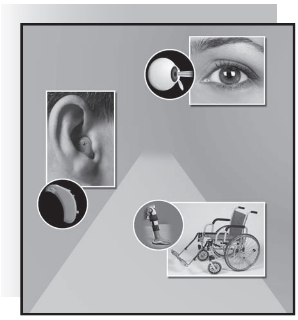

Assistive Technology for Cognition

Understanding the Needs of Persons with Disabilities

BY EDMUND F. LoPRESTI, CATHY BODINE, AND CLAYTON LEWIS

A cognitive disability represents a substantial limitation in mental tasks (such as planning, information processing, and understanding of social cues) that reduces a person's ability to perform desired activities. Cognitive disabilities can arise because of congenital or acquired causes. Assistive technology can reduce the affect of these disabilities and provide improved quality of life. A number of technologies are currently being explored. The success of these technologies requires understanding barriers to use of current technology, including people with cognitive disabilities in the design process, and transitioning technology from research settings into the marketplace.

Cognitive Disabilities

More than 21 million persons living in the United States have a cognitive disability (Figure 1), and this number is expected to increase rapidly as the nation's population ages [1]. Cognitive impairment, often labeled as a hidden disability, is a substantial limitation in one's capacity for mental tasks, including conceptualizing, planning, sequencing thoughts and actions, remembering, interpreting subtle social cues, and manipulating numbers and symbols.

The *Diagnostic and Statistical Manual of Mental Disorders-IV* defines a person with cognitive disability as one who is "significantly limited in at least two of the following areas: self-care, communication, home living social/interpersonal skills, self-direction, use of community resources, functional academic skills, work, leisure, health, and safety" [2]. Individuals with cognitive impairments may have difficulty learning new things, expressing themselves through spoken or written language, and making generalizations from one situation to another.

There is no one-size-fits-all definition or description of individuals with cognitive impairments. Cognitive disabilities may be neurobiological [autism, Alzheimer's disease (AD)]. They can also be acquired [traumatic brain injury (TBI)] or inherited (fragile X syndrome). Whatever the cause of a particular cognitive disability, the functional capability of the individual and his or her interaction(s) within multiple environments and social contexts at home, school, work, or play dictate the level of supports necessary to accomplish specific tasks or activities. The presence or absence of these supports, it might be argued, also dictates the level or degree of disability that is present during any particular task.

Although space does not permit an extensive review of all cognitive disabilities and their impact on daily life, the following sections serve to exemplify a few of the most common forms of cognitive disability and their personal, social, and economic impacts.

Intellectual Disability

The terms mental retardation and intellectual disabilities (IDs) are considered synonyms by the President's Committee for People with Intellectual Disability (PCPID). The driving force for the name change was to decrease negative connotations associated with the term mental retardation. According to the PCPID, the American Association on Mental Retardation's definition for mental retardation serves as the definition for ID: "Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18."

It is estimated that there are 7–8 million Americans of all ages who experience IDs. IDs affect about one in ten families in the United States. The following was observed in the PCPID's 2004 report:

- Around 90% of adults with IDs were not employed.
- Fewer than 1% of people with IDs owned their own home.
- 26% of youth with IDs dropped out of school.
- Fewer than 15% participated in postsecondary education.
- Over 365,000 people were employed in sheltered workshops or were in day programs or prevocational services.
- Supplemental security income (SSI) and social security disability insurance (SSDI) were a major source of income for people with IDs.
- At least 50,000 people with IDs were on waiting lists for Medicaid waiver services for individual and family supports.
- Over 700,000 people with IDs lived with parents aged 60 or older [3].

ID is a category that includes a number of conditions with different causes and symptoms. One example, fragile X syndrome, is discussed in the sidebar "Rehabilitation Engineering Research Center on Advancing Cognitive Technologies."

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Autism Spectrum Disorder

Autism is a developmental disability that affects cognitive skills including social interaction, language acquisition, and imaginative abilities [4]. As many as 1.5 million Americans today are believed to have some form of autism, with many more having related pervasive developmental disorders, such as Asperger's disorder. Because autism is a spectrum disorder, it affects each individual differently and has varying degrees. One model of autism, the weak central coherence account, addresses the fact that people with autism often focus on component parts rather than wholes [5]. As a result, people with autism often show superior performance on some visually presented tasks and other tasks that favor such focus. However, tasks that require integration or discrimination among many sensory stimuli or abstract concepts can be difficult. This can include such computationally heavy tasks as envisioning another's state of mind in social settings or imaging future states sufficiently to plan a task [6]. This can also put people with autism at risk for sensory overload, and difficulty functioning in the presence of many visual or auditory distracters.

Learning Disabilities

Learning disability is a general term for a variety of information processing difficulties that can impact learning and other functional activities [7]. Learning disabilities are sometimes classified in terms of scholastic areas affected; e.g., dyslexia (difficulty reading), dysgraphia (difficulty writing), and dyscalculia (difficulty with arithmetic). Learning disabilities may arise from visual processing difficulties, auditory perception difficulties, or memory difficulties or a combination of these. For example, the following difficulties could all contribute to reading difficulties [8], [9]:

- difficulties with visual recognition of letters, numbers, punctuation, and entire words, especially, confusion of characters or words with similar shapes
- letter reversal (e.g., interpreting a "b" as a "d")
- poor visual memory, which leads to problems with letter and word recollection
- spelling problems, often reflecting a phonic strategy with words like "of" and "all" being spelled "ov" and "olh"
- tendency to add duplicate or extra words, omit words, or reverse word order.

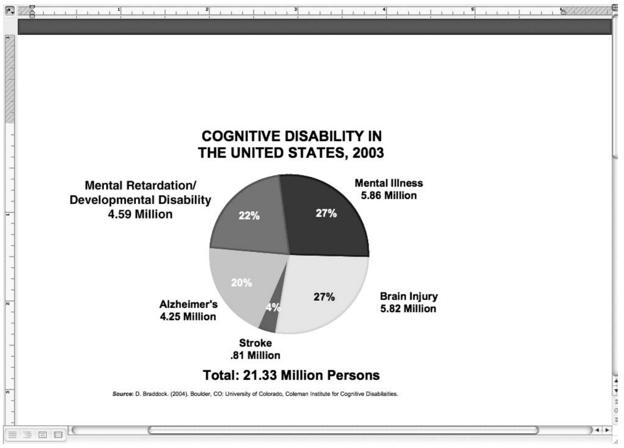


Fig. 1. Population of people with cognitive disabilities in the United States (by diagnostic group) (1).

Difficulties can also stem from cognitive difficulties related to sequencing (e.g., placing visual or auditory stimuli in the proper sequence) or abstraction (e.g., connecting a visual stimulus such as a written word with an abstract concept) [7]. Learning disabilities affect about 15% of the population [10].

Attention deficit hyperactivity disorder (ADHD) is often associated with learning disabilities but is a distinct condition. It is estimated that between 3 and 5% of children have ADHD (approximately 2 million children in the United States) [11]. The principal characteristics of ADHD are inattention, hyperactivity, and impulsivity. Diagnosis can be difficult as these symptoms are shown by all people, especially children, at some level; but they must be demonstrated to a degree that is inappropriate for the person's age for the person to be diagnosed with ADHD. The symptoms must also appear early in life (before age seven) and continue for at least six months and must create a real handicap in at least two areas of a person's life (e.g., school or social settings) [11].

Alzheimer's Disease

Dementia is a brain disorder that seriously affects a person's ability to carry out daily activities. The most common form of dementia among older people is AD. AD initially involves the parts of the brain that control thought, memory, and language. It is estimated that 4.5 million Americans have AD. This number includes 10% of those older than 65 years and nearly 50% of those 85 and older. By 2050, this number may reach 16 million. Because 70% of those with AD live at home, the impact of this disease extends to millions of family members, friends, and caregivers [12].

For persons with early-stage AD, mild forgetfulness and confusion can lead to medication errors, missed appointments, and anxiety. As individuals progress through the disease, significant cognitive disabilities manifest, eventually requiring 24-h care and supports. As with many types of cognitive disabilities, the role of caregivers and their need for additional supports cannot be underestimated. Within the next decade, annual Medicare costs for beneficiaries with AD will increase from US$32 billion to almost US$50 billion, and the estimated cost to American businesses will be more than US$61 billion. The business costs are primarily due to family care giving—absenteeism, productivity losses, and replacement costs—as workers struggle to balance the overwhelming responsibilities for a loved one who has AD with their obligations on the job [13]. As the numbers of individuals with AD increase, these costs along with the need for individual and caregiver supports will also rise exponentially.

Acquired Brain Injury

Cognitive impairment can be associated with an acquired brain injury due to TBI or cerebrovascular accident (CVA) (stroke). TBI is an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects the individual. The term applies to open or closed head injuries resulting in impairments in one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; and information processing. An estimated 4.5 million persons living in the United States have disabilities because of a TBI. For 80,000–90,000 individuals each year, TBI creates lifelong disabilities

[14]. A CVA occurs when a blood vessel that carries oxygen and nutrients to the brain is either blocked by a clot or bursts, which results in a lack of blood supply to the brain. Stroke survivors may experience impairments in memory and other cognitive functions. An estimated 5.5 million persons living in the United States have experienced a CVA, and another 543,000 individuals each year survive a CVA [15].

For persons with acquired brain injury, the recovery of functional capacity can take many turns and many years, with no guarantee of complete recovery. As with AD, caregivers also share in the cost and burden of acquired brain injury. The need for supports for individuals with acquired brain injury and their caregivers covers a wide range of functional skill sets requiring cognitive skills as diverse as complex attention, executive reasoning, prospective memory, self-monitoring for either the enhancement or inhibition of specific behaviors, and sequential processing [16].

Mental Illness

A person with mental illness may also experience cognitive impairments affecting memory, attention, or other cognitive skills. Cognitive impairments may be a symptom of the illness itself or a result of sleep or appetite disturbances associated with the illness. An estimated 5.9 million people in the United States have cognitive impairments secondary to mental illness [1].

Needs

Cognitive disabilities such as those described earlier can lead to barriers in performing daily activities at home, at work, or in the community. Technology could help people reduce or remove many of these barriers and achieve greater involvement in personal, social, and vocational activities. Technologies are emerging that help people with cognitive disabilities in a variety of domains, including planning, execution, attention, and memory [16]; literacy [17]–[19]; and social and behavioral issues [20]. However, before technology can be applied to meet the needs of people with cognitive disabilities, it is necessary to understand what those needs are and what barriers exist to technology use. Almost 60% of persons with disabilities have never used a computer, compared with less than 25% of persons without disabilities, and less than 10% of persons with disabilities have access to the Internet, compared with 38% of persons without disabilities [21], [22]. Large proportions of those who own devices either do not use them at all or do not effectively use them. In one study of elderly persons with cognitive disabilities, 15% of the devices people owned were not used, mostly because they did not match the owners' needs [23]. Psychosocial factors also underlie many instances in which technology is not sought or is abandoned. These factors include unrealistic expectations of the technology, poor confidence in using technology, lack of awareness of one's limitations, inappropriate needs assessment, poor device selection, and lack of support from caregivers [24].

A series of recent studies have investigated technology use among adults with ID [25], [26], adults with TBI [27], youth with ID [28], [29], and youth with TBI [29]. One study of 1,218 individuals with ID indicated that the need for assistive technologies is not being met by currently available devices [25]. About 34% of the respondents who reported a need for communication assistance were currently using technology in that arena; 54% of people who reported a need for home adaptation technologies were using such technologies; and 42% of people who reported a need for environmental controls were using them. Barriers to technology use included both technology issues and social or psychological issues.

A major technological barrier is the complexity of available technologies. Most technologies are not designed for people who have cognitive disabilities, and procedures for operating devices can be complex. Possible accommodations for people with cognitive disabilities include visual displays with reduced clutter, provision of information in nontext formats (e.g., graphics, video, audio), minimization of the number and complexity of decision-making points, presentation of information sequentially, and reduced reliance on memory [25].

Social issues include lack of training, lack of assessment of technological need, lack of information on the benefits of using a computer, and cost of technology. Results indicate a need for greater interaction between consumers and device manufacturers, a need to inform service providers about available technologies and assessment methods, and a need for more training and technical support from the manufacturer or service provider [25]. A study of 516 youths with ID found that these students had limited access to assistive technology partly because of lack of funding, lack of training, and lack of information about how technology could provide assistance. However, these younger individuals did have more access to computers, particularly through school [28].

In another series of studies, the Assistive Technology and Cognitive Disability Collaborative (sidebar "Assistive Technology Collaborative") looked at computer use across a variety of diagnoses and age groups, including 80 adults with moderate to severe TBIs [27], 53 youths with ID or TBIs [29], and 83 adults with ID [26]. Rates of computer use were 41% for adults with ID, 66% for adults with TBI, and 85% for youths with cognitive disabilities. Among adults with ID, computer users felt that their computers would be easier to use

Rehabilitation Engineering Research Center on Advancing Cognitive Technologies

The National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, acknowledged the critical need to foster research and development in the area of cognitive technologies and in 2004 awarded a Rehabilitation Engineering Research Center for the Advancement of Cognitive Technologies (RERC-ACT) grant to the University of Colorado at Denver and Health Sciences Center. The RERC-ACT is a unique partnership that encompasses multiple university programs, private and public sector agencies, and persons with cognitive disabilities and their caregivers throughout the United States. The RERC-ACT is designed to produce outcomes that directly impact the quality of life of persons with significant cognitive disabilities and their families. A number of research and development activities (many discussed in the main article) are geared toward exploring and developing innovative technology solutions for persons with cognitive disabilities.

The goal of the RERC-ACT is to contribute to improved rehabilitation, independent living, community integration, and overall quality of life for persons with significant cognitive disabilities through the use of innovative cognitive technologies. Information on the RERC-ACT can be found at http://www.rerc-act.org/.

with larger buttons and screens, if the devices had easier commands, and if the users had more personal assistance to help them learn the computer's features. People who were not currently using a computer most often cited lack of access to a computer, lack of training support, and cost as barriers [26].

Rates of use of electronic organizers (a category including handheld computers and other portable electronic devices) were 11% for adults with ID, 7.5% for adults with TBI, and 11% for youths with cognitive disabilities. Despite this low rate of use, there was high interest in using portable devices for memory and organizational tasks. Of those adults with TBI not currently using portable devices, 75% indicated that they definitely or probably would use a portable electronic device for tasks such as remembering things to do, remembering what other people say, and keeping track of money spent [27]. Most youths with ID or TBI did not report using any current high-tech or low-tech memory aids but rather relied on other people to remind them or attempted to remember things independently [29]. Across all three groups, participants expressed a desire for devices with a long battery life and readily available technical support [26], [27], [29]. Other features of interest included a large memory capacity [27], [29]; ease of use, a device that beeps or flashes so you can find it, better help functions (possibly with audio instructions), and higher durability [27]; ease of learning and flexibility [29]; and voice output [26]. Apart from potential assistance with memory and organizational issues, people were interested in standard features such as a cell phone or calculator [27]. Participants with ID were interested in using a portable device for music and games and more productive applications, suggesting that recreational uses might have a motivating effect in convincing people to adopt technology solutions [26].

Participants identified a number of barriers to use of portable electronic devices, which include cost, lack of confidence in their ability to select or use a device, and lack of confidence in current devices to meet their needs [26], [27]. Current or former device users reported difficulty learning or using their systems, difficulty remembering to use the device (i.e., remembering to carry it), and incomprehensible instruction manuals [27]. Other problems related to sensor and motor issues, such as being able to see small print on the screen or manipulate small buttons or a stylus [27]. Some users reported problems with their devices being lost or stolen [26].

The RERC-ACT is seeking to expand upon these earlier studies to further investigate technology needs and barriers among people with cognitive disabilities. Researchers at multiple sites (Denver, Colorado; Chicago, Illinois; Ann Arbor, Michigan; Rochester, New York; Pittsburgh, Pennsylvania) are conducting a series of focus groups involving people with ID, TBI, and early onset dementia and caregivers. Feedback from focus groups, along with results from the studies described earlier, are being incorporated in the design of a nationwide study to investigate how technology is being used, what barriers exist, and perceived unmet needs. A nationwide survey was distributed in late 2007.

Assistive Technology Collaborative

The Assistive Technology Research and Development Collaborative on Cognitive Disabilities (principal investigator (PI), Dr. Roberta DePompei, the University of Akron) is funded by the NIDRR. Partners in this project include the University of Akron School of Speech-Language Pathology and Audiology; Temple University, Institute on Disabilities; Spaulding Rehabilitation Hospital; and the Brain Injury Association of America. The project examines the potential of generic (everyday devices that all people use) electronic organizers, such as personal data assistants (PDAs), to enhance the independence of persons who have cognitive challenges as a result of TBI or ID. Use of such generic devices may support memory and organizational skills and lead to personal responsibility for daily participation.

The partner organizations have conducted a range of user surveys and effectiveness studies using a variety of handheld devices. Preliminary results of in vivo trials indicate that handheld devices and smartphones have potential for use with persons who have cognitive challenges. They have a catalog of product information, several PowerPoint presentations, a webcast, and a summary white paper available on the Brain Injury Association of America's Web site at http://www.biausa.org/Pages/AT/.

Assistive Technologies

Prompting

One area in which technology can assist people with cognitive impairments is memory and organization [16], [30]. External cueing systems can assist people with cognitive disabilities by reminding someone to perform a task at the appropriate time [31]–[33] or by providing a series of prompts related to steps in a task [34], [35].

Step-by-step task guidance can provide information about how to complete an activity or recover from errors or interruptions. In a series of studies, participants with memory impairments were able to perform tasks with reduced occurrence and severity of errors when receiving automated task guidance compared with a baseline condition with only written cues [34], [36]. Such task guidance could also be provided remotely over an Internet connection [37], [38], which allows the user to receive reminders on any device with an Internet connection while allowing a caregiver or clinician to remotely monitor the user's safety and success.

A device may be able to provide more appropriate or efficient reminders if it is able to detect a person's context; e.g., their location, the state of a task they are performing, or the presence of other people. Such a system might monitor a scheduled task to determine whether a person is having difficulties or needs reminders [39], or could continuously monitor a person's actions to deduce what activity the person is attempting, and what help would be appropriate [40].

A special case of context-aware task guidance is wayfinding assistance; i.e., using sensor information about a person's location to assist the person in navigating through his or her environment [37], [41]. Indoor environments can be instrumented with sensors such as radiofrequency beacons [42] whereas a global positioning system (GPS) can be used in some outdoor environments. Using knowledge of the person's location, a system could provide cues appropriate to that location or provide prompts to help the person navigate on foot to another location [41]. For longer distance travel, the system could interact with a transportation infrastructure, such as GPS-equipped public transportation

[43], to help the user identify the appropriate bus to take to a desired location.

At the RERC-ACT, projects are underway to design reminding, task guidance, and context aware technologies [43], [44]. One project is designing residential support systems that empower people with disabilities to live independently while providing individualized remote assistance from a professional caregiver when a resident has a problem. Caregiver support is a critical issue given the scarcity and high turnover in professional caregivers for people with cognitive disabilities and the physical and emotional demands often experienced by family members who care for people with cognitive disabilities. It is therefore necessary to understand when and how to engage the caregiver and the information needed to effectively resolve problems [43], [44]. Researchers are also exploring power sources to support context-aware sensors by harvesting power in the environment [45].

To support caregivers, it is also important for the task-definition process to be as easy as possible. This goal can be approached through user interface design [44] and other tools. For example, AbleLink Technologies (www.ablelinktech.com; Figure 2) has developed the AbleLink Instructional Media Standard (AIMS), a standardized XML format for defining a set of related picture, audio, and video files used for presenting instructional content. The instructional content may be step-by-step task instructions for individuals with cognitive disabilities, detailed instructions for complicated tasks for individuals without disabilities, training tasks for new employees at a job site, or home health care instructions for family caregivers. The AIMS protocol provides a common language to present the instructional prompts so that content can be created once and then played on multiple systems and platforms and easily shared with other individuals or organizations, reducing the frequency with which caregivers must create content. The authors of the AIMS (www.aimsxml.com) standards have created a toolkit designed to enable others who use task prompting systems to upload and download various task prompting libraries [46].

Assistive technology can also support decision making, which leads to greater self-determination [47]. Researchers at the RERC-ACT are developing technologies to support decision making in vocational and personal health domains [48] and to provide vocational training through animated tutors (Figure 3) [49].

Literacy

Cognitive disabilities often result in an inability of the brain to properly process and integrate sensory information. This can make it difficult to read printed text or to produce text with a pen or keyboard. By allowing information to be presented in different ways, computers can provide people with the flexibility to utilize their strengths and accommodate information-processing deficits. For example, computers can translate information between printed text and audible speech. Adjustments to the interface between human and computer, made with attention to a particular client's needs and strengths, can greatly improve a client's performance.

One area where such adjustments can be beneficial is the understanding and production of written text. Computers offer options such as changing text size and contrast or changing the color of the text or the background [50]. These interventions can make text easier to read for some people with learning disabilities. To further make information accessible, computers can augment visible text using speech synthesis software. Speech output can be an alternative to text or an adjunct, with the person reading most of the text and using the computer to speak unrecognizable words [51].

Computers also offer alternatives for text production. Speech recognition provides an alternative to handwriting or keyboarding. In one study, students with learning disabilities

Fig. 2. People with memory impairments can benefit from prompting technologies. A mainstream PDA running Pocket Coach software (www.ablelinktech.com) is shown here. Photo courtesy of AbleLink Technologies.

Fig. 3. Prototype being developed by the RERC-ACT to test the utility of perceptive animated agents as job selection and job training coaches for persons with cognitive disabilities.

University of Toronto

Researchers at the University of Toronto are exploring cueing strategies for people with cognitive impairments. Projects include exploration of context-aware prompting for older adults (39), research on visual prompting for people with dementia, investigation of the acceptability of home monitoring technologies, identification of effective communication strategies used by caregivers of people dementia, and the development of systems to provide safe, independent mobility for wheelchair users with cognitive impairments. For more information on work at the University of Toronto, see http://www.ot.utoronto.ca/iatsl/.

received higher standardized scores on written essays when using speech recognition than when using standard text production ($p < 0.05$), and their essays were longer and had a higher proportion of words with seven or more letters [51].

Researchers at the RERC-ACT are conducting efficacy research in the utilization of assistive technology to aid written communication. Evidence of efficacy is necessary to justify the use of assistive technology in schools. To provide support for anecdotal reports of educational improvements [17]–[19], [52], researchers are conducting controlled studies to determine whether the use of these systems is related to significant, measurable improvements in educational participation and writing tasks.

Sociobehavioral Issues

Cognitive impairments can also lead to social and behavioral difficulties. Some individuals experience poor impulse control or a tendency toward compulsive behavior patterns. Examples can range from simple hand wringing or rocking to self-injuring behaviors and from poor recognition of others' personal space to hostile behavior. Other people with cognitive disabilities are easily overwhelmed by environmental stimuli and therefore may have difficulties with concentration and social engagement. Difficulties in processing visual information about faces or auditory information about a person's tone of voice can also impair a person's ability to recognize social cues. Other people simply have difficulty learning social norms for behavior.

Some work has considered the application of assistive technology to neurobehavioral changes. The WatchMinder (www.watchminder.com) is an alarm wristwatch that can provide cues for a behavioral modification program. Other devices have attempted to use vibration or deep pressure to provide sensory stimulation and thereby help people with autism or other impairments relax and concentrate [53].

Researchers at the RERC-ACT are exploring use of a wireless device to present prompts related to behavioral issues subsequent to TBI. Findings suggest that a client's behavior could be moderated using alternate cues that are based on the requirements of different social settings [20].

Cognitive disabilities can also lead to social isolation for people who have fewer opportunities to travel in the community and who also have difficulty learning mainstream communication technologies such as e-mail. Researchers at the RERC-ACT have developed a digital mailbox for elders, including those with early onset dementias. The digital mailbox includes a fax-like machine in the elder's home, connected to an existing phone line, and a Web site for his or her family members that allows members to send, receive, and share communications. Family members can post messages (including pictures) to the Web site, which are delivered in a hardcopy, newsletter-like format to the elder's home. If someone in the home wishes to reply or send a message, he or she places handwritten material, photographs, or other content on the tray of the digital mailbox and presses a single button. The content is posted to the Web site, so family members see the message. Pilot work suggests that the digital mailbox helps build family involvement [98]. Using the digital mailbox, people in the care recipient's home get the benefit of two-way electronic communication without the necessity of owning or operating a computer. The digital mailbox user interface consists of a single button, with no dialing, menu selection, configuration, or other interaction required.

Design Guidelines

Designers can better understand users' needs by referring to models of typical user needs (user modeling). Since existing user models largely rely on data collected for individuals without disabilities, some researchers are now beginning to develop models that incorporate data for people with disabilities [54] or that encourage thought experiments in which the designer tries to put himself or herself in the position of a person with a disability [55] (see sidebar "Thought Experiments"). Designers also need to consider many factors that influence the human–machine interface, including user priorities, functional deficits, and the environment where the activity is performed, such as home, community, school, and work [24], [56].

Including People with Cognitive Disabilities in Research and Development Activities

User Testing

Although design guidelines are useful, it has long been recognized that developing effective user interfaces requires iterative refinement based on user testing [57]. Design guidelines cannot cover the details that need to be dealt with in fitting a user interface into a specific situation of use. Rather, developers must supplement adherence to guidelines with testing with representative users and tasks.

The need for user testing is even clearer for users with cognitive disabilities than it is for other user groups for two reasons. First, the available guidelines are only weakly supported by research [58]. Second, because few system designers and developers have experience working with people with cognitive disabilities, they lack good intuitions about their capabilities and needs [59].

Despite this need, many developers do not include people with cognitive disabilities in their test panels. Informal discussion with interested developers suggests two obstacles: uncertainty about how to work with people with cognitive disabilities [60] and concern about obtaining approval for inclusion of people with cognitive disabilities from institutional review boards.

To some extent, uncertainty about working with people with cognitive disabilities is a chicken-and-egg problem, which will be resolved as more developers take the step of including them in their user test panels. There is guidance available for those willing to try.

University of Oregon

Researchers at the University of Oregon have been exploring technology use by people with cognitive impairment to support community integration. The Get Outside project has explored technical supports to allow people with cognitive impairment to navigate in the community (93). Recognizing that people often have a network of possible support persons, the project focuses on providing coordination of the person with disabilities and this social network. The Think and Link project has explored the factors that affect the use of a typical software application (e-mail) by people with cognitive impairments and the social and emotional affects of having access to this communication medium (94). This project has resulted in a commercial product, CogLink (http://www.coglink.com/). More information on work at the University of Oregon can be found at http://www.go-outside.org/ and http://www.think-and-link.org/.

More attention is being focused on the design of technologies specific to people with cognitive disabilities.

Henry [61], in her online text on accessibility in user-centered design, provides useful coverage of issues on working with people with various disabilities, including some attention to cognitive disabilities. For example, she notes that more time may need to be scheduled for test sessions. She also reminds investigators that many people with cognitive disabilities have other disabilities also, so that (for example) wheelchair access is especially important as there is provision for the use of other assistive technology such as communication aids. Investigators can also profit from reading descriptions of user tests that have included people with cognitive disabilities such as that described by [62].

Concerns about obtaining review board approval are a reflection of serious issues in research ethics. Tragically, people with cognitive disabilities have been abused in research programs (see [63] for a discussion of the Willowbrook experiments, in which institutionalized children with cognitive disabilities were deliberately exposed to meningitis). Because of this history, institutional review boards are properly very cautious in examining proposals for studies with people with cognitive disabilities.

A key concern in all research is that participants provide voluntary informed consent [64]. People with cognitive disabilities may be strongly influenced by caregivers or family members, raising the question of coerced rather than voluntary participation. If participants cannot understand the description of the study, their consent cannot be informed.

One response to these concerns is for institutional review boards to require consent auditors, persons not affiliated with the project or with potential participants, who will monitor the process by which consent is obtained [65]. But this arrangement is potentially costly and may act as a deterrent to the inclusion of people with cognitive disabilities as participants. In some cases, boards can require that a surrogate be included in the consent process, someone who can act on behalf of the participant and withhold consent to participate if he or she judges it proper to do so [66].

In applying these considerations to participation in user tests, it is important to recognize that the risks to participants are much less than in many biomedical studies. The chief risks are frustration or embarrassment, and appropriate test procedures, including terminating sessions if these reactions start to appear, can minimize these. A further risk is overpromising, allowing participants to believe that the new technology under development offers them a benefit that may not be realized [67]. Again, care in how participants are briefed can limit this risk.

Given the low level of risk, investigators (and review boards) should consider that there is an ethical responsibility to include, not exclude, people with cognitive disabilities in user tests. The Belmont report [68], a basic document in the development of federal protections for human subjects, presents the principle of justice: the risks of research participation should not fall unequally on any population. But later developments have brought out the importance of the corresponding principle that research benefits should also not fall unequally [69, p. 43]. The report argues that excluding children from clinical research has limited medical progress from which children benefit. The report quotes a mother: "We have to make sure that in our attempts to protect children we aren't making the consent process so onerous and paper heavy that we're actually prohibiting or inhibiting new studies from opening, or conversely scaring families away" [69, p. 196].

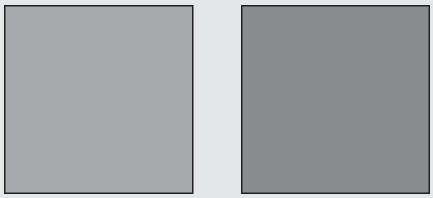
The same argument applies to the inclusion of people with cognitive disabilities as participants in user tests. Technology will not be accessible to, or useful and helpful for, people with cognitive disabilities if they are not included in the testing that shapes the technology. Indications are [60] that researchers who seek review board approval for such participation can obtain it; more should do so.

Participatory Design and Participatory Action Research

Although user testing improves the quality of user interfaces, it is not an adequate approach to the overall design of a useful system. Many system designers have recognized that they

Thought Experiments

People with cognitive disabilities often face difficulties with skills that others take for granted; Svensk presents the problem of telling time (55). If someone cannot tell time using a traditional analog clock, clinicians or technologists may recommend a digital clock, thinking this is more straightforward. However, this will not help if the user's problem is an inability to associate numbers with spans of time. To help people better imagine the difficulty, Svensk developed a blue clock that indicates time by shades of blue. People with typical cognitive abilities will have difficulty telling the difference in time between two shades of blue (or, here, gray):



This provides a simulation of the difficulties faced by someone with a disability trying to tell the difference in time between 3 and 5 (55). By better understanding the difficulty, technology developers or clinicians might be in a better position to find effective solutions (e.g., a more concrete representation of elapsed time).

need to understand the context in which a system is to be used and that the necessary understanding can only be gained by working in the application setting and with the intended user to shape ideas for the system. This approach is called participatory design in the human–computer interaction research community [70]. The ideas owe much to a tradition of cooperative design in the Scandinavian countries [71], [72].

At the same time, a family of research methods called participatory action research (PAR) has grown up within social science and research on social services, and some have called for its application in the development of assistive technology [73], [74]. PAR is a form of action research, research whose goal is intervention in some situation, rather than just gaining understanding [74], [75]. The participatory in PAR refers to research in which the beneficiaries of the action research are included in the research process at every step, from planning through to data collection and interpretation.

PAR can be traced back as far as the 1930s in the work of the sociologist William Whyte [76]–[78]. Whyte's definition is as follows.

> In participatory action research (PAR) some of the people in the organization or community under study participate actively with the professional researcher throughout the research process from the initial design to the final presentation of results and discussion of action implications. The social purpose underlying PAR is to empower low status people in the organization or community to make decisions and take actions which were previously foreclosed to them [78, pp. 111–112].

PAR can be seen as the result of a shift in the role of the researcher in action research projects. Traditionally, the researcher was seen as the expert, bringing assistance to passive beneficiaries. As the importance of stakeholder involvement began to be recognized, there was a shift to the expert as consultant and then, in PAR, to expert as colearner along with the beneficiaries.

The late disability activist Tanis Doe, with Whyte's son John, a rehabilitation researcher, promoted PAR as an approach to disability research [79]. For the development of cognitive assistive technology, PAR means the inclusion of people with cognitive disabilities not just as participants in user tests but as partners in the planning and evaluation of research.

There are two motives for the partnership structure in PAR or participatory design. The epistemological motive is that good system design requires learning a great deal about the situation in which a system will be used and about the practices and ideas of the people who will use it. This information cannot be gathered without the cooperation of the users. Further, unless the users are respected by the technologists, and not just observed by them, technologists are likely to propose overly simple tools that do not support the full complexity of users' tasks or exploit their real capabilities.

The political motive for partnership derives from the principle of self-determination in democratic theory. Whyte's definition of PAR includes empowerment of low-status people as a defining aim. There is a strong convergence here with the self-advocacy movement, with its emphasis on increasing the self-determination of people with cognitive disabilities [80].

The transition to PAR and participatory design will be difficult for many technologists. It may not be possible with all user groups (see, e.g., [81] on working with people with profound disabilities). But as work like that described in [6] shows, many people with cognitive disabilities are capable of much more than is often assumed, and as has been found in other applications of PAR, including them as partners will pay important dividends.

PAR will also assist in the inclusion of people with cognitive disabilities in user tests, which was our earlier concern. To help find the appropriate balance of risk and benefit, and to develop appropriate approaches to consent procedures, some review boards are asking that people from vulnerable participant groups be included in project teams [60], [82]. Meeting this requirement will move projects in the right direction.

Commercialization of Assistive Technologies

The ultimate goal of research and design efforts in cognitive assistive technology is to get useful and usable technologies into the hands of people with disabilities. Therefore, technologies eventually must transition from the drawing board and research lab into the marketplace. There is a vibrant, though small, industry in assistive technology (see http://www.atia.org; [83]; sidebar "Vendors of Cognitive Assistive Technology") including cognitive assistive technology. But although there are hundreds of millions of people worldwide with cognitive disabilities, the diversity of conditions and situations means that sales volumes for any given product are low, and prices are correspondingly high. High prices not only mean that consumers must pay more but also that the growth of the industry is restricted since many potential consumers cannot afford the prices. Lower prices would benefit producer and consumer.

Lower prices can be attained in three ways. First, the needs of people with cognitive disabilities may be met with devices that are or can be marketed to mainstream consumers, carrying the low prices that come from high volumes. Work by Gillette and DePompei shows that consumer-model PDAs can be used effectively by people with cognitive disabilities to schedule tasks [84]. The potential for this kind of market crossover is large if we consider the overlap of needs between people with cognitive disabilities, people with normal aging, and people with low literacy [85]. New developments in language technology [86] may allow automatic simplification and

The Institute for Cognitive Prosthetics

The Institute for Cognitive Prosthetics (Bala Cynwyd, Pennsylvania; http://www.brain-rehab.com/) has been developing assistive technology interventions for people with cognitive impairments for more than 20 years (95), (96). Its approach has been to meet with the individual client, identify specific functional needs, and develop a customized computer-based system designed to increase self-sufficiency for tasks of interest to the client (56). Clients have shown significant increases in function, increased relaxation and self-confidence, and improved planning, problem solving, and self-initiation using cognitive prosthetic systems (56), (97).

The institute's approach shows its commitment to consumer participation throughout the design, feedback, and implementation stages of device development. Technology development is guided by frequent interactions with representatives of the user populations to discuss general needs and possible features and to review prototypes (97). This process includes not only people with disabilities but all the people who will be affected by the technology, including clinicians and caregivers (96).

summarization of text; this technology will clearly have great value not only for people with cognitive disabilities but also for many other people seeking to process information efficiently. It has recently been recognized that initiatives to increase the accessibility of the World Wide Web for people with disabilities will meet the needs of many people without disabilities who are using devices with nonstandard information presentation capabilities, such as speech-only devices for use in eyes-busy environments [87].

Second, when assistive devices are too specialized to find a mainstream market, they can be developed using mainstream components as a base. For example, communication aids can be implemented by programming mainstream handheld computers rather than by creating custom electronics. An obstacle is the policy in the United States that limits reimbursement for mainstream technology, even when used as assistive technology [88]. This policy acts to limit the development of inexpensive adaptations of mainstream devices (there are significant issues in reimbursement for specialized devices also; see [83]).

An additional obstacle is that durability and user interface requirements for assistive devices may not be met by the mainstream products. Mainstream consumer preferences for very small phones, with small screens and tiny keyboards rather than button or touch screen operation, conflict with the need to produce assistive devices with pictorial, low-dexterity interfaces.

Progress is possible here through better communication with mainstream vendors. The parallel case of support for people with visual impairment shows that mainstream smart phone technology can be adapted to increase accessibility [89]. Here, progress was made by three-way cooperation between the mainstream vendor, the accessibility community, and third-party developers specializing in speech technology. The cognitive assistive technology community needs to develop similar partnerships.

Third, costs of cognitive assistive technology can be reduced by greater coopetition in the industry. Coopetition describes the relationship between competitors in mainstream technology who cooperate to develop standards that define a market in which they compete. For example, competition among companies like Sun, IBM, and Microsoft to deliver services over the Web depends on those same companies agreeing to standardize the communication protocols these services use. Without these standards, no competitor's implementation could command a large enough user base to be useful.

In cognitive assistive technology, the AIMS standard, mentioned earlier, proposed by AbleLink Technologies (http://www.aimsxml.com/), permits people developing task descriptions for prompting systems to use a common format that can be delivered on any compliant prompting device [46]. If the standard is adopted, task descriptions for all compliant devices, from any vendor, will be cheaper.

The V2 Remote Control Standard [90] will permit compliant devices, such as home entertainment systems, to be controlled by any compliant remote control device. Thus, a compliant remote control with a specialized interface (e.g., speech control) could provide a speech-only interface to any compliant home entertainment system. Similarly, a remote control could have a pictorial interface. The potential to increase the usefulness and scope of assistive technology devices is large if the standard is embraced.

These standards, like most of those that underlie the recent explosion of information technology, are voluntary. No party is compelled to adopt them. Instead, they are adopted because the adopters see commercial value in them. This logic means that the cognitive assistive technology community need not fear that standards will stifle innovation. Unless a standard has been proved extremely useful, there is no barrier in the way of adopting a more useful new standard if one emerges. We can hope to see more emphasis being placed on standards development [91].

Vendors of Cognitive Assistive Technology

The Assistive Technology Industry Association (ATIA) represents companies that develop and sell assistive technology, including technology that supports people with cognitive disabilities. As of 2008, the association lists 23 companies that provide augmentative and alternative communication devices and 34 companies that provide supports for people with learning disabilities, among 97 full member organizations.

ATIA hosts an annual conference that brings together a cross section of people interested in the development of assistive technology. The 2008 conference is expected to feature more than 125 exhibitors and 2,400 attendees.

Information about ATIA, including Web sites of participating vendors, can be found at http://www.atia.org.

Conclusions

For many years, the application of assistive technologies for people with cognitive disabilities received relatively little attention. This may have been due to the difficulty of addressing cognitive issues through technology applications, the underestimation of the needs and abilities of people with cognitive disabilities, or the cognitive disabilities being hidden compared with other conditions. However, in recent years, this area of assistive technology has been receiving increased attention. This article and its sidebars provide a few examples of the researchers and institutions addressing this topic; the representation is by no means exhaustive. With more than 21 million people experiencing cognitive disabilities in the United States alone, and an increasing rate of incidence, this attention is greatly needed.

Although there remain significant technological and social barriers to matching people with cognitive disabilities with appropriate technologies, there are also many promising trends. Computer technology provides increasing flexibility for people of all abilities, thus offering features with special importance for those with cognitive disabilities. The increased pace of modern society is also bringing attention to bear on the use of technology to support memory and organization for all people. Meanwhile, more attention is being focused on the design of technologies specific to people with cognitive disabilities. These technologies vary widely in terms of the difficulties they address and the environments where they will be used. However, they share a need to involve people with cognitive disabilities in both the design process and the evaluation process to better understand the abilities and needs of these populations.

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Edmund F. LoPresti is the president of AT Sciences, LLC, Pittsburgh, Pennsylvania. He is also an adjunct faculty member at the University of Pittsburgh Department of Rehabilitation Science and Technology, a participant in the RERC-

ACT, and a Senior Member of IEEE. He received his bachelor's degree in electrical and computer engineering at Carnegie Mellon University and his Ph.D. degree in bioengineering from the University of Pittsburgh. His research interests include cognitive assistive technologies and robotic mobility devices.

Cathy Bodine is an assistant professor and section head, Department of Rehabilitation Medicine, University of Colorado; director of AT Partners; AT advisor to the Coleman Institute for Cognitive Disabilities; and principal investigator (PI) of the Rehabilitation Engineering Research Center on Advancing Cognitive Technologies. She is a highly valued and trusted member of the assistive technology manufacturing community, a powerful liaison with the commercial manufacturing community, and a nationally recognized leader in the field of assistive technology. She has served as the PI for a number of preservice preparation grants in assistive technology (223 graduate students), is the PI for the Colorado AT Act (P.L. 105-394), and has served as the PI for a number of research and development projects leading to new designs in assistive technology devices (Joseph P. Kennedy, Jr., Foundation, Watson Research Centre-IBM, and four small business innovation research grants). She serves as the secretary of the board of directors of the Rehabilitation Engineering and Assistive Technology Society of North America and is the past president of the ALS Association Board.

Clayton Lewis is a professor in the Department of Computer Science and fellow of the Institute of Cognitive Science at the University of Colorado, Boulder. He is also a scientist in residence at the Coleman Institute for Cognitive Disabilities and a participant in the RERC-ACT. His research and teaching interests are game design for education, cognitive assistive technology, human–computer interaction, and educational technology. He holds a Ph.D. in experimental psychology from the University of Michigan.

Address for Correspondence: Edmund F. LoPresti, AT Sciences, 160 N. Craig St., Suite 117, Pittsburgh, PA 15213 USA. E-mail: edlopresti@at-sciences.com.

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