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# Patient-Centered design as a research strategy for cognitive prosthetics: Lessons learned from working with patients and clinicians for 2 decades

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**Abstract**

Patient-centered design addresses the priorities of the individual patient, and is advocated as a research strategy for the design of cognitive assistive technology. From the patient's perspective, a robust system can be viewed as one that optimally increases her/his level of functioning over the long haul, for his/her priority activities, as they reveal themselves over time. Prosthetic software customization and use is integrated into the

user's therapy sessions. These sessions are conducted in the patient's home via tele-rehabilitation. The advantages of this strategy are described, along with research findings that were obtained using this strategy. The need for training rehabilitation therapists is also discussed.

**Keywords**

Assistive technology, cognitive disabilities, cognitive prosthetics, institutional resistance to change, user training.

**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**

Cognitive assistive technologies is an important emerging field. It is important because of its potential in understanding brain function; its potential in rehabilitative and preventive medicine; the challenges it raises

for CHI; and the design of information systems; and of course helping people with cognitive disabilities. Cognitive technologies is also important because of the talent it has recently attracted. And finally, work in this area provides both intellectual satisfaction and emotional satisfaction. When we deliver functionality, it is at an entirely different level of social significance.

Interface design relies heavily on users' cognitive functioning to deliver the functionality of applications. There are now well-developed approaches for dealing with users who have normal cognitive functioning, even as our field strives for new types of applications, and new platforms.

Working with individuals with cognitive deficits, we are able to see many tacit assumptions that UI designers have been able to make in dealing with the (statistically) normal user. These tacit assumptions simplify the design problem, by allowing designers to deal with the easiest cases<sup>1</sup>.

What is left are the cases that permit us to see the simplifying tacit assumptions. It allows us to more fully understand cognitive mechanisms of UI design. Therefore, UI design becomes more demanding, and no doubt will require additional models and methodologies.

Two decades ago, I began a project exploring how computer technology could help

people with cognitive deficits. Actually, I was doing office automation consulting to a national mental health organization, working with managers and clinicians on their information overload, disorganized day planners, etc. These people were stressed and frustrated. I was given a tour of a residential brain injury rehab facility, and saw people clutching their Memory Logs, and expressing stress and frustration.

It seemed like a relatively straightforward application of work in end-user computing and personal productivity tools – the premise that computer technology can increase cognitive productivity [16]. Here were people with cognitive deficits who could benefit, in compellingly important ways, by an increase in their cognitive productivity. You can imagine how surprised I was when a literature review in '84 revealed no one working on cognitive disabilities either in computer science or psychology. Later Ned Kirsch's [24] excellent work appeared; he took an extended sabbatical and has now rejoined the field. In science, it is not good to be virtually the one working on a problem, which was the situation most of the 90s. Prominent among the exceptions is Alan Newell's group at Dundee, which has recently collaborated with Barbara Wilson and her group at the MRC. However, cognitive prosthetics was compelling socially and intellectually, and emotionally, so it seemed worth the risk to pursue this stream of research.

I was thrilled to read your position papers, and to see the broad array of issues – technical, social, medical, policy – that are being explored even at this early stage. Tacit assumptions in interface design quickly percolate to the surface by the issues of voting methods and international (and national) standards. Conceptually, computers

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<sup>1</sup> It should be noted, however, that personal productivity software is able to address a broad array of relatively mild learning disabilities and cognitive deficits, through spelling and grammar checkers, supporting organization activities, and supporting calculations.

can be designed to promote inclusion in social and political activities. Some barriers to inclusion are situational and temporary, some are structural, and some will vary with the life cycle. Thus there are opportunities for collaboration with policy fields.

Represented in these papers are prosthetic restorative, and potentially preventative applications. You are exploring cognitive deficits which are caused by many different medical conditions. Thus there are opportunities for collaboration with various clinical fields.

Most of the papers raised issues of CAT as a science, which generates heat and light is most disciplines. An interesting point is raised by Moffatt, Findlater, and Allen [] that "individual differences are often very pronounced, and, generally, crucial to the success or failure of the design". But, they note, individual differences are statistically removed in the "gold standard" of conventional research. Carmien addresses the same issue in his discussion of "Universe of One".

Some of you are big budget centers and others are minimally funded with talented researchers. The involvement of well-endowed centers helps to assure that work in cognitive assistive technologies will continue without regard to trends in external funding. The ability of meagerly funded researchers to make important contributions will promote economic inclusion. It is likely that the most critical research resource is the ability to work effectively with the impaired user, what other sciences call lab technique.

Patient-centered design is a productive research strategy for this area. We have defined patient-centered design a focus on the evolving priorities of patient, who is a member of a clinical population of interest. This research strategy can be applied to both small

and large scale research projects, and produce both stimulating and important results. The major factors will be research design, research technique, an ability to collaborate with individuals with cognitive deficits, and an ability to show an increase in level of function, preferably in the individual's priority activities. And what will surprise so many of our colleagues, our users – with their cognitive deficits – will have design insights that we – with our degrees and publications – will not have been able to anticipate.

While clinical rehabilitation disciplines have been disappointing in their adoption of cognitive assistive technologies, we have done little to develop educational programs for these disciplines. A patient-centered approach can lead to fruitful collaboration with clinicians and a breadth of clinical disciplines, with substantial benefit to our discipline and theirs.

### **An Overview of the Institute for Cognitive Prosthetics<sup>2</sup>**

In the late 80s, I founded the Institute for Cognitive Prosthetics to deal with the plight of traumatic brain injury (TBI) patients with disabling cognitive problems. We have treated scores of patients with TBI and other acquired brain injuries, and delivered tens of thousands of therapy-hours of services.

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<sup>2</sup> Some concrete examples might be helpful to the reader. Because it is the specific details that are so important to understanding the design, examples will be provided as a supplement on the workshop website about 2 weeks before the workshop.

Initially, we designed for people who were not expected to have further recovery. The epidemiology of TBI was compelling, both in the numbers affected, their need for caregivers, and the cost of their care. In addition, the TBI population had medical characteristics that made it a desirable research population. Each enduring brain injury was seen as unique in cognitive deficits, many patients couldn't be effectively rehabilitated, and spontaneous recovery lasted only 2 years.

The concept of cognitive prosthetics seemed like a straightforward extension of Doug Englebart [16], focusing on activities requiring cognitive skills, rather than the cognitive skills themselves. Typical difficulties for TBI patients involved writing, organizing, learning new things, remembering to do a specific task at a specific time, remembering follow-up details about a task, problem-solving, following a check list for a task. In the mid-80s, there was software that had the basic functionality needed. However, it was the user interface that made the software unusable by most in the cognitively impaired population. Cognitive prosthetics would be a special kind of personal productivity software.

The technical challenges were 1) learning how to work with and design for this population; 2) how to develop an effective UI when cognitive skills required to use a UI are the cognitive skills needing support; 3) what functionality should the software support to be useful for a given individual with disabilities in performing their everyday activities; 4) developing models and methods that can inform the design process; and 5) developing an IDE.

Our initial domain knowledge was minimal with respect to the technical challenges.

Consequently, I decided to develop custom applications for each of patient, which was similar to many consulting projects. In time, we would hope to increase our knowledge to the point where it was practical to scale up the design process to the next level. Ultimately we might be able to scale up to a product (a goal which we achieved after about a dozen years). Also, we were working closely with clinicians, whose unit of analysis and of concern was "the patient".

TBI patients and their therapists were used to failure, both in activities and treatment. We wanted our patient-users to quickly experience success with using AT technology. Our usability standard was for the patient to effectively to use the prosthetic system with less than a 3 half-hour training sessions. Theoretically, it seemed possible. In fact, we developed a methodology that could repeatedly achieve these results.

After a few years, we created a small clinical brain injury rehabilitation program as a vehicle for our multidisciplinary R&D activities. Also it was a model program people in the rehabilitation industry to visit, a proactive approach to the resistance we saw to AAC as well as our own work.

Bell Labs got us into distance-therapy in 1993, when one of their scientists had aphasia from a stroke. The following year, we added telerehabilitation to our therapeutic model. As the videoconferencing technology improved, we were able to conduct therapy sessions at a distance of thousands of miles, and patients with severe cognitive deficits. Evaluation methods were developed, and clinicians developed therapy techniques that took advantage the opportunities that the technology provides.

Patients typically began with a half-day therapy program, technology-based, delivered to their home with videoconferencing, with licensed clinicians. Each patient was discussed several times a week by a small team of clinicians and computer scientists, in both formal meetings and over lunch. Over the years, clinicians included an MD PhD behavioral neurologist, a PhD speech therapist, a PhD program evaluator, occupational therapists, speech therapists, psychologists, a neuropsychologist, and a special educator. We also became a field site for occupational therapy students.

We discovered that patients with profound memory deficits, had abilities that helped them to refine and fine-tune their prosthetic systems. Our first system took 1.7 programmer-years to develop (Cole and Dehdashti 1990 []; by 1999, the same system took a couple of hours of effort. Initially, little of our user software could be recycled. After a few years, we were able to reuse much of our code in designing for new patients (see Cole et al, 1994 [2]).

In the mid-90s, we developed a number of engines that formed our prosthetic software and system logging tools. In the late 1990s, we developed a full-fledged turnkey delivery system ready for use in rehabilitation programs. We developed a cognitive prosthetic suite of software, based on several different engines (text, date, email, multimedia, patient safety net, and patient management & reporting), "therapist friendly" tools, and tele-rehabilitation tools including duplex videoconferencing into the patient's home (Ziegmann et al 2001 []; Wilt, 2002 []). These tools were used by therapists to customize patient software, do high level and detailed treatment planning, write clinical notes, recycle plans and notes for reports to

insurance companies, examine patient log data and work-products, and allowed user-support staff to do remote configuration and troubleshooting.

Research results were quickly integrated into the clinical program, and papers were presented at CHI, RESNA, the Brain Injury Association, and clinical meetings. Most importantly, our clinicians developed new techniques of treatment. These new techniques were a direct result of the therapists extended use with both our prosthetic software, and delivering therapy services into the patient's natural setting (home, office, and school). Our patients – living with deficits and trying to resolve them -- constantly came up with new ideas for features that could help them to do more of the activities they wanted to do. This environment gave us the energy to develop software for each patient that maximized her/his level of functioning (see [3] and [5]). It was also intellectually stimulating and emotionally rewarding.

### **Cognitive prosthetics – a video**

The video will be played during the workshop

### **Method, models, and techniques**

People with cognitive disabilities form a very heterogeneous population. The number of cognitive dimensions or skills is large and growing, as are the number of clinical symptoms and functional activities that require one or more of these skills. Furthermore, our studies have shown that individuals in this population take months to achieve stability in their performance on

individual prosthetic applications. This favors in-depth single subject case studies, with replicates. Working with 1 patient at a time on actual activities and in their actual setting simplifies the problem. Our first study presented data on the first 314 days of prosthetic system usage.

Most individuals with cognitive disabilities are outpatients, which provide the opportunity to work with the individual in their natural settings – typically begins with the home, but can include the office, school, and community. As a discipline, when we work with users, it's typically in their natural settings.

Our research methodology followed techniques in our discipline, which we adapted for the topic of design for cognitive deficits. 1) we worked in the user's setting; 2) we addressed user's activities, and as in consulting, we addressed priorities to the user; 3) as in science, we used a hypothesis-testing approach of identifying a user's functional performance failure, developing a software intervention to fix the failure, and evaluated the intervention with the patient's activity performance. The intervention was deemed successful if the patient was able to use it effectively and rapidly after introduction, for the target activity.

Two early models we developed and presented at CHI 88 were "Self-sufficiency" and "Stress Reduction" Self-Sufficiency involved having a patient be able to complete core subtasks using the technology, without caregiver assistance; caregivers were allocated some pre- and post- activities, e.g., receiving bills in the mail, highlighting the due-date, and mailing the completed check. This seems to be similar to Fischer's Distributed Cognition. Stress Reduction was an issue raised in our first user, in the form

of pain from using software she used under a therapist's guidance.

Our research methods involved CHI usability measures (see Figure 1), system logging, work products, videotaped usability testing and redesign sessions, and ethnographic techniques (see [1990] and [1994b]).

A design methodology needs to fit the problem. Cognitive AT is a unique problem area, so we used elements of existing methodologies, and wove them together, to better fit the requirements of our research.

#### *User-centered design*

Our implementation of user-centered design is patient-centered design. We focus on the needs and more especially the **priorities** of the patient. Thus our patient-centered design involves both the selection of activities – and applications – as well as the functionality to be included in a prosthetic intervention. Ethnographic methods are used, which involves extensive user participation; we also have the primary caregivers provide input.

User centered design addresses the issue of system user requirements, what functionality does the user need to perform desired activities. The cognitively challenged user has many activities that they need to or would like to perform, and cognitive prosthetic software is either the only vehicle for delivering the functionality, or the most effective means. Effective cognitive AT must be able to address the needs for the individual patient or client.

This methodology increases the likelihood that the functionality of an application will meet the needs of the user. At this point, the design rationale is hypothetical with respect to the user. It will not be known until the user is working with the application under real

conditions, and has learned how to use the necessary features. At this point, it becomes concrete, and part of the user's life.

Rapid prototyping (discussed below) is a means of having the user be able to test-drive functionality and interface design.

#### *Participatory design*

We implement participatory design at the UI customization stage, and for the specific patient. It is the user interface which provides the greatest barrier to the cognitively impaired user.

The patient is asked for their ideas on how the computer can help them perform a priority activity. We will then prototype the interface of the design, and begin usability testing. The patient's greatest value in participatory design is in fine-tuning the interface and the functionality. Patients turn out to be the most sensitive evaluator of their interface's usability. They will often be able to make small suggestions for changes that increase the usability of the system. And after the patient has been begun using the application, the user or therapist will identify places in the application where the interface can be improved, thereby reducing the patient's cognitive load.

#### *Failure analysis*

We use failure analysis as the initial step in understanding why a patient can't perform a priority activity selected for prosthetic intervention. In the patient's setting (home), we observe and videotape the patient's attempt to perform the activity, subtask by subtask. We have them get the materials and work-products they use, and to describe specific instances of success and problems. When computer software is being used, we observe its use by the patient, including the help provided by caregivers. Portions of

subtasks that the individual can't perform become candidate functionality for prosthetic software. Ethnographic methods are used here.

#### *Usability testing*

Our standard for usability is that the patient should be able to effectively use the application after an hour or less of training. Usability testing is a key part of our design process, and our way of dealing with the impact of the patient's cognitive deficits. Systematic usability testing takes place before the patient begins using a prosthetic application or enhancement.

Then the patient is shown a set of interface designs, and asked to use them. We apply the criteria set out in Figure 1 below. The patient then may comment on one or more screen, which often will include suggestions for modifying the design for them. With our Customizer package, the therapist (or user support personnel) is able to make the changes on the spot, and then retest the system.

Usability testing is the stage where valuable anomalies of cognitive functioning are seen. We define anomalies as behavioral differences in functioning for a seemingly identical skill in different instances, i.e., contexts. Our ability to manage these anomalies provides us with the opportunity to achieve higher levels of patient functionality. We also suspect that these context-specific findings have some relevance to neuroscience.

We have exploited color, sound, music, pictures, icons, and typeface in modifying interface elements. We have also color-coded function keys on the keyboard.

Usability testing is also involved in reducing the level of support needed as patient performance improves.

#### *Mental Models*

Mental models underlie our approach to the patient. Software is easier to use when the patient's mental model is closer to the conceptual model of the system. In some extreme instances – where the user is very cognitively rigid – we have had to modify applications so that they match the user's mental model.

#### *Rapid prototyping*

We expected and found that a small percentage of our development time would be spent on the initial design. Most of the programming time and effort would be redesign and customization. This we were willing to trade off execution efficiency for programming speed.

We began our efforts with a 4GL language. We also used several program generator and interface generator libraries. Later we migrated to Visual Basic, and implemented our applications in object-oriented design and programming. These tools enabled us to quickly change the code to implement patient-required customization. Sometimes it required increasing the amount of RAM on patient machines, but this was well worth it.

#### *"Training Wheels" and minimalist design*

We wanted our patient-users to be able to use a prosthetic application for performing a priority activity with less than an hour's training. This was accomplished by providing an initial intervention that was a stripped down version, which we could begin enhancing relatively soon. Because we knew

the details of the activity that the patient wanted to perform for the initial intervention, we were able to package the initial version.

When the user was able to go beyond the initial intervention, the patient would ask for enhancements. Patients have taken considerable satisfaction – and raised their self-esteem – in being able to say that they needed more than the computer was providing.

#### *The "Customizer"*

The Customizer is a prosthetic software generator. It is our belief that the therapist is in the best position to effectively customize prosthetic applications for their patients. The Customizer allows a therapist to be able to build and customize prosthetic software. The Customizer also allows the therapist to have interactive design sessions with a patient, or to prepare a working trial version of an application, and test it with the patient later.

Being patient-centered enables us to delve into the minute details of our selected domain. Domain knowledge takes on particular importance for success when the user-patient's characteristics are relatively rigid. Domain knowledge includes the individual patient, their abilities and deficits, priority activities, their therapy environment, their caregiver environment, the environment where priority activities are performed and their quest for independence again. Over time, we see the patient reducing the amount of effort to perform one unit of an activity, and reduce the amount of time it takes to perform that unit-activity. We see that the patient can expand the range of activities s/he can perform.

The patient-user is a moving target, and iterative design is required, as we strive to



improve design performance. Factors include corrections due to limitations in the initial scenario, modifications due to our gaining a more detailed understanding of the user's needs, modifications due to the patient's learning and needing less support, and modifications to application scope as the user asks for more features. And finally, adding new applications as the patient's level of functioning improves, and more activity can be squeezed into the day.

We get to review our assumptions on user behavior. Our user-patients are able to guide us to better designs, component by component, and we get to see the significant differences that subtle changes in design can produce. We get to see the changes in the design, and the length of time, and amount of application usage it takes for the patient's design to become stable. Patients will allow us to see the nuances of their condition through interface design modifications. We are enabling our user to decrease the amount of thought and mental energy necessary to perform target activities. And they are making us more aware of the subtle problems that need to be addressed.

### **Measuring system performance**

We have long used some early CHI performance measures, which have 3 sets of variables, user characteristics, task characteristics, and system characteristics which predict various aspects of software usability (see Figure 1).

This model has been revised, in part for cognitive prosthetics, but perhaps for broader user models as well.

Performance measures include how long it takes the user-patient to perform a unit activity (and if the user can perform it);

endurance, in terms of how long the user can work at the activity; the number of errors committed, but more importantly, the ease of error recovery; the ease of state to state transition; the level of stress which the user experiences; training time per feature; and training time for a version of an application.

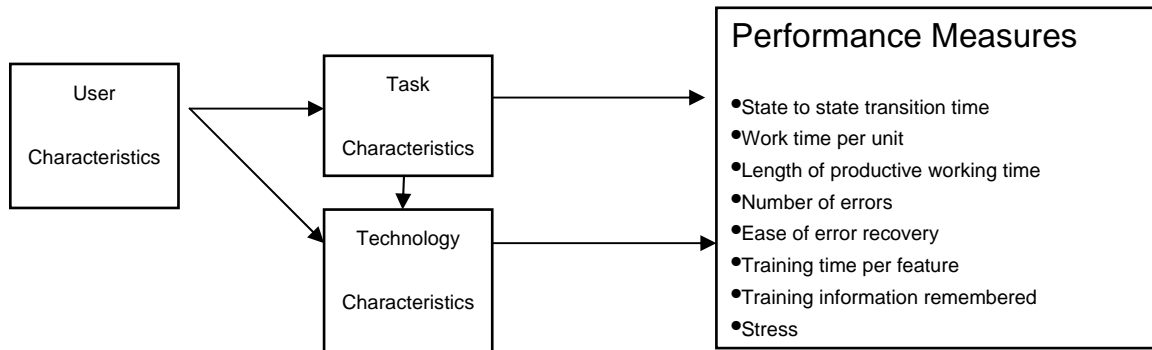
With conventional populations, users are a pliable component, and, are able to adapt to the performance limitations of our commercial designs and across different tasks, although sometimes with some hand-ringing and exasperation. Also, users are able to map their activities onto the software's process so as to achieve successful task performance.

In contrast are cognitively impaired users, who are unable to use commercial designs. These users are much less pliable, so the system needs to be able to adapt to the user's limitations, i.e., be the more pliable component. Note also that task characteristics are a set of independent variables. One should not be surprised to see that especially for cognitive AT, a given interface design will perform differently for different tasks which seem to use the same cognitive skills. This was our experience. More importantly, it suggests that a focus on the needs of an individual patient will produce a complex set of interface and functional designs as we work to maximize our performance measures.

We adapted usability testing methods for use with individual cognitively impaired patients, with relevant dependent variables. In this way we were able to quantitatively evaluate specific interface designs of module components. With Talking Out Loud protocols, the patient often described what was difficult with an interface, and often made redesign suggestions. Once the patient

started using the delivered application or feature, patients also would ask for a modification of the design, which typically would increase a performance measure. In

this way, we were able to increase the efficiency of a prosthetic system for a patient with traumatic brain injury or stroke.



**Figure 1.** Performance measures and predictor variables used in evaluating interface designs by cognitively impaired users.

### Notable findings and anomalies in behavior

Good research produces surprises, as does exploring domains where there are stereotypes. Working closely with individuals who are described as cognitively impaired or brain-damaged, you get to see the strengths, abilities, and insights that these individuals have, and I have learned so much. It is the synthesis of 1) patient-centered computing 2) in the patient's natural environment 3) with participatory design and 4) working on small granularity design issues.

- Computer software can be a cognitive prosthesis.

- Using a computer is both status-enhancing and normalizing for the individual with cognitive disabilities.
- Cognitive AT requires substantial customization for each patient, extending across tasks and during therapy. This is an area which can benefit from automation.
- Detailed system logging provides clinically useful data, and the analysis of this data can benefit from automation.
- Participatory design – cognitively impaired users have demonstrated considerable insight in fine-tune designs for customizing their systems. Their requests and suggestions helped us produce highly efficient designs.

- Highly efficient software for patient priority activities significantly increased the patient's level of functioning. Over the past few years, some very fine grained clinical evaluation protocols have emerged, and can be applied to cognitive AT.
- It takes a period of usage for a patient to achieve a stable pattern of behavior for an AT-supported activity
- During our sessions with patients, we occasionally observed paradoxical behaviors
  - Activities that are objectively seen as complex and difficult turn out to be easy for the specific patient, coupled with
  - Activities that are objectively seen as simple, turn out to be hard for the specific patient.
- During detailed interactive design and usability testing sessions, we often uncover
  - Islands of deficits in seas of abilities – a context in which the patient cannot perform a cognitive skill that has been performed easily in other contexts. This is especially important in explaining why a patient has difficulty performing a subtask of an activity
  - Islands of abilities in seas of deficits – a context in which the patient surprisingly can perform a specific skill that s/he has not been able to perform in other contexts. This simplifies the prosthetic design because no support is needed for performing the subtask.
- This suggests that usability testing can quantify small-granularity skills that potentially has some clinical significance.
- Different contexts produce different results for the same cognitive skill – context is apparently a proxy for important variables.
- Brain plasticity has been seen as a result of intensive use of cognitive prosthetics
- Patients exhibited vast apparent differences in the objective size of cognitive chunks, especially for sequence cuing
- Cognitively impaired patients will develop creative and unanticipated uses for our designs. The process of discovery is often exhilarating for the patient. Perhaps our designs can incorporate tools that can directly or indirectly support the patient in this process.
  - These uses increase their individual level of functioning, often in some subtle way
  - Creative uses may appear as error conditions in our system logs
- Just because a computer can perform a subtask more accurately doesn't mean that the patient shouldn't be allowed the satisfaction of performing the subtask him/herself

- Fast program execution and system response is generally unimportant. Patents often process slowly, and they appreciate waiting a bit for the system to respond.

### Collaborating with clinical disciplines

Clinicians should be important participants in the development of effective cognitive AT, and should be our participating colleagues in the adoption process. That has been our tradition at the Institute for Cognitive Prosthetics. But, key rehabilitation disciplines demonstrate institutional resistance to adoption of assistive technology, as measured by conference papers, journal publications, course offerings in clinically accredited programs, and the many AT products and research for decades at ACM, IEEE, and RESNA.

An argument can be made that we as computer scientists have not reached out to and trained clinicians in use of complex AT which includes AAC and cognitive prosthetics. Patent-centered design gives us the opportunity to have unique collaborations with clinicians. Collaboration between us and academic clinicians is necessary for training the next generation of clinicians in the use of assistive technology. We need to find ways of enabling professors in rehabilitation disciplines to use cognitive assistive technologies in clinical settings. They are also our users, and their participation in the design process will increase the effectiveness of our assistive technologies.

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