1. Introduction

In the spring of 2000, the two PIs began collaborating on a difficult problem: what forms of computer technology might mitigate social isolation in the brain injury population? Through a series of graduate seminars, lab studies, focus groups and surveys, the PIs arrived at two potential technologies that could help: (1) internet-based communication, and (2) community access using wearable navigation devices. The former addresses the problem of staying in contact with friends, family, congressional representatives and advocacy and support groups that have an online presence. The latter addresses the problem of providing some independence of movement within the physical and social community outside of the survivor’s dwelling.

Prior to this proposal, we chose to focus on email as our first application with the Traumatic Brain Injury (TBI) population. It is an application that many of us take for granted, but one that is currently beyond reach of most TBI survivors. We have spent the last 3 years studying the domain, working with TBI survivors and domain experts to scope the problem. One conclusion that is clear is that email is a composite system problem (Fickas & Helm, 1992). While it is natural to focus on the TBI user and his or her email client (GUI and associated software) as the major concern, we have found it is just as important to include the other components of the “email system”, including the various human agents (family, friends, careproviders, clinicians), computing hardware available, internet connectivity available, the hardware components in the user’s living environment (e.g., TV, phone), and software agents that may assist to mitigate impairments that impinge on email use. We have attempted to define a personal requirements engineering process that treats email for TBI users as a composite system problem. It is personal because our lab findings indicate that delivered systems must be tailored, if not fully custom (Sohlberg et al, 2002a). As discussed in subsequent sections, we have built a Personal Requirements Engineering Process (PREP) to support the email task. In this proposal, we propose to take on the 2nd of the two major pieces of social isolation for the TBI population: (physical) community access. Our approach will be to leverage, heavily, the results we have obtained with email.

2. A more detailed characterization of the problem

The PIs are part of a larger group (www.think-and-link.org) that is studying a specific set of tools to facilitate social interaction for persons with cognitive-linguistic impairments due to traumatic brain injury. Our goal is to reduce social isolation for TBI survivors. We offer some background information relevant to the TBI population.

Prevalence estimates range from 2.5 to 6.5 million individuals living with the consequences of TBI, with that number growing with advances in medical procedures at the scene of the accident, in emergency medical care, and in neurosurgery. Many of these individuals are left with long-lasting alterations in social, behavioral, physical, and cognitive functions. The incidence rates for the most severe traumatic brain injuries are higher than those for spinal cord injury, multiple sclerosis, cerebral palsy, and muscular dystrophy combined (BIA, Inc., 2000). A typical TBI survivor is a young to mid-life adult, living either in (a) government-assisted housing, (b) with their family, or (c) in rarer cases, in their own house or apartment. Survivors are universally afflicted with social isolation (Zencius & Wesolowski, 1999). The brain injury can have as cause one or more of the types listed in figure 1. (Note that we will use material directly from our RE process documents (Sohlberg et al, 2002b) for some of our figures. Figure 1 is an example. It is part of the information we gather about an individual’s injury.)

![Figure 1. Causes of TBI](image)

TBI is part of a larger group of acquired neurological disorders (e.g., dementia) that share some common cognitive-linguistic impairments, such as memory loss and language impairment (e.g., aphasia).
TBI can be differentiated both on the demographics of survivors (younger, different interests) and the highly individualized nature of impairments that each survivor experiences. As an overview, figure 2 describes those impairments.

**Primary cognitive impairment:**
- memory
- planning/organization
- language(reading/writing)
- limited self awareness
- memory
- attention
- problem solving
- visuoperceptual processing
- language(reading/writing)
- impulsivity
- error detection/correction

**Sensory impairment:**
- vision
- hearing
- touch/temperature
- difficulty ambulating
- reduced hand/finger use
- movement/coordination
- restlessness
- anger
- sadness
- loneliness
- reduced self esteem
- fear
- anxiety

**Motor impairment:**
- right hemiplegia
- left hemiplegia
- reduced hand/finger use
- movement/coordination

Figure 2. Impairments

Each impairment can come in combination with others, and each has its own range of severity.

### 3. Why isn’t high technology the answer?

Fickas supervises research in the Wearable Computing Lab at the University of Oregon. In this role, he sees much in the way of new technology in the mobile and ubiquitous computing domain. There are new gadgets coming out of his lab, and labs around the country every month. Some of these find their way to commercial products. Hence, at first blush, it may appear we have plenty of technology to help with the problems we are concerned about. And this may be so; it is possible we have all the hardware and software we need to solve the problem. However, a well established phenomenon in the field of assistive technology (AT) is *system abandonment*. Studies suggest that the ability to match individual needs to the selection and development of devices is critical, and that assessment practices for assistive technology must extensively involve the individual consumer (Bryant&Bryant, 1998; Reimer-Reiss, 1999; Scherer, 2002). Our experience is that most assistive devices are gathering dust in the closet within 3 months. We hypothesize that those who build and deliver assistive devices must consider the composite system aspect of the user, as well as the user’s individual requirements. To do so will require AT manufacturers to come to grips with three difficult issues: (1) how to ascertain the requirements of all the components in the solution system, (2) how to scale the construction of custom solutions once this information is known, and (3) how to integrate the solutions with existing components (human, hardware, software) that can sustain a solution over months and years. In particular, what we lack today are (1) an understanding of what the needs are of the TBI population to gain access to their community, and (2) a means of matching up their needs with assistive devices. Whether we will need new devices/technology in the end, or whether some of the devices available now will suffice is a moot question until we derive knowledge of the needs and a means of assessing a user’s skills. This proposal focuses on both of these problems. We propose to study the needs of the TBI population in terms of moving about their community. We propose to use these results to do an initial set of lab studies that will provide the range of navigation interfaces that can be used by the TBI population. We will develop an assessment protocol that will produce a “prescription” for a wearable navigation device.

More generally, the proposed project seeks to answer the following research questions.

1. What are the individual and environmental factors that affect community access by persons with cognitive disabilities?
(2) Does the evaluation of (a) environmental factors and (b) individual skills and behaviors identified as important to successful community access provide sufficient information to identify needed supports?

(3) How should manuals and software for navigation devices be designed to facilitate training of users with cognitive disabilities by care-providers and practitioners?

4. Prior work

The work we propose is focused on community navigation: allowing TBI survivors to make social, medical, and business trips within their town or city. Our proposed research will build on our results from our email project and hence, we will describe the email project first.

Sohlberg’s work focuses on developing and evaluating compensatory cognitive systems for persons with brain injury. In recent years, her laboratory and university clinical practice has noted the increased interest on the part of clients to explore using electronic devices such as prosthetic memory aids (Sohlberg & Mateer, 2001). More systematic study of the barriers and needs of persons using electronic devices requires the development of monitoring devices and an understanding of computer technology on the part of rehabilitation researchers. In the spring of 2000, the mutual interests of Sohlberg and Fickas led to the formation of a graduate seminar at the University of Oregon for students in Computer Science with the help of several persons with brain injury and their caregivers. The topic was the use of technology to overcome social isolation suffered by people with cognitive impairments. The students in the course worked to develop two separate tools: (1) a web enabled system that supported e-mail interaction, and (2) a wearable navigation device to support community access, e.g., use of the city bus system, navigation in a shopping mall. The prototypes that came out of the seminar provided enough of a proof of concept to encourage further exploration. A decision was made at that point to concentrate first on the email task, putting the navigation task in abeyance until progress had been made on email.

The PIs ran a more formal, follow-up study during summer 2000. This study focused on HCI issues in the population, and as a spin-off, the effectiveness of traditional UI usability experiments with the population. Eight survivor/caregiver pairs displaying different cognitive profiles were recruited to help evaluate the different e-mail interface conditions. All subjects indicated feeling socially isolated and desired more contact with family and friends. None were currently able to use a computer independently and had little or no experience with electronic mail. We can summarize the results as they pertain to this proposal as follows: There is high variability in the ability of those in the population to use traditional user interface designs. A one-size-fits-all approach that attempts to design the "cognitive-impaired interface" is not possible. The study further helped to refine methods to measure user e-mail skills and document user response to support. Specifically, we developed a qualitative evaluation process to log and analyze critical incidents observed by a multidisciplinary team of researchers in computer science, social science and cognitive rehabilitation while jointly watching participants compose and send e-mails. A summary of this work can be found in (Sohlberg et al, 2002a). More recently, we conducted focus groups around the state of Oregon, in both rural and urban settings. We interviewed over 80 individuals and collected useful and previously undocumented information on issues of social isolation faced by TBI survivors and, indirectly, by their caregivers.

Harder to quantify, but consistent throughout focus group sessions and lab studies, was a general enthusiasm by survivors for a prospect of gaining access to email. The current feeling is one of resignation that they will not be able to use a computer, let alone email – it is typical that TBI survivors have more than one computer gathering dust in a corner or closet. In the focus groups we met with, participants expressed unqualified excitement at the prospect of being able to perform an activity previously thought to be inaccessible to them.

5. One result of our email work: A Personal RE Process

We have defined a personal RE process we call CORE (Comprehensive Overview of Requisite Email skills). CORE allows us to evaluate a TBI survivor and his or her ecology/environment to gain the knowledge necessary to deliver an email solution as a composite system. A critical feature of CORE is the
emphasis on functional assessment rather than exclusive use of standardized, norm-referenced tools to determine the potential for success using an AT/AAC system (Assistive Technology, Augmentative and Alternative Communication). Functional assessment concentrates on the client's performance during everyday tasks, particularly those tasks most relevant to the client and his/her use of the AT/AAC system. Unlike standardized testing, which requires strict adherence to task instructions, the examiners are free to modify their input to the individual (e.g., repeat instructions; increase prompting) in order to determine the conditions necessary for optimal performance.

At present, CORE is an examiner-based process. Contrast this with an automated process that attempts to remove a human examiner from the loop. This is neither feasible nor desirable with the TBI population. In particular, much of the challenge is to find a means of putting CORE in the hands of professionals who work with survivors and their family and careproviders on a day-to-day basis. This said, we retain a goal of automating the components of CORE that make sense. The CORE process consists of the following elements.

(1) **Computer User Profile.** Provides background information on the client’s injury, cognitive-linguistic symptoms, social communication and computer use.

(2) **E-Mail Task Assessment.** Provides a functional assessment of the client’s strengths and impairments by observing performance on a variety of email tasks under different conditions.

(3) **Environmental and Capabilities Self-Assessment.** Identifies access and opportunity barriers and resources from the perspectives of the client and caregiver.

(4) **User Requirements.** Elicits the goals and expectations of the user in terms of email.

(5) **Observation of Natural Communication and Activity Patterns and Physical Environment.** Provides information on the client’s communication and social activity as observed at home and in the community.

(6) **Technology Fit Summary.** Filled out by the examiner, this provides information on the types of issues that are expected to arise when attempting to install an email system in the client’s living space.

(7) **Training plan.** Identifies areas where the user has the potential to be trained to overcome current problems, thus obviating the need for scaffolding built into the email client.

The CORE process is currently a mixture of handbook material (e.g., forms and instructions for conducting an assessment session) and software for performing laboratory assessment of a client’s skills (Sohlberg et al, 2000b). In summary, CORE is focused on providing a highly individualized view of a client’s goals, corresponding skills, and overarching environment. In the next section, we will describe our initial evaluation of CORE on a TBI survivor.

6. **Michael: A case study**

   We have recently completed the CORE evaluation process with two TBI survivors. We report our results for one of those survivors here. For privacy reasons, we use fictitious names and limit reporting specific details of each survivor’s life. Michael is one participant in a longitudinal study we are conducting over a five year period. We have completed Michael’s CORE assessment, training plan, technology fit summary, and construction and delivery of his email client and hardware. (We have also developed a low cost, Linux-based box and modified OS interface for Michael to use.) At the time of writing, Michael has had the hardware and software for a month, and is producing an average of 30 emails a week of 10 sentences each to family and friends. This is truly astounding given the meager communication Michael had with this social circle prior to our study.

   We are using Michael as a case study in this proposal because of his potential for community navigation assistance. First we will describe his CORE results and then discuss our proposal for similar methods and tools to be applied to give him (used as an exemplar) access to social opportunities in the larger community.
6.1 Michael’s background

Through use of CORE, we gathered the following information. Michael had a brain tumor in mid-life and subsequent surgery fifteen years ago. He was a teacher and did not work after his brain surgery. He lives alone with occasional support from friends. He has school age children, although he and his wife are divorced. He has approximately five people with whom he would like to correspond via email. He has two computers that he has never turned on – he cannot figure out how to use them. He rides his bike for short trips, but often gets lost.

6.2 Michael’s email skill assessment

A central piece of the CORE process is an online email skills assessment. This is held in an office setting, and can have from 1 to 3 professionals involved. For research purposes, we chose to use: an examiner trained in cognitive rehabilitation, a note taker trained in qualitative methods, and a computer science expert. Our goal is to eventually generate enough documenting material to allow a single cognitive rehabilitation specialist to administer the assessment. The assessment consists of a computer tool for generating mock email GUIs in context. Currently, all GUIs are built in advance and the tool allows the examiner to sequence through them in arbitrary order. Each comes up in the context of a focused task, e.g., “read the email from your doctor and create and send a reply.” The tasks are constructed to evaluate potential problems affecting email due to: physical impairment (motoric, visuoperceptual), language impairment (auditory comprehension, reading, writing), cognitive impairment (attention/memory, executive functions, procedural learning), response to help modes (graphic prompts, speech prompts, text prompts), computer skills (mouse movement, button-click, keyboard use), and task conceptualization (ability to understand and stay on task). There are three key outcomes from the assessment: (1) A training plan that will target certain skills through what we call direct instruction and meta-cognitive strategy training. It is hypothesized that the application of these two instructional/rehabilitation models will permit individuals with amnesia and executive function impairments to learn a functional multi-step task such as reading, composing, and sending e-mail. (2) Parameter settings for the email client delivered to the user, settings that reflect data obtained in each of the areas assessed. (3) A set of monitoring specifications for runtime analysis of a user’s goals. A partial summary of Michael’s assessment is given below, along with ties to training, assistance, and monitoring.

Motoric

- **Assessment:** hunt-and-peck, slow release of keys.
- **Training:** standard keyboarding skills.
- **Email tailoring:** set key sensitivity to low.
- **Monitoring:** focus on multi-key patterns. Readjust key sensitivity to reflect typing skills.

Language

- **Assessment:** reading comprehension adequate for short paragraphs. Writing is telegraphic and very slow (see Motoric).
- **Training:** none.
- **Email tailoring:** offer form-based replies that minimize typing.
- **Monitoring:** track use of forms supplied. Track change in length of replies (either improvement or declination).

Cognition

- **Assessment:** Moderate difficulty with the following: (a) alternating attention between elements on screen, (b) holding on to task instructions, (c) written replies did not correspond to requested information in sender’s email. Uses trial-and-error strategy when stuck. Lack of procedural learning across trials.
- **Training:** Replace trial-and-error strategy with meta-cognitive strategy (e.g., teach to read email twice, write response and recheck that it corresponds to senders).
- **Email tailoring:** Include a to-do list recipe/prompt for replying to email.
- **Monitoring:** Track latency between known steps in replying. Gather feedback from email partners on coherence of Michael’s email replies (manually through field notes or automatically through computer generated questionnaires).
6.3 Michael’s Home Environment (Ecology)

Michael lives in his own house. A home visit was arranged for two field researchers on the project. Many minor problems were found (e.g., no clear space to place box, access to phone is partially blocked, general mess and disorganization). Michael was given a set of tasks to prepare for the delivery of the computer. Placement and access to computer remains a question (e.g., Will Michael remember that the computer is there? Will it eventually become buried under junk? Will floor access become restricted with accumulating junk?). The first three months will be critical in solving these issues.

6.4 Michael’s Expectations and Goals

The importance of doing a personal RE process is evident with Michael. While he does share some of the goals and expectations seen in focus group meetings, his primary goals were not captured, and we argue, could not be captured by a general TBI set of requirements taken from a broad study. We reproduce the results of Michael’s goal identification session in the table below. Note that Michael’s top goal is not to become more social, but to pick up a new skill. He is intellectually curious and email is a new challenge. His most favorable outcome is to reduce any dependency on online assistance. Hence, a goal of the system we deliver should be to remove assistance whenever feasible (e.g., monitor for continuing need of assistance and adapt the system to remove it when possible). On the downside, it appears from other parts of CORE results that Michael will never be able to fully use a raw email client. However, his goal can be translated into an aggressive monitoring and adaptation strategy that removes assistance when it makes sense.

<table>
<thead>
<tr>
<th>Goal #1:</th>
<th>&quot;I want to improve my ability to learn a new skill, specifically e-mail.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most favorable outcome thought likely:</td>
<td>&quot;proof of e-mailing independently; no help required&quot;</td>
</tr>
<tr>
<td>Expected level of success:</td>
<td>&quot;I want to learn how to e-mail. I may occasionally get stuck and need help (i.e., someone comes to my home to show me what to do).&quot;</td>
</tr>
<tr>
<td>Less than expected success:</td>
<td>&quot;I will need lots of help.&quot;</td>
</tr>
<tr>
<td>Most unfavorable outcome thought likely:</td>
<td>&quot;I can’t learn e-mail. You have to tell me how to do it.&quot;</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal #2:</th>
<th>&quot;I want to feel more connected with my e-mail partners, particularly [my family].&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most favorable outcome thought likely:</td>
<td>&quot;I want to feel like I’m sharing authentic/interesting information with everyone, especially [my family].&quot; &quot;Not just talking about the weather.&quot;</td>
</tr>
<tr>
<td>More than expected success:</td>
<td>&quot;Sharing interesting content with at least one person.&quot;</td>
</tr>
<tr>
<td>Less than expected success:</td>
<td>&quot;E-mails will be mostly superficial.&quot;</td>
</tr>
<tr>
<td>Most unfavorable outcome thought likely:</td>
<td>&quot;Responses to e-mails will be negative. They will hate what I say.&quot;</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Goal #3:</th>
<th>&quot;I want to decrease my impulsivity and increase my social judgment, and organization.&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most favorable outcome thought likely:</td>
<td>&quot;Very few instances of impulsivity &amp; lapses in social judgment; less than 1 per week.&quot;</td>
</tr>
<tr>
<td>More than expected success:</td>
<td>&quot;Instances of impulsivity &amp; lapses in social judgment decrease to no more than 1-2 instances per week.&quot;</td>
</tr>
</tbody>
</table>
6.5 Summary of Michael’s CORE results

By using a personal RE process with Michael, we were able to learn critical information that must be factored in to any system delivered to support him in email use. First, we obtained a snapshot of his current strengths and weaknesses in terms of email skills. Second, we gained information on his personal environment. Third, we got a snapshot of his current social circle. Fourth, we acquired his requirements (goals and expectations) in introducing email into his life. We cannot say that paying attention to each of these guarantees success. But we can confidently argue that if we did not pay attention to each, and delivered a generic system, there are too many paths to failure. What can we do to close off even more of those paths? Perhaps first and foremost, we can train Michael to improve some of his email skills. The second way we can enable success is to remove the potential for failure. Our approach here is to build an email client that is tailored to Michael’s skills, and avoids putting him in situations where his weaknesses come into play. If he becomes easily frustrated with typing, and cannot be trained to be a better typist, then minimize typing. Currently we are exploring fill-in-the-blank style messages, although a word-completion type of assistant might also help. Of course, at some point it is impossible to remove barriers and still retain the ability to email. In these cases, we provide standard assistance (e.g., a to-do list or recipe for composing a reply).

Third, we can view the initial CORE results as just that, initial. There is only a limited amount of data that can be gathered in an office setting. The initial results can set up hypotheses about what type of system will work, and can raise potential warning flags. Monitoring is necessary to assess their validity. Clearly, monitoring is a tricky issue here. Gathering quantitative data is straightforward (e.g., number of emails sent, length of emails, occurrences when help was needed). However, we also need qualitative data (e.g., Are Michael’s goals and expectations being met? Are his email partners satisfied with their interaction with him?). Instead of trying to take a high-tech approach to the problem by building sophisticated inferencing mechanisms and NLP parsers, we have chosen a more direct approach: ask the humans involved for feedback. This shifts the problem from one of AI to one of HCI: can we find a means of collecting qualitative data that is (1) automated, and (2) likely to be effective and used by the humans in the system? Clearly there are negative examples of such data collection, the proliferating set of web pop-up survey boxes being one. The question we are exploring is whether very specific and in-situ questions can be effective. We are building such questionnaires into Michael’s system.

6.6 A 2 month Update

At the time of writing, Michael has finished his training and has been emailing for approximately 2 months. We are astounded at his success to this point. He has gone from never sending electronic mail to sending an average of 30 emails a week of 300 sentences total (10 sentences per email). Michael did little writing before agreeing to participate in our study. He is in contact with family members and friends that he had little contact with prior to using email. Our analysis at this point is that our CORE assessment produced a training plan and email client that was a good fit with Michael. Of course, we have yet to pass the 3 month milestone. However, we have put monitoring into place, and expect to be alerted to changes in Michael’s needs. In fact, we have already used monitoring data to make small adjustments to the email client. And we have begun to train Michael’s careprovider in techniques to be used to do monitoring and maintenance of Michael’s system, in anticipation of handing off these tasks from our research group to the careprovider.
7. Breaking isolation through community access

The previous section was a look at our email project and a specific survivor who is participating in that project. Why the emphasis on email when this proposal targets community access? We expect to be able to heavily leverage our email work on this new project. In particular, we expect the same general principles to apply:

1. A solution that uses technology to mitigate social isolation with the TBI population will require a composite system approach. This means paying attention to the user’s ecology as well as the new technology introduced.
2. The triad of assessment-training-monitoring is a cornerstone to a successful uptake by a user.
3. Assessment is best done through functional means, i.e., using as much realism in assessment tasks as possible.
4. Focus groups and surveys can be used to give a first cut to the problems faced by the population in navigating within the community.

Our goal with CORE was providing survivors with a usable email tool. Our goal here is to give some travel independence to those that currently view this as beyond their means. We argue that we first need basic data on the population in terms of their abilities and limitations using navigations devices. We need a repeatable assessment process, akin to CORE, for matching up a TBI survivor with a composite system solution. If we can solve these problems, then we expect to allow users to begin to make successful forays into the community. This will certainly be in proscribed areas and following proscribed routes. Nevertheless, we believe that this can be of great social and confidence-building benefit to many TBI survivors.

As an approach, we propose to use the same basic structure as we have for email. This will include the following:

1. Extension of our focus group study. We have already captured basic information about a large number of TBI survivors in Oregon. We will resurvey these survivors to gain information about community access and navigation problems that they encounter.
2. Construction of a CAN process (Community Access Navigation) that is the analog to CORE. This will provide a personal RE process that (1) matches survivors with assistive technology, (2) prescribes a training regime, and (3) specifies monitoring events.
3. Evaluation through a set of limited case studies. This proposal supports a first look at community access. Its evaluation will be as a pilot study. Hence, its submission as a small ITR proposal.

The following sections take each of these up in turn.

8. Focus groups and user surveys

Having established a working relationship with the TBI population in Oregon through the email project, we propose to build on that relationship to find the problems associated with navigation within the community. Specifically, we will build on the following sections of the email survey. (Note that we have a space problem in this proposal. We cannot provide a full copy of the surveys and other CORE material here; it would run to 30 pages. Instead, we will summarize the portions of CORE that we will build on. The full CORE report can be found off the www.think-and-link.org site.)

CORE sections I and III relate to the survivor’s injury and impairments, and will be used as is. Section II of the user survey currently gathers information related to the survivor’s social activities. We will use this as is: it is not tied to cyberspace activities. Section IV discusses general computing skills. We will modify this to focus on a PDA or wearable computing device. Related to this, we are interested in a survivor’s current ability to use a TV remote control, to follow simple on-screen directions, to follow a phone-tree type of answering service. These all have more in common with the navigation devices we envision than a desktop computer setup. The CORE version of section IV is given below. We will work within our PAR team (see section 10) to redefine this to focus on use of a community navigation device.

Section IV (CORE)

1. Used computer prior to injury? □ yes □ no
2. Used computer following to injury?  yes  no
3. Do you currently own a computer?  yes  no
4. Are you able to read a short, type-written note?  yes  no
5. Are you able to write (compose) a short, type-written note?  yes  no
6. When you use the keyboard do you:  hunt and peck/1 finger  type but need to look at all the keys  type without looking much at keyboard
7. Is there someone available to help you if you want to use computer?  yes  no
8. If you are not using a computer, why not:  financial  it is too complicated  motor problems  takes too long  visual problems  feel intimidated  hand-eye problems  not interested  other  
9. In the past six months, how frequently have you used a computer or the Internet for the following purposes? (CHECK ONE BOX FOR EACH ITEM)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Severa times a day</th>
<th>About once a day</th>
<th>3-5 days a week</th>
<th>1-2 days a week</th>
<th>Every few weeks</th>
<th>Less often</th>
<th>Never</th>
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<tbody>
<tr>
<td>a. Word processing</td>
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<td>b. Organization (schedule, reminders, etc)</td>
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<td>c. Work</td>
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<td>e. Finding information</td>
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<td>f. Buying a product or service</td>
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<td>g. Downloading (music, images, etc)</td>
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<td>i. Chatrooms</td>
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We will re-administer our modified section IV to those who participated in our focus groups and survey.

**9. CAN: A personal requirements engineering process for navigation**

We have found that the components of CORE are effective to success in matching TBI survivor to email access (see section 6). We propose to use this as a foundation, but transfer it to the new task of community access. The new process, which we call CAN (Community Access Navigation), will ultimately have the following components:

1. **Computer User Profile.** Provides background information on the client’s injury, executive function symptoms, social communication and potential for use of a navigation device.
2. **Navigation Task Assessment.** Provides a functional assessment of the client’s strengths and impairments by observing performance on a variety of navigation tasks under different conditions.
3. **Environmental and Capabilities Self-Assessment.** Identifies access and opportunity barriers and resources from the perspectives of the client and caregiver.
4. **User Requirements.** Elicits the goals and expectations of the user in terms of community access.
5. **Observation of Natural Navigation and Activity Patterns and Physical Environment.** Provides information on the client’s navigation and social activity as observed at home and in the community.
6. **Technology Fit Summary.** Filled out by the examiner, this provides information on the types of issues that are expected to arise when attempting to deliver a navigation system for community access.
(7) **Training plan.** Identifies areas where the user has the potential to be trained to overcome current problems, thus obviating the need for scaffolding built into the navigation device.

As with CORE, we will need to do preliminary pilot studies in a lab setting. This establishes the range of assistive technology that is within reach of the population. At the time of writing this proposal, we have two lab efforts ongoing. The first is a study of voice navigation. We are developing a protocol for giving voice navigation in the campus area. Our goal is to discover what type of visual cues (described aurally) and navigation advice can be used effectively. Researchers talk to subjects using cell phones, while following at a distance, to provide “computer” navigation help when requested. Of course, this fineses the issue of accurate location information: the researchers can see where the subject is at all times and which way they are facing. Nevertheless, our first runs of the protocol have given us useful information on the effectiveness of voice-only interfaces for navigation. (Section 13 describes related work in voice navigation in more detail.)

The second study we are currently conducting is the ability of PDA users to interact with a simple GUI, without a stylus. In particular, we are working with (a) using a finger on the touchscreen, and (b) using a two-button “watch” that they wear on their wrist. For this study, we are supported by an equipment grant from Intel – we obtained ten iPaqs with GPS and wireless connectivity. The general goal is to establish several simple interactive options and then assess what an individual user is most comfortable with.

We expect that both of these current studies will evolve into a more formal assessment process that will be at the heart of CAN. In essence, they parallel CORE in the emphasis on functional assessment to determine the potential for success using an assistive technology system. Functional assessment concentrates on the client’s performance during everyday tasks, particularly those tasks most relevant to the client and his/her use of the system.

The final piece is to tie impairments to potential obstacles in community navigation. Both of the studies described above focus more on the device-usage skills of a user. However, work by Boyd and Sautter (1993) examines the ability of an adult with a traumatic brain injury to complete a route finding task. The task presented to the participant is to find a particular destination as quickly and efficiently as possible. While the goal of the study was to validate the use of the task in assessing executive function, it provides a wealth of information on the difficulties of providing navigation assistance to individuals with traumatic brain injuries. Of the cases they discuss, one provides a particularly good example. A participant was able to describe a detailed and complete plan that would allow them to get to the destination quickly and efficiently, as judged by the researcher. However, the participant did not start the plan that he described, nor did he start it when given non-specific cues. In fact, even when given a specific cue (e.g. let’s go) he did not move. The participant stated that he didn’t know how to start, and did not start to execute his plan until the researcher told him to stand up and start walking. After starting, the patient successfully completed the task, including asking other staff members for directions, following them, and using environmental cues to ensure that he was on the correct path.

In order to judge the level of executive function for adults with TBI in cases similar to that described above, Boyd and Sautter (1993) rate a participant’s abilities in a number of specific areas: task understanding, information seeking, retaining information, error detection, error correction, and on-task behavior. Task understanding is the ability to understand instructions and how to go about completing the instructed task. Information seeking measures behaviors such as wandering aimlessly, wandering methodically (e.g. door to door search), and gathering and using information. Retaining directions involves being able to keep directions in short term memory or the ability to compensate for lack of short term memory in some way. Whether or not the participant detects errors, spontaneously or with cues, is noted in error detection. Error correction rates how the participant handles errors. This includes behaviors like helplessness, recovery strategies, and help seeking. Finally, on-task behaviors describe the ability of the participant to keep their attention on the current task. In the example above, the participant scored low in task understanding but did well in all other areas.

Tom Boyd will work with us, as a consultant on this grant, to link up the quantitative and qualitative outcomes of his protocol with a community navigation solution, i.e., to map task understanding,
information seeking, retaining information, error detection, error correction, and on-task behavior to a composite system solution.

10. Involving individuals with cognitive disabilities in the project

A unifying methodology fundamental to all our research activities is adherence to a research method that involves a partnership between professional researchers and the people with the potential to be most affected by the research outcomes—those with cognitive impairments and their support communities. We have a long history of conducting consumer-driven research with individuals with disabilities including those with traumatic brain injury (TBI) (Sohlberg, Todis, & Glang, 1998; Sohlberg, Mateer, Penkman, Glang, & Todis, 1998; Sohlberg, Glang, & Todis, 1998; Glang, Todis, Cooley, Wells, & Voss, 1997; Todis, Glang, & Fabry, 1997), physical and cognitive disabilities (Todis & Walker, 1993; Todis, 1996; Todis, 2001) and developmental disabilities (Todis, Powers, Irvin & Singer, 1996; Todis, 1991) and well established methodologies for ensuring close collaboration with people with cognitive impairments in every phase of the research process, from pre-proposal pilot work to presentation of research findings. Of particular relevance is a recently completed project directed by Sohlberg and Todis that resulted in a therapeutic process and set of procedures to help rehabilitation practitioners form collaborative clinical alliances with families affected by brain injury (Sohlberg, McLaughlin, Todis, Larsen, & Glang, in press).

The current proposal is a product of information generated by persons with cognitive disabilities. Drs. Fickas and Sohlberg held a joint graduate seminar at the University of Oregon in the spring of 2000 with support from people in the community with cognitive disabilities and their care-providers. The topic of the course was the use of technology to overcome social isolation suffered by people with cognitive impairments. As the graduate computer programming students developed prototype technological solutions, they were given feedback from people with cognitive disabilities who tried to use the proposed technology solutions. These prototypes provided enough of a proof of concept to conduct more formal research.

Our approach will be to use Participatory Action Research (PAR). PAR is a method of social inquiry that involves cooperation between participants under study and professional researchers throughout the research process from initial design to presentation of results. PAR contrasts with conventional research models in which members of organizations are treated as passive subjects, with some participating only to the extent of authorizing the project, serving as subjects and receiving the results. PAR also contrasts with commonly applied research approaches in which researchers serve as professional experts designing the project, gathering the data, interpreting the findings, and recommending action to the client organization (Hall, 1984). Guiding principles of PAR include the following:

1. Research should involve people who are the subjects of the research in the entire process. Researchers include relevant persons who collaborate with professional researchers to define a problem, choose investigation methods, and determine how information will be used or disseminated (Schwandt, 1997).

2. The research should result in some direct and positive benefits for those communities and people involved (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998).

3. Knowledge is made more socially usable when it is produced collectively (Hall, 1984).

PAR has been used extensively, with positive results, to include employees in improving business practices (e.g., Santos, 1989); in education using students and teachers to develop school-based curriculum (e.g., Peck & Curley, 1992); and more recently, in our own investigation of cognitive rehabilitation with persons affected by brain injury to develop methods to improve adoption of external compensatory cognitive systems and methods to build upon family expertise to manage issues of concern following brain injury (Sohlberg, Todis & Glang, 1998; Sohlberg, et al., in press). The principles of PAR have particular appeal for cognitive rehabilitation specialists who too often are the focus of pilot and field
testing of assistive technology devices designed by researchers without input from people using the
devices or helping coach persons who will be using the devices (Beukelman, Yorkston & Reichle, 2000).

PAR is also of increasing interest to persons with disabilities and their families who feel that research in
education and rehabilitation has ignored their perspective on the experience of having a disability. An
enormous advantage of PAR is that it leads to a more accurate and authentic analysis of social reality for
persons with disabilities (Balcazar, et al., 1998).

Recognizing the efficacy, appropriateness and importance of including those who are most directly
affected by research in its design and activities, we will employ a PAR approach in this research project.

11. Evaluation

The research will be divided into three overlapping research strands:

(1) a series of focus groups to further identify needs, perceived barriers and solution ideas
incorporating perspectives from a wide group of people with cognitive disabilities in different
living environments and professional researchers as described above;

(2) controlled laboratory studies evaluating specific navigation interface components (e.g.,
auditory vs. visual prompts; interaction mechanisms) using a series of within-subject
experiments employing people with cognitive disabilities; and

(3) feasibility trials with naive users and care-providers who are supplied with manuals, hardware
and software.

Because of the heterogeneity of both our research participants (individuals with a variety of types,
extent, effects and sequelae of TBI) and our proposed intervention program (the AT interventions are
customized to meet the needs of each individual research participant), a traditional between-subjects
experimental or quasi-experimental design involving random selection and/or random assignment to
contrasting conditions is not appropriate. Given the large variation we expect across participating
subjects and that is inherent within the independent variable (i.e., our individualized AT interventions),
achieving equivalent and independent units of analysis in experimental and control groups is not feasible,
nor would it produce meaningful data for analysis. Clearly our population of interest and our
individualized intervention are not consonant with requirements for either experimental or quasi-
experimental designs.

Thus, we propose a case study research design for our investigation of the effectiveness of our AT
intervention program. The purposes and context for our proposed project are most consistent with the
strengths of a case study research strategy as described by Yin (1989), wherein an individualized -- and
therefore variable-across-subjects -- intervention can be studied in all of its potential richness and
complexity with multiple measures as sources of evidence.

Measures will be taken to record a comprehensive list of parameters related to individuals’ skills and
supports when taking community excursions. These measurements will be in the form of structured diary
records completed by significant others who will be trained to log the following information: purpose of
the outing, mode of transportation, who initiated and organized the outing, a rating of the individual’s
enjoyment or satisfaction with the outing; a rating of the significant other’s enjoyment or satisfaction, a
record of type and instances of assistance provided to the individual during the outing and a record of
observations of independent behaviors exhibited by the individual. Significant others will receive training
in field note observation with a well developed curriculum we have successfully used on other projects
that incorporate family or careproviders as field researchers. The community outing logs will be taken
during a baseline period of two weeks prior to introducing the navigation device and then for a 6 week
period of device use and continued for a two week period following removal of the device. This will
allow us to learn the effects of the device from the perspective of those who are using it. Additionally the
device will capture the following data:

(1) Travel information on all trips. This will include time-stamped GPS coordinates, along with
the goals of the trip.
All device-user interaction as time-stamped events. This will include information/prompts presented by the device and actuation/replies of the user.

All external interaction (often unseen by the user) with remote devices or hosts.

12. Year 4 and beyond

Our 3 year proposal is to do the science necessary to produce a personal requirements engineering process (PREP) for community navigation for the TBI population. Our results will be made available both to those who work in the cognitive rehabilitation community and to those who work in the wearable computing community. We expect our data and prototype tools will be useful, in particular, to those companies who aspire to produce assistive technology to the cognitively impaired population.

Our personal plans beyond this grant will be to do a full evaluation of the CAN process, using multi-year (longitudinal) case studies. We also plan to take on scale issues related to technology transfer: How can something like CAN be integrated with current clinical practice? How can monitoring be taken over by those in a survivor’s social or professional circle? We do include one such clinical professional, Tom Boyd, as part of this grant and as part of our PAR team.

13. Related work

The CAN process will be developed based on assessment models used in the fields of assistive technology (AT) and augmentative and alternative communication (AAC). The Assistive Technology Outcomes Measurement (ATOM) model (Weiss-Lambrou, 2002) emphasizes matching the person and technology (Scherer, 199) within the context of the World Health Organization International Classification system of disablement (i.e., integration of impairment, activity, participation, and environment/context assessment) (WHO, 2001). The Participation Model (Beukelman&Mirenda, 1998), used in the related field of AAC, emphasizes a comparison of the functional participant requirements of non-disabled peers of the same chronological age as the AAC user. This model also includes an assessment of "opportunity" and "access" barriers for communication.

Singh provides a comprehensive discussion of access barriers due to language limitations in elderly and non-disabled adult users on the analysis of hypertext on the Internet (Singh, 2000). The paper also explores options for providing visual, cognitive, and linguistic aids through sophisticated interface design. What is not discussed is how to evaluate and monitor individual user needs, match the needs to interface design options, and monitor user satisfaction.

Work on walking navigation can be divided into two general categories. The first group contains research on the technological aspects while the second examines the cognitive aspects of pedestrian navigation. Within the area of technology, the primary areas of related research are determining the location and orientation of the user and how the system interacts with her. Outdoors, differential GPS can overcome some of the error of standard GPS, especially when combined with local information provided by a magnetic compass, altimeter, and step detection. The Personal Guidance System (Loomis, et al. 2001), Drishti, (Helal, et al. 2001) and REAL (Baus, et al. 2002) all make use of similar technologies in their systems designed to assist with blind and elderly pedestrian navigation. The location of indoor pedestrians presents even more of a problem since GPS signals do not work indoors. Drishti and REAL both allow for limited indoor navigation as well.

Despite all of these systems using the same basic technologies for outdoor navigation, they each interact with the user in different ways. Drishti takes verbal input and presents auditory output in an interactive, conversational style. The Personal Guidance System takes keyboard input, but presents routine information aurally to blind users. Interestingly, in the most successful version the sound appears to come from the direction and distance the user should move towards. The REAL system uses a visual display that clips onto glasses, combined with a two button 3-D pointing device, to direct the user with text, maps, and way-directions.

The related cognitive work is much more varied. Related work includes cognitive orthotics from computer science as well as route-finding investigations in psychology, geographic information science, and artificial intelligence. Especially important is previous work using route finding tasks as a means to
measure cognitive ability. Pollack (2002) describes *Autominder*, a tool meant to live with elderly individuals and remind them of their daily plans. As the author points out, cognitive orthotics are much more than just a glorified alarm clock since they need to have an accurate representation of the user’s daily plan in addition to monitoring how it is being carried out and adjusting accordingly. Kautz (2002) and Carmien (2002) both examine relevant hand held, personal data assistant based cognitive orthotics. The proposed work of Jones (2002) under the Wireless RERC at Georgia Tech is especially relevant since he has future plans to investigate how individuals with cognitive impairments interact with a wayfinding orthotic.

Significant work has also been performed in determining what route information should be presented to user and how it is used. Michon and Denis (2001) and Lovelace, Hegary, and Montello (1999) both examine the importance of landmarks in route directions. Tversky and Lee (1999) describe how these landmarks are used to navigate through the environment. Stocky (2002) presents a model of how people give route directions, implemented in an animated information kiosk.

Spikman et al (2000) have further validated Boyd’s Executive Route Finding (ERF) method for determining the extent of executive function impairments. In their study, the ERF was the only method to prove reliable in assessing impairments. The authors conclude that the power of ERF is in its use of unstructured, day to day tasks. This is similar to our findings in the development of the CORE process for email.