Tested and proven technology innovation for autism treatment is uncommon and almost entirely limited to genetics studies. Although very valuable, this work does not provide any immediate relief or feedback for parents and autistic children. Electronic devices or software suitable for early intervention with severely autistic children are unavailable. This is troublesome since early intervention is believed by many to have the highest impact [4]. Currently, the most popular system to teach autistic children communication skills is the Picture Exchange Communication Systems (PECS) [2], an approach of which the popularity precedes scientific validation. Using PECS, children learn to combine cardboard pictures to form a message. All pictures are kept in a plastic folder and grouped for usage. Pictures and groupings are personalized for each child. We believe a digital approach to communication may provide the same advantages and prove to be superior because it provides more media options, such as the use of high quality photographs, animated images, or sounds. Moreover, this approach leads to better data collection to support diagnoses and treatment. The existing intervention method, which is paper-based, makes systematic data gathering very difficult. As a result, many therapies are proclaimed to be the best without scientific evidence or based on ad hoc data collection. The software environment we are developing provides early intervention communication software for severely autistic children and evaluation support for therapists, teachers, and parents [5-8].

The communication software can be used with smartphones or PDAs to enable on-the-go communication. Images are uploaded, grouped into folders, and synchronized with the smartphone or PDA via a website, hereby eliminating the need for printing, laminating, cutting, and gluing Velcro strips to images. Teachers can reuse images by synchronizing several smartphones. They can also share images with each other. Our approach is unique because it allows, for the first time, tracking of communication behavior by young and severely autistic children. The online support environment will let teachers and therapists evaluate longitudinal communication data gathered via the smartphones. We will make it possible for many to discuss findings, complement the data with other child-specific information, and analyze progress using modern data analysis and mining tools. Our goal is to have 50 teachers or therapists actively engaged by the end of the year. The communication software prototype is ready to demonstrate; the online support environment is under development. In addition to an immediate effect on teaching communication to autistic children, we hope that increased interaction between caregivers and availability of systematically collected data will lead to new hypotheses, testing of existing hypotheses, and a scientific base for the many existing therapy models. Ultimately, it will improve quality of life for autistic children and their caregivers.

The research challenges are twofold. The first challenge is the human-computer interaction for the smartphone software and online community website. The second challenge is the business model that will allow the community to become self-sustaining. We work with parents, teachers, special education teachers, and therapists for whom the children in their care differ enormously in socio-economic status. One group in Southern California consists of public school teachers who report that parents are in survival mode, sometimes single mothers holding down two jobs to make ends meet. Many teachers have no special education training and there is no time for one-

on-one training with the children. For these teachers our software needs to be zero-learning time, reduce time spent outside the classroom, and be minimally disruptive in class. In addition, since teachers are not 'required' to gather data, updating the tracked communication data needs to be fast and easy to encourage voluntary participation. Our second user group is a private school in Northern Carolina where all children are taught on a one-on-one basis by therapists who try to measure progress systematically. Many parents are intensely involved. This group requires sophisticated software to review communication data and combine it with standardized test data or other observations. The third group consists of graduate students earning their teaching credentials in the School of Educational Studies at Claremont Graduate University. Some of these students are starting their own autism programs. They require easy-to-use software and an online community where they can consult experienced teachers and therapists. While we are developing the technology components we need to apply lessons learned from existing online communities [9] to ensure that we build an active community with a positive impact to which people want to belong. Current funding from Microsoft Research enables us to provide the PDA software as open source and develop the online community. However, a model is needed that enables this community to grow and become self-sustaining. People interested in joining the community and/or using the software should visit: www.communicationautism.org.

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