

Running Head: ABI NAVIGATION TECHNOLOGY SOLUTIONS

Technology Based Community Navigation Solutions for Individuals with Acquired Brain Injury and  
Executive Functioning Deficits

May 15, 2014

This project, submitted by Marcy Phillips and Jessica Murray, has been approved and accepted  
in partial fulfillment of the requirements for the degree of  
Master of Occupational Therapy from the University of Puget Sound.

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### Abstract

One area of function that has been identified as particularly difficult for individuals with acquired brain injury (ABI) is that of community mobility and transportation. The aim of this project was to create an instructional manual describing a two-day training program to assist caregivers of individuals with ABI and resulting executive dysfunction. Caregivers can implement the training program to aid their care-recipients in identifying and using technology devices to aid in community mobility. The first day focuses on assisting individuals with ABI in identifying cognitive strategies and appropriate technology for navigating public transportation. Caregivers and their care recipients also learn facts about public transportation, along with solutions to common barriers, such as route finding and appropriate behavior while on the bus. During the second day, caregivers guide participants in using technology to navigate King County public transit while taking a trip on the bus. After completing the training program, caregivers can be better prepared to teach individuals with ABI how to navigate public transportation with technology and know the next steps for assisting their care recipients to use public transportation. With assistance from caregivers, the participants can learn skills necessary to navigate public transportation with technology, thereby increasing their independence and sense of self-efficacy with community mobility.

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### **Introduction**

Accessing the community is important to the everyday well-being and quality of life for all. A community is where individuals socialize, engage in important life activities, and complete everyday business. Individuals with acquired brain injury (ABI) often find themselves with cognitive impairments that limit their ability to drive or navigate successfully in the community (Formisano et al., 2005; Preece, Geffen, & Horswill, 2013; Preece, Horswill, & Geffen 2010). These impairments can include deficits in memory, skills related to various types of attention, ability to identify and use effective methods to carry out tasks, and transferability of learning (Toglia, Goverover, Johnston, & Dain, 2011; Toglia, 1991). This project aims to help individuals with ABI, access the community by using everyday technology as a compensatory strategy for navigating in the community, specifically using public transportation.

Research done by Huebner, Johnson, Miller-Bennett, and Schneck (2003) shows that many individuals with ABI are dependent on caregivers for their transportation needs or have simply given up on integrating into the community. Reliance on caregivers not only decreases an individual's independence, it also increases the burden of responsibilities on his/her caregivers. According to the Family Caregiver Alliance (2006), caregivers have higher rates of depression and experience higher rates of stress and frustration than non-caregivers. Increasing independence in transportation among individuals with ABI may help reduce caregiver burden, in turn reducing depression and stress. The research shows that using everyday technology (Lindén, Lexell, & Larsson Lund, 2011) and specific navigation technology (Sohlberg, Fickas, Hung, & Fortier, 2007) may provide this population with cognitive compensatory aids to improve their independence in this area. Everyday technology also has the potential to improve the satisfaction individuals with ABI have with their occupational performance (Lindén et al., 2011). An instructional manual, intended for caregivers, on teaching people with brain injury how to navigate public transportation, could potentially decrease dependence on caregivers and increase self-efficacy and independence in the person with brain injury.

Several local Seattle, Washington organizations provide assistance to individuals with brain injury and their families. The Brain Injury Alliance of Washington, Headstrong for Life, and Seattle Brain

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Works are all organizations that serve the Western Washington area. These organizations will be provided with a manual, intended for caregivers, describing an instructional course on helping people with brain injury use technology to navigate in the community. The content will be geared specifically to individuals with traumatic brain injury (TBI), which is a specific form of ABI, and will focus on the use of navigation technology as a compensatory aid for cognitive difficulties. The manual will be provided to the organizations in a digital format that can be housed on a website, e-mailed to a caregiver, or provided to a caregiver on a CD or USB device.

Sustainability of this project will be maintained by building a connection between caregivers and King County Metro Transit (KCMT). KCMT currently provides travel instruction training on navigating public transportation for individuals with disabilities (King County Metro Transit [KCMT], 2013). After completing this course, caregivers and individuals with TBI will be encouraged to continue training in basic navigation skills through the KCMT travel instruction program.

### **Literature Review**

#### **Acquired Brain Injury: Definitions, Prevalence, and Trends**

Acquired brain injury (ABI) is a diverse and prevalent classification of disability that impacts both physical and cognitive functioning. According to the Brain Injury Association of America (BIAA) and the Brain Injury Network (BIN), an ABI is classified as any insult to the brain caused by traumatic injury, cerebrovascular accident (CVA), disease, or other condition acquired after birth (Brain Injury Association of America [BIAA], 2012; Brain Injury Network [BIN], 2008). The targeted population for this project is individuals with ABI, with a focus on traumatic brain injury (TBI).

A TBI is any insult or injury to the brain delivered by external forces, which causes changes and deficiencies in normal brain functioning (Scherer, 2012). The leading causes of TBI in order of most prevalent to least prevalent are: falls, motor vehicle or traffic accidents, collisions with or against objects, and assault (Centers for Disease Control and Prevention [CDC], 2013). Fall related TBIs are most prevalent among children age zero to four and adults age 75 and older (CDC, 2013). The populations most likely to sustain a TBI are: males of all ages, children age zero to four years, adolescents age 15 to

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19 years, and adults age 65 and older (CDC, 2013).

The annual incidence, long-term costs, and effects of TBI in the United States (U.S.) are significant. According to the BIAA, the current annual incidence of TBI in the U.S. is 1,700,000 cases. The BIAA also reports that 5.3 million Americans are currently living with long-term disabilities as a consequence of TBI. Society spends an estimated \$76.5 billion annually on TBI related costs (BIAA, 2012). These numbers are substantial, but do not fully reflect the social, emotional, and functional impact that a brain injury can have on individuals and their families.

### **Human Cognition and Impact of ABI**

Human cognition is a highly complex system and impairment of that system, as a result of ABI, can have widespread and debilitating effects on a person's daily functioning. Brown (2011) categorizes cognition into several components including attention, memory, and executive functioning. She further subdivides attention into automatic, selective, or divided attention, as well as vigilance. Memory refers to short-term, long-term, and working memory (Brown, 2011). Vaughan and Giovanello (2010) define executive functioning as a "broad attentional construct that commonly refers to goal-oriented, higher level cognitive processes" (p. 343). Executive functioning encompasses the skills of concept formation, categorization, schemas, problem-solving, decision-making, and metacognition (Brown, 2011).

Individuals with TBI often have cognitive deficits secondary to their injury. Colantonio et al. (2004) found, in a long term outcome study of 286 survivors of TBI, that individuals with TBI had significant impairments on outcome measures involving memory and psychomotor speed. McDonald, Flashman, and Saykin (2002) indicate that a majority of TBI cases involve some level of disruption to the frontal-subcortical systems. This area of the brain is considered the anatomical site of executive function and thus a possibility of executive dysfunction can be expected in most individuals with TBI (McDonald, Flashman, & Saykin (2002). Because cognitive disability is associated with TBI, and because cognitive impairment leads to decreased independence, individuals with a TBI are very likely to have difficulties participating in occupations, especially tasks such as instrumental activities of daily living (IADLs), which require complex planning and thought (Colantonio et al., 2004).

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### **Impact of Executive Dysfunction on Navigation**

IADLs are activities that “support daily life within the home and community that often require more complex interactions than self-care” (American Occupational Therapy Association [AOTA], 2008, p. 631). Colantonio et al. (2004) correlated executive functioning deficits after TBI with performance difficulties in IADLs. Specifically, they found that people with TBI needed more support in IADL tasks such as money management, shopping, and getting to places out of walking distance (Colantonio et al., 2004). Erez, Rothschild, Katz, Tuchner, and Hartman-Maeir (2009) found that executive function deficits restrict performance in individuals with ABI in the areas of initiation, leisure, residence, and employment. These occupations often require the person to have the ability to travel to other locations; for many, this means using public transportation. Without the ability to safely and effectively navigate public transportation due to executive dysfunction, individuals with TBI will therefore have trouble accessing these valued occupations.

The IADL of navigation, particularly navigating public transportation, is important to the independence of individuals with TBI and executive functioning deficits. In the U.S., driving is an important way for individuals to access valued everyday occupations, such as work and community based leisure or IADL (AOTA, 2010). However, it may not be possible for individuals with TBI to return to driving. Driving is a complex task that requires “motor coordination, visual perception, and aspects of higher-order cognition” (Preece et al., 2010, p. 493). Formisano et al. (2005) investigated traffic accident rates in individuals who had resumed driving after severe brain injury. The researchers found that these individuals had a statistically significantly higher risk of being involved in traffic accidents than those with no history of TBI. Preece et al. (2010) examined the driving hazard perception of individuals with acute mild traumatic brain injury (mTBI). These individuals were statistically significantly slower to respond to traffic hazards than the comparative group individuals with minor orthopedic injuries. This research shows that brain injury has a negative impact on driving performance and correlates with increased chances of getting into a traffic accident.

Unfortunately, 52 percent of individuals with mTBI reported that they would not reduce their

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driving at all after their injury (Preece et al., 2013). As a result of the increased risk of injury, both to themselves and to other drivers on the road, it is essential that the driving ability of people with TBI be carefully assessed. If these individuals are found to be unsafe to drive, and can therefore no longer access valued community-based occupations by driving, another alternative for community mobility should be available to them. Public transportation systems can be that alternative. However, to use public transportation safely, individuals with TBI may need to use additional strategies, such as cognitive rehabilitation and technological aids.

### **Cognitive Impairment Interventions**

Cognitive rehabilitation interventions have both remedial and adaptive elements (Gartland, 2004). The desired outcome of these interventions is that the skills and strategies taught will generalize into the everyday life functions of individuals with brain injury (Gartland, 2004). In a remedial intervention approach, the specific cognitive skills that have been affected are addressed through targeted practice. Interventions may include “worksheets, computerized exercises, and electronic scanning devices” (Toglia, Golisz, & Goverover, 2009, p. 747). Proponents of the remedial approach assert that focusing on the improvement of underlying cognitive skills will facilitate a greater effect on functional outcomes because those skills apply to a wide range of activities (Toglia, et al., 2009; Toglia, 1991). In an adaptive intervention approach, the activity or the context in which the activity occurs is altered to decrease the cognitive skills required to engage in that activity. The goal of an adaptive intervention is to improve occupational performance and reduce activity restrictions (Toglia, et al., 2009). Elements of both remedial and adaptive approaches should be individualized according to client factors and circumstances in order to obtain the greatest functional outcomes.

To benefit from remedial or adaptive interventions, an individual with brain injury must first demonstrate an awareness of his/her cognitive deficits and how those deficits impact his/her everyday functioning (Von Cramon, Matthes-von Cramon & Mai, 1991; Fasotti, Kovacs, Eling, & Brouwer, 2000). Research has shown that self-awareness is impacted in a majority of individuals with TBI (Noé, Ferri, Caballero, Villodre, Sanchez, & Chirivella, 2005; Anderson & Tranel, 1989 as cited in Gillen, 2009).

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Self-awareness has been classified into three categories (Crosson et al., 1989). Intellectual awareness refers to the ability to understand when cognitive function is impaired. Emergent awareness is the ability to recognize when a problem is occurring, as it is happening. Anticipatory awareness is the ability to anticipate problems before they occur (Crosson et al., 1989). All of these forms of awareness are required to effectively plan and carry out complex tasks.

Cognitive intervention programs implement a variety of strategies to increase self-awareness. In her dynamic interactional approach, Toglia (1991) identified several unique strategies to increase awareness. The following is a selection of Toglia's strategies from this approach. Self-estimation is when an individual with a brain injury estimates how difficult a task will be for him/herself or how much assistance he/she will need with the task. Self-questioning is when he/she periodically asks him/herself how the task is going. Self-evaluation is when individual with brain injury evaluates his/her performance following task completion. All of these strategies are aimed at increasing an individual's awareness of his/her abilities (Toglia, 1991). Other cognitive interventions designed to help individuals with brain injury compensate for mental slowness (Fasotti et al., 2000) and use self-instruction (Cicerone & Wood, 1987) include elements aimed at increasing all three types of awareness. Fasotti and colleagues' (2000) Time Pressure Management strategy works to help participants attain sufficient anticipatory awareness to strategically plan for tasks that will require more time management in the future. Cicerone and Wood's (1987) self-instruction training program requires participants to verbalize plans prior to and during a task, which requires anticipatory and emergent awareness.

While increasing awareness is essential to an individual's success with cognitive rehabilitation, his/her ability to transfer learning from one context to another is equally important for improving functional cognitive skills. Toglia's multi-context approach to treatment focuses on restoring an individual's capacity to learn and generalize that learning to different situations. (Toglia, 1991; Toglia et al., 2011; Toglia, Johnston, Goverover, & Dain, 2010). Toglia designed her treatment intervention strategy to facilitate transfer of learning from one context into another by "systematically varying treatment activities and context and gradually increasing transfer distance," (Toglia et al. 2010, p. 664).



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She accomplishes this “increasing transfer distance” by gradually increasing first the physical and then the conceptual differences between related tasks (Toglia, 1991). As physical and conceptual differences are altered from task to task, “underlying skills and strategies required for performance of the task remain consistent across varied conditions,” (Toglia, 1991, p. 514). The goal of treatment is for the individual to recognize and use these skills and strategies in a variety of different situations (Toglia et al., 2010; Toglia et al., 2011).

Other researchers have implemented cognitive intervention programs designed to give their participants with brain injury strategies that may transfer learning to different situations if used in conjunction with Toglia’s multi-context approach. Von Cramon et al. (1991) used different forms of cueing, from general to specific, to facilitate problem solving in participants with brain injury. Cicerone and Wood (1987) also used external and internal cues in their self-instruction program. Breaking down the task into steps also proved to be effective in Von Cramon and associates’ work in problem solving training (1991). Levine et al. (2000) implemented strategies aimed at identifying specific goals and sub-goals of a task in order to help individuals with brain injury maintain effective goal directed actions.

The effectiveness of the above strategies and interventions depends on how well the different approaches match with the disabilities and personal contexts of the individual receiving the intervention. Fasotti et al. (2000) wrote of the importance of tailoring interventions to the individual: “Depending on the preserved cognitive skills of the user and on the task requirements, these strategies may entail the enhancement of awareness, the optimization of planning and organization, the rehearsal of task requirements, or the modification of the task environment” (p. 48-49). Research has synthesized a multitude of effective cognitive intervention strategies. Using materials from this project, caregivers will implement some of these strategies with the individual with brain injury participating in the training program.

### **Technology as a Compensatory Aid for Executive Dysfunction**

Technology is another resource that caregivers can use to help individuals with brain injury become more independent. Several types of technology devices can be used as compensatory aids for

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individuals with TBI. Assistive technology (AT) is one such type and is defined by the 1988 Technology-Related Assistance for Individuals with Disabilities Act (reauthorized in 1994, 1998, 2004, and 2010) as “any item, piece of equipment, or product system, whether acquired commercially, modified or customized that is used to increase, maintain, or improve functional capabilities of individuals with disabilities,” (AT Act, as cited in Scherer, 2012, p. 122). While the term AT refers to any device that aids in function, the term ‘everyday technology’ is classified as electronic devices that already exist in the lives of both individuals with ABI and typically functioning individuals alike (Lindén et al., 2011). People with ABI and executive dysfunction have many factors to consider when deciding what kind of technology to use to improve function. A study conducted by Lindén et al. (2011), showed that individuals with ABI who used everyday technology to compensate for executive functioning deficits, increased their self-perception of and satisfaction with their occupational performance. More than half of the everyday technologies used in the interventions in this study were the participants’ own, which negated the need to purchase expensive equipment (Lindén et al., 2011). In a systematic review of articles concerning the use of AT by individuals with cognitive impairment, cost was identified as a significant barrier to access to AT (De Joode, van Heugten, Verhey, & van Boxtel, 2010). Using everyday technology that individuals with ABI already own could lessen the financial demands on the individual. It may also reduce the time and effort required to learn how to use technology to aid in cognitive functioning if the person is already familiar with the technology (Lindén et al., 2011).

Individuals with TBI may also prefer to use everyday technology to avoid the social stigma associated with using AT. Dedicated assistive devices are often more recognizable as devices used by individuals with disabilities. Lindén et al. (2011), in their study on the benefits of everyday technology use, cited decreased social stigma as a possible reason why participants maintained the use of everyday technology as a cognitive aid at follow-up. These researchers also remarked on the high rate of abandonment of dedicated assistive technology, especially when compared to everyday technology within this population (Lindén et al., 2011). Evidence shows that the use of everyday technology has the potential to be more sustainable and effective than dedicated assistive devices.

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A common technological device that can be used in an assistive capacity is the smartphone. As of May 2012, 110 million Americans owned smartphones (Brownlow, 2012). Smartphones include a myriad of applications and functions that can provide compensatory intervention for executive dysfunction, such as using a calendar to schedule appointments, an alarm as a reminder to take medication, or a record function to take notes (Lindén, et al., 2011). However, the complex nature of the device also presents a challenge to individuals with cognitive impairments as a consequence of ABI (Engström, Lexell, & Larsson Lund, 2010; Lindén, Lexell, & Larsson Lund, 2010). Other high technology devices that can be used as compensatory aids include personal digital assistants and desktop computers (Gillespie, Best, & O'Neill, 2012). Less complex technology devices such as talking alarm clocks and paper schedules can mitigate the difficulties that individuals with ABI might have with high technology (Lindstedt & Umb-Carlsson, 2013). When selecting appropriate AT devices for individuals with brain injury, simplicity and ease of use of less complex devices must be weighed against the versatility of high technology devices.

There is currently a wide spectrum of high and low tech AT to aid in navigation. Researchers have been working to determine what features on navigational devices work best for individuals with ABI, TBI, and executive dysfunction. A comprehensive study done by Sohlberg, Todis, Fickas, Hung, and Lemoncello (2005) examined community navigation in adults with chronic cognitive impairments (CI). In one part of this study, the researchers conducted focus groups to gain feedback about navigational devices. Focus group members supported the use of these devices with the condition that they have specific features. Some of the desired features were: directions should be concise, devices should have audible/repeatable directions, and the user should have the ability to make personal notations. These features could improve the effectiveness of how individuals with cognitive impairments navigate in their community.

### **Public Transportation**

As described previously, public transportation can be a safer alternative to driving, but there are still considerable barriers to individuals with ABI, TBI, and executive functioning deficits accessing these systems. In the first part of a study done by Sohlberg et al. (2005), six individuals with severe ABIs were

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followed over a four month period. These participants met each week to discuss what locations they visited, barriers they encountered, and other questions related to navigation in the community. Results for this portion of the study showed that a high level of assistance was needed during trips for all participants and if a trip was taken unaccompanied the most likely form of travel was walking or the bus. The most frequently reported problems were forgetting to begin the trip, forgetting the destination while en route, and trouble deciphering written directions (Sohlberg et al., 2005). The second portion of the study was made up of focus groups that included: individuals with CI, care providers for individuals with CI, and public transportation workers (Sohlberg et al., 2005). Analysis of the focus group data produced the following categories: preferred travel modes, challenges, strategies, and suggestions for navigation device features. Some of the challenges included: fear of asking strangers for help, getting separated from companion, and forgetting destination or purpose for travel, all of which create barriers to community transportation (Sohlberg et al., 2005). Other challenges that individuals with TBI face in accessing community transportation stem from poor impulse control, which may lead to problematic behaviors. Research has found that individuals with TBI have increased: urgency (acting without thinking), lack of premeditation (thinking carefully before doing), and lack of perseverance (seeing things through to the end) (Rochat et al., 2010). Cognitive impairments combined with behavioral issues can present serious challenges to individuals with TBI who are trying to access public transportation.

Another barrier to individuals with ABI accessing the community is difficulty with wayfinding. Lemoncello, Sohlberg, and Fickas (2010b) found that individuals with ABI had considerably more difficulty navigating and problem solving en route than a matched control group. A feature of this study was that all participants had a cellular telephone they could use to call a researcher for help with wayfinding. The individuals with ABI called more frequently for help than the control group and, when interviewed later, indicated that they would have discontinued travel without the help (Lemoncello et al., 2010b). This has interesting implications for future programs involving wayfinding, as having the ability to call a human being for assistance helped these individuals persist with the task. For this project specifically, caregivers will be able to provide that one-on-one human assistance during the training

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sessions.

Overcoming these barriers is important to the quality of life of individuals with ABI (specifically TBI) because without the ability to navigate the community, valued occupations may be given up or shifted to someone else. For example, Huebner et al. (2003) found that 52 percent of individuals with TBI have their shopping and finance occupations done by someone else, 48 percent have their housework done by someone else, 24 percent never go shopping, and 20 percent of them never go out for leisure activities or visiting friends or relatives. This indicates that there is a need for specialized programming to help individuals with TBI and executive dysfunction access the community through public transportation.

### **Successful Navigation Strategies and Training**

Several successful strategies and training programs have been implemented to assist individuals with ABI and executive dysfunction with navigation. Lemoncello, Sohlberg, and Fickas (2010a) examined three different directional prompts and compared their efficacy in orienting individuals with ABI. The three prompts were cardinal, landmark, and left/right directions. Cardinal directions orient travelers by north, south, east, and west. Landmark directions orient travelers by a recognizable object or feature of a specific location. Left/right directions orient travelers by assuming that they are facing a certain direction and giving them directions to turn left or right at particular points along a route. The researchers found that the most effective of these three prompts was using landmarks to orient.

Sohlberg, Fickas, Hung, and Fortier (2007) examined how technology can specifically assist with navigation skills. The researchers compared four different modes of directional prompting, which were housed in an electronic device designed to assist people with cognitive impairments to navigate walking routes. The investigators had participants navigate pre-determined routes with verbal prompts delivered via headphones, textual prompts displayed on a screen, aerial view map images, and first person point of view map images. It was hypothesized that, since cognitive rehabilitation literature shows the efficacy of using checklists, that the textual directions would be most effective and most preferred. In actuality, the audio cues were most effective in assisting navigation and most preferred by the participants (Sohlberg et al., 2007). Any training program attempting to use technology to improve navigational skills for

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individuals with TBI will need to take these findings into account.

Research has shown that training programs can successfully mitigate the impact of cognitive deficits. For example, McInerney and McInerney (1992) implemented a mobility skills training program using behavioral analysis techniques with adults with developmental disabilities. The population in this study had significant cognitive limitations similar to those in individuals with TBI. McInerney and McInerney (1992) found that before the training these individuals relied on others to help them access public transportation and after the training the individuals were able to independently travel to community leisure activities. While the training program in this study focused on cognitive limitations, other travel training programs are available to individuals with disabilities to assist with navigation of public transportation. The Association of Travel Instruction (ATI) defines travel training as “one-to-one, short-term, intensive, comprehensive instruction in the skills necessary to travel safely and independently on public transportation” (Association of Travel Instruction, 2014). Programs like ATI and Easter Seals Project Action (ESPA, 2013) have recognized the need for individuals with disabilities to have access to public transportation and are implementing travel training programs across the country. These programs provide training in general community mobility skills but do not explicitly address the needs of people with TBI and executive dysfunction. This project was designed to fill that gap and is to be used in conjunction with travel training programs as it focuses specifically on use of technology for TBI related executive dysfunction. This project also connects caregivers and individuals with TBI with the local Seattle, Washington travel training program through King County Metro to support sustainability of learned skills.

### **Purpose Statement**

The purpose of this project was to create a training program, implemented by caregivers, that teaches individuals with ABI (specifically TBI) and executive dysfunction how to use technology to navigate the community using public transportation.

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### Procedures

We first performed a needs assessment of the TBI population to determine areas where more support and/or resources were needed. Through this needs assessment, we identified and contacted organizations that provide services to individuals with TBI and informed these organizations of our project scope. We interviewed administrators and/or staff members and determined that community navigation was an area of difficulty for the TBI population. We also solicited the perspective of individuals with TBI and their caregivers to gain a deeper understanding of community mobility and technology use. After this needs assessment, we determined that a training program on teaching individuals with brain injury to use technology to access public transportation would be beneficial to this population. The final form of the training program would be a manual intended for caregivers to implement with care recipients. The manual would then be distributed by brain injury support organizations via digital means.

Headstrong for Life (a local mentorship group for youth with TBIs) was interested in the manual and implementation of our project was initially intended to take place through them. We had several meetings with Headstrong for Life (Headstrong) president Desiree Douglass and began planning an event in which Headstrong mentors or family members of individuals with TBI would implement our manual. At the end of February, Ms. Douglass indicated that the training program may be beyond the ability of the youth that Headstrong serves. In response to this development, we shifted the focus of our manual to target only caregivers, taking the focus away from any one organization. This new manual could then be distributed to any local support organization to use with caregivers and individuals with TBI as they saw fit.

In order to create a manual with content that informed our training program, we spent time researching and improving our knowledge base in several areas. We researched technology devices and their effectiveness by exploring manufacturers' websites and using the technology our-selves. To gain a better understanding of travel training and public transportation we read "A Guide to Travel Training" (Ride Connection, 2009), observed one individual and one group travel instruction session through King

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County Metro, and rode public transportation. We also examined TBI support organization websites, visions, and missions. Through internet sources and peer reviewed journal articles we learned about current standards for teaching technology and effectively communicating with individuals with TBI. We also learned about general demographics for the ABI and TBI populations.

We used occupational therapy strategies to inform several pieces of our manual. For example, activity analysis and grading were used to describe how to best fit technology to individuals with TBI and executive dysfunction. Our knowledge of the importance of occupation based interventions informed the design of several learning activities included in the manual. These activities were interactive and engaging for the caregivers as well as the participants of the training program. In order to help caregivers best address learning challenges associated with executive dysfunction, we expanded and used prior knowledge of Toglia's multi-context and dynamic interactional approaches to cognitive intervention.

We then compiled the above information and resources to create a manual that details a technology based travel training program specific to individuals with ABI (specifically TBI) and executive dysfunction. This program was intended to assist caregivers in training their care recipients to use King County Metro public transit. In order to create an esthetically pleasing and easy-to-read final product, we learned how to use a desktop publishing program to design the layout of the manual. We also drew ideas for providing navigation instruction from "A Guide to Travel Training" (Ride Connection, 2009) and obtained permission from Ride Connection to do so. Content for the manual included: detailed instructions on how to do the activities that take place on training days, quizzes, learning activities, and worksheets. In order to determine the usability of our manual, we distributed it to several caregivers of individuals with brain injury and developed feedback forms for them to complete.

After finalizing our manual, we created digital copies to be housed on the websites of brain injury support organizations. We also printed a paper copy to have as a resource for the University of Puget Sound Policy Advocacy and Leadership program. We plan to follow up with the organizations that currently have digital copies of our manual and determine whether the manual is being used, and to what degree caregivers are having success with the training program.



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### **Description of Final Product**

This project culminated with the creation of a two day navigation training program that caregivers can implement with individuals with TBI. Through this program, caregivers can assist individuals with TBI in the selection and implementation of compensatory technology to successfully navigate the community through public transportation. Day one of the training program is designed to teach individuals with TBI how to use technology to navigate public transportation. Day two is a practical training day, in which participants practice the skills learned on day one, by riding the bus with support from a caregiver and their chosen technology. Detailed instructions outlining how to implement the training program are compiled in a manual. This manual was designed to give caregivers of individuals with TBI the necessary knowledge and tools to conduct the above two day training session.

The manual outlining the navigation training program has been distributed to regional brain injury support organizations who will post it on their websites in PDF form. These organizations can refer caregivers of the people with TBI to this manual. Headstrong for Life (Headstrong), established in 2006, is one such organization that supports youth TBI survivors through family support groups, social events, and mentorship. Headstrong's mentorship program pairs youth with TBIs with peer mentors who can provide them with support and practical advice (HeadStrong, 2013). A second organization, established earlier in 1982, the Brain Injury Alliance of Washington (BIAWA) serves a broader population of individuals with brain injury in Washington. Similar to Headstrong, BIAWA serves its target population by supporting individuals with brain injury and their families through education, advocacy and by connecting this population with essential resources and support groups (Brain Injury Alliance of Washington, 2012). Seattle Brain Works is another organization that works with individuals with TBI on gaining self-esteem and self-determination necessary to increase skills for improved independence and accessing the community (Seattle Brain Works, 2010). A digital copy of the manual has been distributed to all of the above organizations, who will refer individuals with brain injury and their caregivers to the final product of this project.

Through these organizations, the manual and materials provided can support caregivers in

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implementing a two day training program that will teach individuals with TBI to use technology such as online mapping sites, cell-phone applications, dedicated GPS, etc. These devices may increase the independence of individuals with TBI in navigating public transportation. The manual for carrying out this training consists of two parts. Part one of the manual provides caregivers with the information they will need to teach individuals with TBI how to use technology to access public transportation. Part two of the manual provides a detailed outline for how the two training days should be conducted and includes a variety of learning activities for the caregiver to implement with the participant.

Part one is further subdivided into five sections and two appendices. Each section concludes with a quiz designed to help the caregiver evaluate his/her understanding of the material. Section one is an introduction to the manual and training program and includes basic information, statistics, and definitions concerning ABI and TBI. The second section in part one of the manual provides the caregiver with tools and information regarding teaching individuals with brain injury effectively. Section three provides information about how navigation is affected by TBI and methods that caregivers can use to teach navigation skills. Section four gives the caregiver information about how best to fit technology to the participant and how to teach individuals with TBI how to use technology. Section five provides the caregiver with step-by-step tutorials to explore two navigation applications (Google Maps and One Bus Away). This section is designed to encourage caregivers to become familiar with navigation technology before teaching it to their participants. Appendix A provides caregivers with a list of technology devices and applications that can be used to support community navigation, as well as a variety of other IADL occupations. Appendix B contains answers to the quizzes in part one; caregivers can then check their answers to evaluate their understanding of the material.

While part one of the manual is designed to give the caregiver knowledge and information necessary to carry out the training program, part two provides the caregiver with step-by-step procedures for the training program. It contains detailed learning activities and worksheets that will support the caregiver throughout the training program. Part two begins with a broad outline of what the caregiver needs to do before training, during training day one, and during training day two. After this outline, the

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first section of part two details what should occur prior to training. This section includes a pre-training form that the caregiver fills out with the participant to help determine the participant's current skills and abilities. The second section of part two provides information and learning activities for the caregiver to implement the training day one. On this day, caregivers work with their participants to set goals and practice: self-advocacy, safety, appropriate behavior, how to plan trips, how to ride the bus, and how to use technology to ride the bus. At the end of section two, the caregiver is provided a checklist to help him/her determine whether or not it is feasible and/or safe to have his/her care recipient participate in training day two. If the feasibility checklist reveals that the participant is not ready to ride the bus, the caregiver is referred to King County Metro Transit Instruction to obtain further training and practice for his/her care recipient. If the feasibility checklist shows that the participant is ready to ride the bus, the caregiver proceeds to section three of part two, which provides details about how caregivers should conduct the second training day. During training day two the caregiver provides support to participant as the participant practices using technology to ride the bus in a real life situation. The participant is assisted in completing a public transportation scavenger hunt with his/her technology.

The manual provides caregivers with the tools to help individuals with TBI gain improved independence through the use of public transportation. Participants are not expected to be completely proficient and independent in navigating the bus system after two days of training. The manual is designed to provide caregivers with knowledge and teaching tools to facilitate guided exploration of public transportation in a safe environment. This exploration provides the foundation on which participants can build new skills and strategies. These skills and strategies may minimize the effects of executive dysfunction on performance and maximize current abilities through the use of technology. At the conclusion of the two training days, caregivers and participants are referred on to King County Metro Transit Training services to continue travel training, practice skills learned from the training program, and gain further confidence and independence.

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### Outcomes

Many of the goals and objectives outlined below were written with the intention that the manual would be provided to Headstrong for Life mentors for implementation. After it was determined that this was not feasible, our goals and objectives shifted to obtaining feedback from caregivers. The feedback solicited was intended to help us determine the feasibility and usefulness of the manual and training program for future use. We distributed the manual to four caregivers, along with questionnaires designed to elicit specific feedback for part one and part two of the manual. We received two responses to the part one questionnaire and three responses to the part two questionnaire. In general, the caregivers felt that the manual was a clear and useful tool for assisting them to teach their care recipient how to use technology to navigate the bus system.

#### Goal One – In Progress

After attending the training day one, individuals with TBI and cognitive deficits will improve their knowledge in technological and non-technological community navigation strategies.

**Objective one.** During the training day one, participants will be able to identify three navigation strategies that they will use during the second in-service day.

**Objective two.** At the beginning and end of the training day one, participants will fill out a Likert scale of how confident they are in their abilities to navigate public transportation and demonstrate improved awareness of navigation skills necessary to use public transportation.

#### Goal Two – In Progress

After attending the training day two, individuals with TBI and cognitive deficits will use technology to navigate public transportation with King County Metro Transit.

**Objective one.** Participants will demonstrate use of technology to navigate to one preset location in Seattle with caregiver providing verbal cues no more than 50 percent of the time.

**Objective two.** Participants will demonstrate use of one navigational strategy identified from the training day two by using that strategy once during second training day scavenger hunt with caregiver

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providing verbal cues no more than 50 percent of the time.

### **Goal Three – In Progress**

Caregivers will use the project manual to train individuals with TBI and cognitive deficits to ride public transportation on King County Metro Transit.

**Objective one.** Caregivers will read part one of the manual and demonstrate knowledge of that part by identifying one way that TBI impacts cognition and one strategy that they can use to teach individuals with TBI.

**Objective two.** Caregivers will read part two of the manual and demonstrate knowledge of that part by correctly identifying the first two steps for using “Google Maps” and “One Bus Away”.

**Objective three.** Caregivers will read part two of the manual and demonstrate knowledge of that section by describing the steps necessary to complete both in-service days.

**Objective four.** After implementing the manual, caregivers will report that the manual provided adequate information to complete the two training days effectively. Caregiver responses will be collected via feedback questionnaires.

### **Goal Four – In progress**

Individuals with TBI and cognitive deficits will report increased participation in community occupations through public transportation.

**Objective one.** One month after participating in the training program, participants will respond to a follow up e-mail questionnaire and report that they have increased participation in at least one occupation in the community using public transportation.

### **Goal Five – Attained**

After reading the manual, caregivers of individuals with TBI and cognitive deficits will report that they found the information and learning activities provided in the manual to be useful and that they would consider implementing the training program.

**Objective one.** Two caregivers will report that three out of five sections in part one of the manual were easy to understand.

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**Objective two.** Two caregivers will report that they found worksheets and learning activities provided in part two of the manual to be useful in preparing them to implement the training program.

**Objective three.** Two caregivers will report that they would recommend this training program to other caregivers of individuals with TBI.

### **Goal Six – In progress**

The manual for the community navigation training program will be available to caregivers through community brain injury support organizations.

**Objective one.** At least one brain injury support organization will agree to make the manual available to the individuals they serve via PDF form on their website. This objective has been met. A representative from BIAWA has agreed to house the manual in PDF form on the organization's website.

**Objective two.** One month after delivery of manual to community organizations, staff from that organization will refer three caregivers to the manual and suggest that they implement the training program with the individuals they provide care for.

### **Progress**

Goals one through four were not attained due to the changes in our project, as described above. Goal five was attained. Using an online questionnaire for part one, two caregivers reported that they "agreed" or "strongly agreed" with the statement that "the information in this section was provided in a way that I could understand" for each of the five sections of part one. Using a questionnaire for part two of the manual, three caregivers reported that the learning activities for all sections of part two of the manual were helpful in their understanding of how to implement the training program with a care recipient. Through this same questionnaire, three caregivers reported that they would recommend the training program, in its finalized form, to other caregivers of individuals with TBI. Objective one of goal six was attained, as Jessica Giordano, a representative of BIAWA, has agreed to make the manual available on the BIAWA website in PDF form.

### **Implications for Occupational Therapy**

Colantonio et al. (2004) note that occupational therapy (OT) is one of the most commonly used

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rehabilitation services for individuals with TBI. This is in part due to the unique blend of occupation-based intervention, purposeful activities, and preparatory methods that occupational therapists use to enhance client performance in areas of occupation (AOTA, 2008). The role of OT is to increase functional performance skills through occupation-based tasks (Giuffrida, Demery, Reyes, Lebowitz, & Hanlon, 2009). Occupational therapists encourage clients to find meaning and motivation in their occupations during rehabilitation efforts, including IADL. This project specifically addressed the IADL of navigation for individuals with TBI. Specifically the training program established through this project aimed to help establish and restore performance skills in the area of community navigation through the use of technology. This goal was supported by research conducted by Lindén et al. (2011), which found that an individualized occupation-based intervention approach using everyday technology resulted in improved occupational task performance and satisfaction in individuals with ABI.

Client factors that may be affected by ABI include higher level cognitive functions like judgment, all forms of attention, metacognition, or awareness, all of which are aspects of executive functioning (McDonald et al., 2002). Executive functioning deficits impact a number of areas of occupation including IADLs. IADLs require a level of planning, problem solving, and decision-making that individuals with executive functioning deficits might find difficult to perform (Brown, 2011). Using public transportation to navigate the community is one such IADL. This project provides caregivers of individuals with ABI (specifically TBI) with the means to conduct an instructional course that encourages the use of technological tools as aids to navigate the community. Through repetitive use of these tools and personalized instruction, cognitive performance skills and performance patterns associated with navigation will likely improve.

### **Limitations**

When the original plan to design a training program for mentors at Headstrong for Life changed, it shifted the focus of our project fairly late in the overall development process. Consequently, we were unable to locate a caregiver who could pilot the training program. This was due to several factors such as time constraints and interested parties eventually deciding not to participate. In creating the manual it was

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necessary to describe critical skills the caregivers need to effectively teach individuals with TBI and executive functioning deficits. However, this does not mean that caregivers would be comfortable teaching these individuals how to ride public transportation. Caregivers may fear for the safety of the individual with brain injury on public transportation. An attempt was made in the manual to address these concerns, but safety concerns could be addressed more thoroughly or in a different format. For example, more role playing activities focused on safety or a video interview with an individual with TBI who currently uses the bus system could be used to alleviate fears. The caregivers' education level and background may also determine their investment in the training and ability to read and understand the manual. As the manual was created for such a broad audience of individuals, the reading level of the manual was created to be readable at grades ten or eleven. This may be appropriate for some of the caregiver population, but in the future an attempt to make materials readable at an eighth grade level may make it even more accessible.

It is also important to consider the broad population of individuals with brain injury that this project will be addressing. Caregivers need to tailor their approaches depending on the level of skill of the care recipient with brain injury. This may be difficult and time consuming for the caregiver. Providing more specific, detailed instructions for different technologies may mitigate this problem. Another limitation is that some of the technologies we address in the most detail in the manual are the more expensive devices. This could prevent caregivers from even starting the training if they think they have to use expensive technology. More low technology options could be included in more detail.

### **Future Steps and Sustainability**

The final product of this project was made available online in PDF format for caregivers to access indefinitely. Because the manual describes a training program that is designed for caregivers to administer, specialized staff or facilities are not required to complete the program. One goal of this project is for local brain injury support groups to refer caregivers to this manual as a resource that they can access independently. The work of future generations of students can help to maintain the relevance of the manual in a world of changing technology and ensure that the manual learning activities are effective.



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Future Policy, Advocacy, and Leadership projects can work to organize groups of caregivers interested in using the manual. They can also facilitate connections between King County Metro's First Transit and brain injury support groups in the area. Research projects can examine the efficacy of the learning activities and specific apps or pieces of technology. This project can provide future groups of students and/or brain injury advocates with a strong foundation on which to base future research and program development projects.

### **Conclusion**

Through a needs assessment of local brain injury support organizations and caregivers, it was determined that community navigation is a problem with this population. The aim of this project was to provide a tool for caregivers that would help to alleviate this problem in the form of a training program for individuals with TBI. Caregivers of individuals with TBI and executive dysfunction may use the manual we created to implement a two day training program that will assist their care recipients in using technology to access public transportation. By using technology to access public transportation, this population may improve their ability to navigate in the community and participate in a variety of IADLs such as shopping, running errands, or participating in leisure activities such as visiting friends and going to the movies. This manual was made available in PDF form to local brain injury support organizations. These organizations have agreed to refer caregivers of individuals with TBI to the manual, potentially increasing the well-being and independence of individuals with TBI throughout Washington State.

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## Resources

**Headstrong For Life**

Name: Desirée Douglass, President, Board of Directors

Phone: 360-220-1422

E-mail: [dld@headstrongforlife.org](mailto:dld@headstrongforlife.org)

Organization website: [www.headstrongforlife.org](http://www.headstrongforlife.org)

**Brain Injury Alliance of Washington**

Name: Jessica Giordano, TBI Resource Center Operations Manager

Phone: 206-467-4802

E-mail: [Jessicag@braininjurywa.org](mailto:Jessicag@braininjurywa.org)

Organization website: [www.braininjurywa.org](http://www.braininjurywa.org)

**King County Metro**Accessible Services

Phone: 206-684-1142

Organization website: [www.metro.kingcounty.gov/tops/accessible/](http://www.metro.kingcounty.gov/tops/accessible/)

Name: Melony Joyce

Phone: 206-205-6576

E-mail: [Melony.joyce@kingcounty.gov](mailto:Melony.joyce@kingcounty.gov)

Transit Instruction

Name: Amanda Bryant

Phone: 206-749-4248

E-mail: [Amanda.Bryant@firstgroup.com](mailto:Amanda.Bryant@firstgroup.com)



## Appendix A

The following pages are selections from part one and part two of the manual to illustrate formatting and content.

PAGE 4

## INTRODUCTION

Being a part of the community is important for the health and happiness of everyone. A community is where we make friends, work at jobs, and enjoy free time. It is also where we take care of everyday business like shopping or going to a doctor's appointment. Those with acquired brain injury (ABI) sometimes have trouble going places in the community on their own. This is because of problems with memory, attention, problem solving, safety awareness, and decision making.<sup>1,2,3</sup> Technology can be used to help people with brain injury travel safely on public transportation. It can also improve the person's ability to get around in the community on their own.<sup>4</sup>

With this manual caregivers will be able to help people with ABI choose a technology that fits their public transportation needs. Caregivers will also teach the person with ABI how to contact local, Seattle, Washington, organizations that will continue to support them with their public transportation needs.



### Important Note

You **should not** expect participants to be able to complete this course and ride the bus alone. It is also necessary for you to read and finish all quizzes and worksheets before taking the person with brain injury on public transportation. In the rest of this manual, the person with a brain injury that you will be teaching will be called "participant".

This manual will help you support a person with brain injury to be more independent. After finishing this program your participant will be more capable of traveling on public transportation.

**Joe: Awareness**

*Joe's wife has noticed that Joe forgets simple items. He forgets to put both socks on before he puts his shoes on. He also often puts his house keys in unusual places such as the refrigerator. He has difficulty remembering the steps for making simple meals like sandwiches. When she asked him if he is having trouble remembering things, Joe says that his memory is fine. Joe's wife is afraid that he will not be able to remember bus routes and numbers well enough to ride the bus without her. In order to increase his awareness of things that are difficult for him, Joe's wife should ask him what parts of riding the bus will be most difficult. When they ride the bus together for the first time, she should also ask him how hard it actually is. When Joe rides does things related to riding the bus like plan a trip, wait at a bus stop, or pay fare, Joe's wife could also ask him how he thinks he's doing. If he runs into challenges, she could ask him what he thinks he could do differently. All of these questions will help Joe identify what is hard for him and what he does well. If Joe can recognize his weaknesses and strengths he may be able to anticipate and deal with potential problems and challenges more easily.*



**QUIZ #1**

**Matching** – Match the letter of the correct response to each statement.

1. \_\_\_\_\_ A permanent alteration of brain function caused by an external force.
2. \_\_\_\_\_ The process of finding solutions to difficult or complex issues.
3. \_\_\_\_\_ A temporary alteration of brain function caused by an external force. It may also include loss of consciousness, problems with memory, and problems with orientation.
4. \_\_\_\_\_ Technology designed for use by the general population such as home computers, the Internet, palmtops, mobile telephones and, more recently, the potentially useful global navigational hardware.
5. \_\_\_\_\_ Thinking skills, including language use, calculation, perception, memory, awareness, reasoning, judgment, learning, intellect, social skills, and imagination.
6. \_\_\_\_\_ A spatial problem-solving process that requires awareness, decision-making, planning and ongoing monitoring for error detection and correction.

- A. Cognition
- B. Navigation
- C. Concussion
- D. Problem-solving
- E. Traumatic brain injury
- F. Everyday Technology

**True or False**

- \_\_\_\_\_ The leading cause of TBI is assault.
- \_\_\_\_\_ After going through this training the person with brain injury will be able to ride a bus alone.
- \_\_\_\_\_ Men are more likely to have a TBI.
- \_\_\_\_\_ 70.5% of all sports and recreation related TBI are among males ages 25-30 years old.
- \_\_\_\_\_ Brain injury could influence a person's ability to complete everyday tasks due to difficulty with complex thinking.

## TEACHING PEOPLE WITH BRAIN INJURY

### Cognitive Impairments

Many individuals with TBI have difficulty with complex cognition. For example, one study found that 286 survivors of TBI had significant problems with memory tasks and processing speed.<sup>8</sup> These difficulties often come from a disruption to the frontal-subcortical area of the brain, located behind the forehead.<sup>27</sup> This area of the brain is considered to be the center for executive function. Executive functioning encompasses many of the skills involved with complex thinking. Some of these skills include<sup>1</sup>:

- Concept formation
- Categorization
- Schemas (learned patterns of behavior)
- Problem-solving
- Decision-making
- Metacognition (understanding your own thinking process)

These skills are necessary for navigating in the community safely. Below are some ways that you can help a person who has problems with executive functioning become more self-sufficient while using public transportation.



*To raise awareness caregivers can guide a person with brain injury in identifying his/her challenges and strengths.*

## TEACHING TECHNOLOGY

### Technology Basics

Technology is becoming more common in our daily lives. Technology can help us:

- Learn new facts
- Look up information
- Communicate
- Remember appointments
- Navigate

Every piece of technology varies in its function and usability. The key to getting the most out of a technology device is understanding needs of the person using that device. It is also important that the user feel comfortable with the device in his/her daily life. Technology can be either “high tech,” “medium tech,” or “low tech.”<sup>23</sup> Examples of “high tech” devices would be smart phones, flip phones, GPS devices, and tablets. Examples of “medium tech” would be simple talking devices and computer internet searches. Examples of “low tech” devices would be pencil and paper checklists or a printed map. Please see Appendix A for possible technology options for your participant (p. 44).



*The key to getting the most out of a technology device is understanding the needs of the person using that device.*

### Goal Setting

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It is important to determine how confident a participant is in his/her abilities to use public transportation before training. This will help you provide individualized support throughout training.

Have the participant rate him/herself on the following scale. You will also come back to this scale at the end of training to see if your participant's confidence has changed.

Circle the number that fits best:

#### BEFORE TRAINING

I am confident in my ability to navigate the bus system.

1	2	3	4	5
Not True At All		Neutral		Very True

#### AFTER TRAINING

I am confident in my ability to navigate the bus system.

1	2	3	4	5
Not True At All		Neutral		Very True

### LEARNING ACTIVITY

There are many different things that bus riders need to do to get to their destination safely. Here are some role playing situations to help your participant learn what to do and what not to do to ride the bus safely and successfully.

- ◇ Paying the right fare. The caregiver assumes the role of the bus driver and the participant takes on the role of the passenger. The participant can ask the bus driver how much the bus fare is and give the appropriate amount. To increase the challenge, the caregiver can act out the role of an impatient bus driver. Other participants and/or caregivers can act out roles of impatient passengers waiting in line behind the participant paying fare.
- ◇ What not to do. Caregivers and participants can take on roles of difficult passengers to illustrate why it is important to be polite and courteous on the bus. Specific problem will vary depending on your participant. Common behaviors to consider include: invading personal space, talking loudly, cursing, or having poor hygiene. Participants can role play strategies to deal with these behaviors such as: ignoring the behavior, asking the bus driver for help, or moving away from the problem behavior.
- ◇ What to do when strangers approach you. Caregivers take on the role of strangers approaching participants. These roles can include: someone asking what time it is, someone asking for money, or a hostile or inappropriate person. Caregivers should give participants strategies to deal with strangers prior to role playing.

## ABI NAVIGATION TECHNOLOGY SOLUTIONS

## Appendix B

The following pages contain questions asked on feedback forms for part one and part two of the manual that were distributed to caregivers.

**Navigation and Technology: Manual PART ONE**

This feedback form is for use with the first part of the manual. This part of the manual describes information necessary for caregivers to implement a training program for people with acquired brain injury and executive dysfunction. Please fill out the form as completely as possible.

INTRODUCTION: The information in this section was presented in a way that I could understand.

1	2	3	4	5
Disagree				Agree

INTRODUCTION: I know what this training program is about and why it is important.

1	2	3	4	5
Disagree				Agree

INTRODUCTION: The definitions and brain injury facts were helpful.

1	2	3	4	5
Disagree				Agree

INTRODUCTION: What part of this section did you find the most useful?

INTRODUCTION: What part of this section do you think needs improvement?

TEACHING PEOPLE WITH BRAIN INJURY: The information in this section was presented in a way that I could understand.

1	2	3	4	5
Disagree				Agree

TEACHING PEOPLE WITH BRAIN INJURY: The following sections were the easiest to understand (check all that apply):

- Cognitive impairments
- Developing awareness
- Changing the amount of support
- Cueing
- Transfer of learning

TEACHING PEOPLE WITH BRAIN INJURY: What part of this section did you find the most useful?

TEACHING PEOPLE WITH BRAIN INJURY: What part of this section do you think needs improvement?







