

A Community Safety-Net for the Brain-Injured Traveler

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1. Introduction

The GO (Get Outside) project at the University of Oregon is focused on giving the cognitively impaired population access to their community. We have spent the last two years studying this population in terms of their ability to get out of their apartments or homes, and access and enjoy the community services that many of us take for granted. One finding of this study is that many in the population are virtual shut-ins, not having the ability or confidence that they can be safe and successful on independent trips (Sohlberg et al, 2004). That this is a significant problem can be seen by the demographics: more than one million adults in the U.S. are diagnosed *each year* with cognitive impairments (CI) due to neurological disease or trauma (e.g., traumatic brain injury, stroke, tumor, epilepsy, infectious disease). Currently, there are between 13.3 to 16.1 million Americans living with chronic brain disorders and associated CI. Incidence rates for severe traumatic brain injury (TBI) are higher than those for spinal cord injury, multiple sclerosis, cerebral palsy, and muscular dystrophy combined (BIA, Inc., 2000). Unfortunately, cognitive disability from trauma and other conditions represents a “silent epidemic”; research and technological resources are disproportionately distributed to help those who are blind, deaf or physically disabled, conditions which are easily observable (Rehabilitation of Persons With Traumatic Brain Injury, NIH Consensus Statement Online 1998). There is much good work on the community-access topic for those with *physical* disabilities. (The United We Ride website is a good clearing house for information on these programs: www.united-we-ride.gov.) We have designed a research program that will extend community access to the brain-injury population, as well.

Research clearly documents the community-integration restriction experienced by persons with cognitive impairments, and in particular, those with TBI (Dawson & Chipman, 1995; Zencius & Wesolowski, 1999). A study of patterns of community integration 2-5 years post-discharge from brain injury rehabilitation revealed that a high percentage of people fell into a “poorly integrated” group, characterized by limited community travel resulting in an absence of shopping or leisure activities outside the home (Doig, Fleming, & Tooth, 2001). A known barrier to community access occurs when people can no longer drive (Code, 2003). Alternative modes of transportation such as using public bus systems (Newbigging & Laskey, 1995) or traveling on foot or by bicycle have not provided widespread solutions to driving cessation following brain injury.

Part of our own studies has been to build travel profiles that included destination “wish lists” that catalogue where people wished, but were unable to travel. This work showed that the overwhelming desire of people with cognitive impairments was to frequent places for social and recreational purposes. Unfortunately, we also learned that the population of people with moderate to severe brain injuries is partially housebound; they

take an average of 2-3 routine, assisted trips each week (Sohlberg, Fickas, Lemoncello & Hung, 2004).

The field of assistive technology offers initial strides into improving community travel for people with cognitive impairments. There are several large research centers devoted to developing travel systems or devices for people with cognitive impairments. For instance, the CLever project (part of the Coleman Institute) has studied the use of PDAs for displaying route information (Sullivan & Fischer, 2003). The Assisted Cognition project has used data collected from a PDA to infer the destination of traveler's within the community (Liao, et al., 2004). Our study leads us to believe that while these tools can be useful, there is a more fundamental issue: many in the population feel anxious about getting help while on a trip. While it may be that a PDA carried by a traveler can offer some of this help (this is in no way proven), it is almost certain that situations will arise where human, face-to-face help will be necessary. We are working on this problem. How can we enlist those in the community to give aid to a traveler in their midst that needs it?

2. Who Can Help?

The logical place to start is with family and careproviders. This is where the majority of research focus is today – allowing people in their home or office to monitor a trip over the Internet. Thus, as the CI traveler makes their way on a trip, a careprovider can follow it. The work reported in (Sullivan & Fischer, 2003) is a good example of linking a remote desktop user (a family member) into a trip. The remote user can see where the user is on a map, and hence, determine if they are off course or stuck. However, we have found that a careprovider can give little useful course-correction assistance from afar – they typically end up extracting the traveler from the trip by going to pick them up. Hence, they are a heavyweight type of help.

Do CI travelers often need this type of extreme help? We hypothesize that in some cases, maybe many cases, they do not. If someone in their vicinity could get them back on track or answer a question, they could continue on the trip. This hypothesis comes from our focus group meetings with the population and by following them on short trips. They do run into problems. They forget a route. They forget the purpose of the trip or where they were going. If they get off course, they may have a hard time getting back on track. Their problem seems to be finding people (a) they trust, and (b) who know enough of their route to give them a bit of assistance. Complicating the issue is that the CI traveler may not be able to clearly articulate the problem, only that they are confused.

One success story in Eugene is the group called the Transit Hosts. They work for the local bus company, LTD, and mingle at the major transit station downtown. Over time, they get to know the riders and many of their schedules. Hence, they can lend a hand without being asked – they can determine when someone is off track from their typical pattern. The travelers get to know them and trust them. Transit Host personnel are distinctive in red caps, and easy to pick out.

3. A Transit Host in Every Pot

The question we ask is can the Transit Host concept spread to the community at large? Can there be transit hosts at the mall, at the large medical center, at the outdoor concerts in the summer, at the public library? The immediate answer is no – there is no funding for

all of these assistance programs, for special staff that can be focused on helping the CI population. However, we are not ready to give up. There are people at all these public places in the community. Some even have an official role in assisting travelers, e.g., those who staff reception desks or information kiosks. Others are members of the general public who happen to be nearby when assistance is needed. Can they be enlisted as part of the safety-net that a CI traveler can access on a trip? If so, then they may be able to supply the lightweight assistance that can enable trips to be completed successfully.

4. At Least Two Major Issues

There are two major hurdles that we see in making members of the community part of a travel-assistance safety-net for CI travelers. First, there are technical issues. How can information be transmitted? How can a potential helper know that help is needed? How can she connect with (find and recognize) the traveler? What type of devices do both helper and traveler need to allow assistance to occur?

Second, there are the social issues. What will helpers tolerate in terms of being interrupted in their tasks to give assistance? What type of training will they need? What will they feel comfortable with in terms of assistance? What will the CI traveler feel comfortable with in terms of getting assistance? How can stranger-danger issues be overcome (but not eliminated) to get assistance? Will, in fact, enough community members volunteer for an assistance program to provide critical mass?

We are just starting an effort to gather information on these questions. We have begun surveying selected members of the community, both those who play an official assistance role now, and those who frequent several key community sites. In this first pass, we are interested in technology. What types of devices do they carry with them now? What type of applications do they run on them? We are also interested in social issues. What is their perception of the CI population? What reluctance do they have in playing an assistance role? Can their worries be mitigated?

Frankly, we will be extremely surprised if there is not a high amount of concern within the general public. This pilot study, we hope, will identify the attitude and perception barriers we face. Once this is known, we can think about how technology can help lower concerns and hopefully, make participation acceptable for a significant portion of the community. In the workshop, we will present the results of the pilot study.

5. The Figures

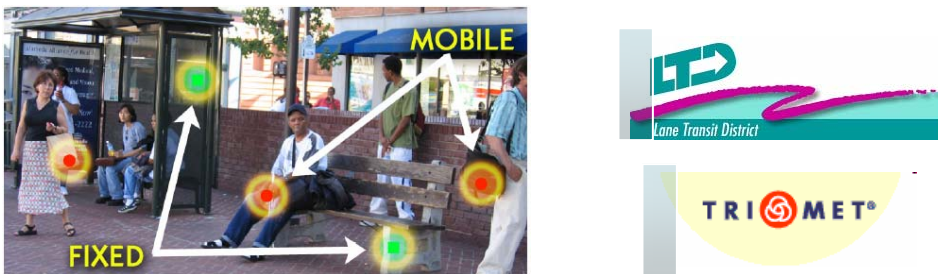
Each paper is required to include a figure to avoid straight text descriptions. We will include more of a collage to give an overall picture of our work.



Our general project is called GO for Get Outside. This was suggested by a focus group of brain-injury folks and we liked it. The web site is www.go-outside.org.



Up until this point, we have been focusing on usage issues with a PDA that is carried by a brain-injury traveler (Narayanan & Fickas 2001). This work has been funded largely by the National Science Foundation with equipment donations from Intel.



With funding and support from Eugene’s Lane Transit District, Portland’s TriMet transit authority, and a sensor network grant from Intel, we are just now turning our attention to what we can do to instrument the urban space and tie the community into the problem.

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