Designing Technology for People with Cognitive Impairments

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CHI 2006, April 22–27, 2006, Montréal, Québec, Canada.
ACM 1-59593-298-4/06/0004.

Keywords
Cognitive impairments, assistive technologies, design and evaluation methodologies, accessibility, inclusive design, universal usability.

ACM Classification Keywords
K.4.2 [Computers and Society]: Social Issues – *Assistive technologies for persons with disabilities*; H.5.2 [Information Interfaces and Presentation]: User Interfaces – *Evaluation/methodology; graphical user interfaces, prototyping, user centered design.*

Introduction

The CHI community recognized long ago the importance of including users with impairments in its mandate. A panel at CHI'86 on *Human Interface and the Handicapped User* [3], tutorials on *Designing for Users with Special Needs,* first offered at InterCHI '93 [5], the Conference on Universal Usability in 2000 and 2003, and the Assets Conference on Assistive Technologies, which started in 1994, provide some evidence. Despite these efforts there is still relatively little research investigating technologies for the cognitively impaired. For example, hcibib.org contains considerably fewer records relating to cognitive {impairment, disability, disorder, deficit} relative to other impairments.

The lack of research into cognitive technologies cannot be explained by an insufficient number of potential

users. Cognitive impairments range from ones that are present at birth (such as Down's syndrome), to ones that are acquired due to some form of head injury or illness (such as aphasia, a speech and language disorder, or amnesia), to ones that emerge through the normal aging process (such as Alzheimer's disease). In the US alone, an estimated 4.32 million people have mental retardation or a developmental disability [2]. Approximately 4.5 million individuals currently have Alzheimer's disease; this number is projected to grow to 14 million by 2050. Aphasia impacts approximately 1.1 million individuals in North America [1]. Cognitive impairments affect senior citizens disproportionately, and worldwide, one in 10 individuals is currently over 60; this is projected by the U.N. to grow to 1 in 5 by the year 2050. Thus there are significant numbers who could benefit from supporting technology.

We briefly highlight some cognitive technologies that have been reported in the literature. Wu et al. created a tool that allows amnesics to more independently explore new locations and situations [9]. MAPS (Memory Aiding Prompting System) provides a simple effective prompting system with an interface for caregivers designed to enable individuals with Down's syndrome to independently navigate in their community [4]. ESI Planner (Enhanced with Sound and Images) is a multi-modal planner that allows individuals with aphasia to maintain their own appointments on a PDA [7]. Think and Link is a project designing e-mail user interfaces for persons with cognitive impairments and a "cyberevaluation" or diagnostic protocol to identify the supports needed for a person to engage in email [8]. The Isaac project [6], a Swedish research initiative in the mid-nineties, outlined a vision of supporting independence for persons with cognitive disabilities, using a PDA incorporating GPS, cell phone, and digital camera technology in an Apple Newton base. The ISAAC project proposed a remarkable combination of technologies that are only now becoming common, ten years later.

In our own experience designing cognitive technologies, we have encountered unique challenges, which at least partially account for the limited research in this area. Those challenges include:

- **Developing appropriate design and evaluation methods.** HCI methods have evolved and achieved a degree of maturity over the last 2 decades, but many of these methods require substantial adjustment to work with the cognitively impaired. For example, individuals with language impairments cannot use a talk aloud protocol, nor can they even complete a standard questionnaire or interview. And amnesics cannot use a standard participatory design process because they don't easily recall events from one session to the next [9]. Adjusting existing methods is one approach, but is there opportunity for totally new methods that would be more appropriate for individuals with cognitive deficits?
- **Managing participant recruitment.** Finding and recruiting appropriate participants is significantly more difficult than in mainstream HCI research. For example, it is not possible to use a psychology subject pool or post calls for participation across a university campus. Recruitment usually requires partnering with medical centres or community outreach programs. How can we build partnerships to facilitate this process, and what special issues must be addressed with regard to conducting human subjects studies with vulnerable populations?

- **Designing for a "universe of one" vs. attaining generalizability.** A typical user study attempts to achieve a representative sample of users (which usually involves at least 8 subjects) and aims to generalize the results to the broader user population. Many cognitive deficits are highly variable (even within an individual), challenging the notion of a typical or representative user. How do we position research on cognitive technologies within a scientific community which espouses generalizability?

- **Understanding the role of diagnoses vs. functional assessments.** Often, new researchers look at diagnosis as holding promise for developing taxonomies of appropriate tools so that guidelines can be derived for system development. When does this approach work, and when might an approach that considers individual abilities vs. functional requirements provide a more appropriate fit? Are there ways to incorporate diagnosis into design requirements? What formal tools for applying a functional study of the user and task are available and used?

- **Requirement for dual user interface development.** Many systems require both an interface for the target user as well as one for the user's caregiver, which adds overall complexity to the system. How can we efficiently and effectively design and evaluate the "dual interface?" What tools and paradigms are useful for designing for a non-technical audience that must work with complex tools and environments?

- **Requirement for strong multi-disciplinary teams.** In HCI research, multi-disciplinary teams are often seen as a "benefit," but designing cognitive technologies seems to *require* teams which include people with the technology skills as well as those with skill in the cognitive deficit. The latter are required not only for their knowledge of a how a particular design might work for the target users, but also for their skill in working with the target user population. Which team models work best?

- **Locating sources for research partnerships and funding.** Research into designing cognitive technologies often falls into a gap between agencies that traditionally fund health research and those that fund technology. What are effective approaches to securing sustainable research funding? What are differences in research methodologies and practices?

In addition to the above challenges, we believe there are important themes that emerge in the research and development of cognitive technologies. These include:

- **North American vs. non-North American perspectives and approaches to developing cognitive technologies.** The European community emphasizes universal design and accessibility, whereas the North American community focuses on individual assistive technology design issues. There are other regional emphases – by explicitly analyzing the common themes, could there be more effective synergy?

- **A fuzzy boundary between assistive technology and rehabilitative technology**. Assistive technology usually refers to technology which increases, maintains, or improves functional capabilities of individuals with disabilities. Rehabilitative technology usually refers to technology that aids the user in regaining lost ability. The two approaches have areas of overlap, but the question is whether this categorization is useful from a design and evaluation perspective.

Goals

The three primary goals for this workshop are:

- To bring together the community of researchers who are creating cognitive technologies to share best practices.
- To generate new conceptual frameworks for how to advance assistive technology research for people with cognitive impairments.
- To identify fundamental differences, similarities, and synergies between different user populations with cognitive impairments and their caregivers.

Structure

Before the workshop: Applicants submit a short position paper related to the workshop challenges, themes, and goals. Authors include two questions they would most like addressed in the workshop. Attendees are expected to read all the position papers prior to the workshop.

At the workshop: Day 1 covers the challenges and themes. Attendees give short presentations of their position papers to refresh the group. Significant time is allocated for group discussion, guided by the questions and issues raised. Demonstrations of cognitive technologies by attendees will follow. Day 2 includes break-out sessions to discuss the remaining challenges, themes and questions. A preliminary conceptual framework on doing research for the cognitively impaired will be generated to summarize the workshop.

After the workshop: Outcomes of the workshop will be disseminated to the HCI community in a SIGCHI Bulletin article as well as to the cognitive rehabilitation community. They will also be made available on a public workshop website.

References

1. The Aphasia Institute. (2005). The Aphasia Institute: What is Aphasia? [Online]. Available: September 2005 at http://www.aphasia.ca/about/whatis.html.
2. Braddock, D., Hemp, R. Rizzolo, & M. Parish, S. (2002). The state of the states in developmental disabilities: Study summary. In Disability at the Dawn of the 21st Century and the State of the States. Braddock, D. (ed.), American Association in Mental Retardation, Washington DC, p. 124.
3. Buxton, W., Scadden, L., Roulds, R., Shein, F., Rosen, M.J., & Vanderheiden, G. (1986). Human interface design and the handicapped user (panel), *Proceedings of CHI'86*, 291-297.
4. Carmien, S. (2004). MAPS: creating socio-technical environments in support of distributed cognition for people with cognitive impairments and their caregivers. *Ext. Abstracts of CHI 2004*, 1051-1052.
5. Edwards, A., Edwards, A., & Mynatt, B. (1993). Designing for users with special needs (tutorial), *InterCHI'93*.
6. Jönsson, B., Svensk, A. (1995). Isaac, A Personal Digital Assistant for the Differently Abled, *Proceedings of the 2nd TIDE Congress*, 356-361.
7. Moffatt, K., McGrenere, J., Purves, B., & Klawe, M. (2004). The participatory design of a sound and image enhanced daily planner for people with aphasia. *Proceedings of CHI 2004*, 407-414.
8. Todis, B., Sohlberg, M., Hood, D., & Fickas, S. (2005). Making electronic mail accessible: Perspectives of people with acquired cognitive impairments, caregivers and professionals, Brain Injury, 19(6), 389-401.
9. Wu, M., Richards, B., and Baecker, R. (2005). Participatory design with individuals who have amnesia, *Proceedings of CHI 2004*, 214-223.