



Brain Injury Association of Texas

Newsletter

Recent News

Winter 2007

The Association wishes to express our sincere thanks to all who attended and sponsored our **Walk for Thought** event this year. It was a huge success generating a significant amount of our operating budget for 2008. Additional thanks to the Texas Medical Association for their Helmets giveaway and support of this event. Our special thanks go out to Melissa Finney and Calysta Spence and all their associates at the TSO APO service fraternity.

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For information, contact

Brain Injury Association of Texas

316 W. 12th Street, Ste 405
Austin, TX 78701

Telephone: (512) 326-1212

Toll Free: (800) 392-0040

Fax: (512) 478-3370

Email: info@biatx.org

The Brain Injury Research Center at Memorial Hermann-TIRR Receives Traumatic Brain Injury Model Systems Funding

The Brain Injury Research Center (BIRC) at Memorial Hermann/TIRR in Houston has been awarded a Traumatic Brain Injury (TBI) Model System grant by the National Institute on Disability and Rehabilitation Research (NIDRR). The NIDRR TBI Model System program began in 1987 and is the largest research program on recovery from TBI in the world. Over 7,500 persons with TBI have participated in this research program.

The overall goal of the TBI Model Systems is to conduct research aimed at improving quality of care and outcomes for patients recovering from traumatic brain injury. Within the TBI Model System program, individuals with traumatic brain injury who consent to participate in the study are followed for many years after their injuries. At this time, some participants in the study have been followed for over 18 years after their injury. This program is designed, in part, to help us better understand what goes on in the long-term recovery of persons with TBI. In addition to the long-term follow-up that is conducted as part of the TBI Model Systems study, each center has additional research projects designed to address specific issues

about TBI, including looking at how different treatments might help in improving recovery and community participation. However, since the TBI Model Systems program is a research program, these grants do not provide support for direct clinical care.

BIRC was one of the original TBI Model Systems sites and was continually funded until 2002. After a five year interruption in funding, BIRC is again a part of the TBI Model System research program beginning on October 1, 2007. When the TBI Model System program was started in 1987, only 5 centers were funded to conduct the research. The TBI Model System program has grown and now consists of 14 centers around the United States. Texas is one of only two states to have two sites: the Texas TBI Model System at Memorial Hermann/TIRR in Houston and the North Texas TBI Model System in Dallas. Memorial Hermann/TIRR is one of only six sites nationwide to have both TBI and Spinal Cord Injury Model Systems programs. The TBI Model System program at Memorial Hermann/TIRR will be led by Dr. Mark Sherer,

Principal Investigator and Director of Research for Memorial Hermann/TIRR, and Drs. Angelle Sander and Margaret Struchen, Co-Directors of BIRC.

The TBI Model System grant award will provide \$2.15 million to BIRC to fund research on TBI over the next five years. These funds will support three main activities. First, BIRC will contribute data on the natural history of TBI to the TBI Model Systems National Database. This database contains data on over 7,500 persons with TBI from all of the TBI Model System sites. Various analyses of this huge database have resulted in new discoveries regarding the time course of recovery after TBI, factors that predict recovery after TBI, medical complications seen in persons with TBI, effects of race and ethnicity on recovery after TBI, and other issues. As participants in the TBI Model Systems program, Drs. Sherer, Sander, and Struchen will have access to this database to conduct investigations of TBI.

In addition to the National Database project, BIRC will investigate the effectiveness of a treatment designed to improve social
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Traumatic Brain Injury Model Systems Funding

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communication after TBI. Social isolation and loneliness are major concerns of families and patients following traumatic brain injury. One of the major factors that contribute to social isolation is thought to be the changes in social communication abilities that many people experience after a TBI. Changes in social communication skills also can affect a person's ability to get and maintain a job and contribute to family stress. Dr. Struchen will lead a study where participants with moderate or severe TBI will either receive the intervention to improve social communication right away, or will be put on a wait-list to receive the treatment later. Participants have an equal chance of being assigned to either of those conditions. Then, we will look at whether those that received the treatment do better on social communication skills and will have better short-term outcomes than do those who were on the wait-list. This kind of study is called a randomized controlled trial. Improved social

communication skills should lead to improved quality of life for persons with TBI and their families.

Also as part of BIRC's TBI Model Systems research program, Dr. Sander will be leading a multi-center, collaborative research project on sexuality after TBI. Collaborating centers are the Mayo Clinic, Craig Hospital in Englewood, Colorado, and Carolinas Rehab in Charlotte, North Carolina. The project will investigate how sexuality is affected by traumatic brain injury, both directly and indirectly. Sexuality after TBI is an area that has not been extensively studied. During the observational component of the study, TBI patients and their partners will be interviewed. Based on the information gathered, an intervention will be developed to increase understanding of sexual changes after TBI, improve sexual satisfaction, and increase comfort in seeking assistance for sexual

dysfunction after TBI. This intervention will be tested using a randomized controlled trial.

In addition to these research activities, BIRC will have activities designed to provide useful information to persons with TBI, family members and friends, and health care professionals who treat persons with TBI. One of these activities will be to publish four articles a year in the BIATX newsletter. BIRC staff will also develop brochures on social communication and sexuality for persons with TBI, significant others, and health care professionals, which will be available by mail or through the BIATX website. BIRC staff will give presentations at meetings attended by persons with TBI and their significant others such as the annual meeting of the BIATX. Finally, BIRC staff are in the final stages of developing initial content for a website that will also provide information.

Visit online:
<http://www.tbicomunity.org/>

SafePlace needs your help Recruiting adults with disabilities to participate in focus groups

SafePlace, the Travis County Domestic Violence and Sexual Assault Survival Center, is seeking your help to recruit adults with disabilities to participate in small focus groups. These confidential meetings will focus on relationships -- both positive and negative -- with spouses, partners, girlfriends, or boyfriends.

SafePlace will use information from these discussions to develop materials for disability service providers and domestic violence and rape crisis center staff. These materials will provide information about components of healthy relationships and abusive relationships when at least one person in the relationship has a disability. All information gathered will be used anonymously, with no identifying details.

Most of the focus groups will be held at SafePlace, located off Riverside Drive in East Austin, and will take place in **January and February 2008**. Flexible times and days will be available, including weekdays, weeknights, and weekends. SafePlace can assist with transportation costs if needed. Each person with a disability who participates in an in-person focus group will receive \$25.

Please distribute the attached flyer to any adults with disabilities you think might be interested in participating, and request that they contact us by **December 21, 2007**. Space is limited, so please encourage interested people with disabilities to contact us as soon as possible.

For more information, contact:

Dianne King Akers, (512) 369-5944, DKing@austin-safeplace.org or
Cema Mastroleo, (512) 356-1588, CMastroleo@austin-safeplace.org

Individualized Support Needs and Traumatic Brain Injury Fact Sheet

by Pamela Targett, Dr. Katherine Inge

INTRODUCTION

The Brain Injury Association of America (BIAA) reports that annually 1.5 million people will sustain a traumatic brain injury (TBI) with 80,000 people experiencing the onset of long-term disabilities. Currently, an estimated 5.3 million Americans live with disabilities resulting from a TBI. Every 23 seconds one person in America will sustain a traumatic brain injury (BIAA, 2007).

Traumatic brain injury is caused by trauma to the brain, which might occur when the head strikes a hard surface such as a windshield during an automobile during an automobile accident. This type of "closed" head injury typically results in damage to the entire brain. Trauma also may result from a penetrating injury such as a gunshot wound. This type of injury is called an "open" head injury and may only damage a specific area of the brain. After an injury, the person may be in a prolonged period of unconsciousness or coma, which may result in severe damage to the brain.

Not very long ago, many people who sustained a TBI died. Today, due to advances in medical care, the vast majority of individuals live. Because some degree of healing does occur to the brain post injury, a person may recover various skills and abilities during the first six months to two years post injury. However, many individuals with TBI will experience life-long difficulties as noted in the statistics from the BIAA.

How well the person does post injury will depend on a number of factors. Some of these factors are related to the individual's skills, abilities, and age before the injury. Other factors are related to the severity of the injury; personal, emotional, and social adjustment after the injury; and the level of support received from family members and others.

KEY POINTS

Supported employment has been shown to be an effective approach to assisting individuals with TBI in gaining and maintaining employment. Community rehabilitation providers (CRPs), offering supported employment services, can play an important role in helping individuals enter or re-enter the workforce post trauma. As always, it is important to remember that everyone is unique. The following key points are offered to assist employment specialists in developing support programs for individuals with TBI.

*Each individual with a TBI will have unique mental and physical abilities and challenges based on the type and severity of the injury.

*The type and intensity of support will vary from person to person depending upon the individual's pre- and post injury skills and abilities, as well as the job tasks, work environment, and existing supports in the workplace.

*The individual's interests, abilities, and support needs should guide the employment process and not the person's disabilities.

*Compensatory strategies can minimize the challenges caused by the TBI.

*Individuals must be involved in the design and implementation of training and support strategies for finding and maintaining employment.

*The natural workplace supports must be identified and facilitated to promote success in the workplace.

CHARACTERISTICS

Some of the more common characteristics associated with TBI are described in this fact sheet. For each characteristic, workplace support examples are provided. Although the characteristics are presented

individually, a person may have difficulties in more than one area. Furthermore, a combination of strategies may be needed to promote success in the workplace. Please keep this in mind when developing a support plan for someone with a TBI that is receiving services from your agency.

1. Physical Disabilities: After an injury, a person may experience some physical or motor changes such as difficulty walking, maintaining balance, coordination, and stamina. The individual's hand use may be affected including a decrease in speed, strength, and accuracy. A person's physical ability to speak also can be impacted by a TBI such as slurred speech patterns. Other communication difficulties associated with the area of the brain that was injured will be presented under the communication category.

Strategies: The person who has physical and motor challenges will need workplace accommodations particularly for jobs that require extended periods of standing or hand use. If the person has problems with endurance and maintaining stamina, it may be helpful to initially work part-time or ask for breaks to be broken down into smaller increments. Examples of supports include but are not limited to the following:

*Divide a 30-minute break into three, 10-minute breaks that are spread out over a block of time.

*Fabricate a stand to help the person maintain balance.

*Arrange opportunities to alternate sitting and standing while performing the task.

*Negotiate completion of a task from a seated rather than standing position. levels.

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It may also be useful to discuss sleep patterns and effects of medications on alertness and energy prior to the job search. Sometimes, physicians can assist with helping the person improve sleep and/or change the type or time of the medication to enhance energy

If hand use is an issue, look for other alternate ways that the job duty can be performed. Something as simple as rearrangement of materials or the workspace can make physical movements less difficult. Technology advancements have made it possible for individuals with physical disabilities to perform many tasks that were once impossible. Devices can be made that specifically assist a person in physically completing job duties. A vocational rehabilitation counselor may fund a visit to the job site by a rehabilitation engineer. This is recommended, particularly if the individual is having difficulty physically completing the various assigned job duties. Also remember, that an alternative job duty could be negotiated with the employer if the individual is still having difficulty performing an essential function of his or her job after an accommodation has been implemented.

2. Communication: Communication issues may result from a loss of motor skills that affect the ability to execute talking as mentioned above or damage to the speech and language centers of the brain. If the person has difficulty understanding what other people are saying, this is referred to as receptive aphasia. When the individual has difficulty expressing him or herself, this is called expressive aphasia.

The person with expressive aphasia may be able to understand what people say and read what is written but have difficulty verbalizing or writing thoughts. The person with receptive aphasia will have difficulty understanding the information conveyed. Depending on the severity and location of the injury, an individual may have only one type of aphasia or both. This can lead to miscommunication and frustration.

Strategies: The individual with a TBI

should consider matching his or her communication support needs to a workplace when conducting his or her job search. For example, a customer service representative is required to constantly communicate with clients over the telephone. An individual with either expressive or receptive aphasia may have difficulty working in this type of position.

However, remember that many positions are performed in different ways. For example, some customer service representatives serve clients over the Internet and communicate in writing via email. Or, consider a teacher who can no longer give long lectures but excels working one-to-one with students in a small classroom tutorial setting.

Education of business personnel who work with an individual with TBI on best ways to communicate may also be useful. Sometimes language deficits are so subtle that they are not visible, yet if misunderstood lead to problems at work. If this occurs, the worker with the TBI should always be involved with determining how and what should be conveyed.

3. Perception: Perceptual problems can impact the person's ability to function in the workplace successfully. This may include difficulties judging distances or recognizing certain things. It can also result in apraxia, an inability to perform skilled movements. The person knows and understands what he or she wants to do, but the brain cannot organize the movements necessary to do it. This may make everyday tasks such as folding a towel, putting a belt through loops, or using eating utensil difficult for the individual. It is not unusual for a person to have difficulty performing tasks that were easily done pre-injury leading to frustration and anger.

Strategies: Oftentimes, assistive technology or devices can make a task doable. Or, the steps followed to perform a task may be modified in a way that allows the worker to do it without sacrificing the quality and speed needed to get the job done. Brainstorm with the individual as well as the employer, coworkers, and other employment specialists to identify accommodations that allow the individual to be successful.

4. Cognitive Challenges: The traumatic brain injury can also affect

a person's ability to think. After a TBI memory capabilities are often damaged including both short and long-term memory. Short-term memory loss affects learning new skills, as a person will have difficulty recalling events and information that just occurred. Long-term memory affects the ability to recall past events. Verbal and spatial memory may be affected too. Verbal memory refers to information heard or read. Spatial memory refers to recalling information seen in three dimensions like height, width, and depth.

To learn and carry out a task, a person needs to be able to sustain concentration on the task at hand. After a TBI, attention and concentration deficits are common. High levels of cognitive processing like problem-solving and abstract reasoning may be affected. After an injury, a person may not be able to solve problems. Not being able to self-correct performance may lead to errors. This is further complicated by a lack of self-awareness and an inability to benefit from constructive feedback resulting in errors being repeated. Organizing a logical sequence of events to accomplish a task may be affected. Again, all can greatly impact the capacity to learn post injury.

Strategies: As always, the employment specialist must be aware of the person's abilities and strengths. Job tasks also should be assessed to determine what memory skills are needed. This information can assist in the identification compensatory memory strategies to assist the worker "remember" and learn what to do. For example, a person with good visual and spatial memory skills may benefit from being shown how to complete job duties rather than being told how to do them. Individuals with good verbal memory may learn best when told how to do something. Strategies to assist with memory include some of the following examples.

*Use a checklist that identifies a sequence of job duties.

*Follow a flow chart to reach a decision about what to do.

*Make an association between a person's face and his or her name to recall it at a later time, and

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*Remove distractions, like noises or visual stimuli.

For example, a door may be shut to cut down on visual movements and sounds in a hallway or earplugs worn to cut back on manufacturing machine noise in a warehouse. Sometimes looking for jobs that rely on learned tasks performed prior to injury may be helpful.

If unfamiliar tasks are to be performed, skills training may be needed. When problem solving is required, a method specific to issues faced at the job may help. Sometimes, depending upon the natural workplace supports of the job and arranging for problem solving assistance with a supervisor or coworker may suffice.

5. Changes in Behavior: After a TBI, the person may act socially inappropriate. The individual with a TBI may also lack self-control and awareness of social rules. To further complicate this matter, the individual may not understand how he or she has changed or is perceived by others.

For example, a worker may repeatedly ask a coworker for a date even if the coworker has rejected the offer several times. Or, the worker with a TBI may invade another person's

personal space while informally chatting in the break room. The worker with a TBI may become frustrated with a sudden change or an inability to do something, which may lead to a temper outburst. These problems are due to damage to the brain and should not be perceived as an "attitude" problem. Such difficulties can lead to miscommunication, agitation, anger, frustration, and social isolation.

Strategies: Instruct the person on more appropriate behaviors. This may involve the use of some type of compensatory strategy to help the person recall what to do. It also requires teaching the new skill via modeling and other techniques suitable to the situation. If a problem behavior continues to persist, it may be helpful to explain the potential negative consequence (i.e. asking person out may be seen as sexual harassment, invading space may result in people avoiding the worker, and so forth). If the person becomes angry, stay as calm as possible. Then redirect the person's attention away from the source of frustration. Once the person regains his or her composure provide some constructive feedback about the effect of the behavior on others. Always model appropriate behavior and give positive feedback.

SUMMARY KEY POINTS

*Supported employment can be used

to assist individuals with TBI to obtain and maintain employment. Services must be individualized and "customer driven".

*Every person's injury and recovery is unique due to reaction to injury, pre-injury personality, past experiences, learning style, severity of injury, and time since injury.

*An array of physical, cognitive, and emotional problem may occur after an injury. Some of these challenges may be difficult to see, which makes it harder to understand and explain to others. Over time, some changes may resolve, but others remain with the person throughout life.

*Individuals with TBI can work. Potential supports should be considered whenever the job seeker with a TBI is considering pursuing a position. When thinking about workplace supports, consideration must not only be given to the job tasks but also the environment in which they will be performed. Once the person becomes employed, other workplace support needs should be evaluated and developed on the job.

*Change is inevitable in the workplace. Supported employment allows for an ongoing assessment of support needs throughout the person's employment.

On-line Resources

Brain Injury Association of America (BIAA) - <http://www.biausa.org>

Founded in 1980, BIAA is the leading national organization serving and representing individuals, families and professionals who are touched by a life-altering, often devastating, traumatic brain injury. Together with its network of more than 40 chartered state affiliates, as well as hundreds of local chapters and support groups across the country, the BIAA provides information, education and support to assist the 5.3 million Americans currently living with traumatic brain injury and their families. Call the Brain Injury Association of America at 1.800.444.6443 for information and resources and/or

visit their website.

National Resource Center for Traumatic Brain Injury -

<http://www.neuro.pmr.vcu.edu>
<<http://www.neuro.pmr.vcu.edu>>

The mission of the center is to provide relevant, practical information for professionals, persons with brain injury, and family members. Nationally recognized experts developed many of the products. The Center has more than 20 years of experience developing intervention programs, assessment tools, and investigating the special needs and problems of people with brain injury and their families.

References

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The authors for this publication are Ms. Pamela Targett, TA Liaison for the District of Columbia, and Dr. Katherine Inge, Region III CRP-RCEP, Project Director. For more information on VCU's CRP-RCEP, please visit <http://www.crp-rcep>. For additional information, contact the TA Liaison for your state:

Delaware - Grant Revell, wgrevell@vcu.edu

Maryland - Howard Green, jhgreen@vcu.edu

Pennsylvania - Valerie Brooke, vbrooke@vcu.edu

Virginia and West Virginia - Jennifer McDonough, jltodd@vcu.edu

Washington D.C. - Pam Targett, psherron@vcu.edu

This fact sheet was funded by the Rehabilitation Services Administration (RSA), which is part of the U.S. Department of Education (#H264B050007).

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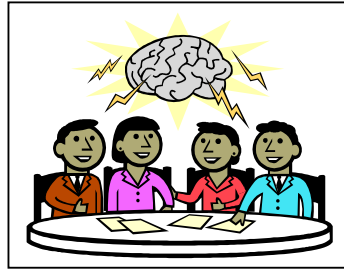
Common Misconceptions By Jason Ferguson

There are many different misconceptions about Traumatic Brain Injury (TBI). Most of the world knows absolutely nothing about TBI. Every brain injury is unique and that is a fact! What may be happening to one person will not happen to another person or what might work for one person may not work for another.

I guess my biggest pet peeve is that just because we may not be able communicate at that moment does not mean we cannot hear them. Like, when people say, "Oh he's thinking this" or "I know what you are thinking". The biggest one is, "I know how you feel", when they have never had a brain injury themselves. Until it's happen to you, you have no clue. Some people think that we are slow or stupid and retarded. Those people are the ones who are stupid and retarded. We have had an injury to our brain and we did not ask for this to happen. I would not wish a TBI on my worst enemy.

Try to keep in mind that people fear the unknown and most shy away because they don't know what to say or do. One of the biggest helps to me was learning and knowing that I could not control other people. When I accepted this things went a lot smoother emotionally for me. I can't change them and can't control what they say or do, I can only try to control me and that's hard enough.

**Are you a person with a disability?
Do you have something to share about
relationships?
SafePlace wants to talk to you!**



SafePlace staff would like to talk to adults with disabilities living in Austin about their relationships with spouses, partners, boyfriends or girlfriends. Those relationships may have been safe and caring, hurtful and abusive, or both. Information shared will be used anonymously to develop resources for disability service providers and domestic violence and rape crisis staff.

*Small focus groups will take place at varying times
in January & February 2008.*

Contact us by Dec. 21, 2007 if interested in participating.

Compensation: \$25 for participation in a focus group.
Snacks and drinks provided.

Space is limited. For more information, and to determine eligibility, contact:

- Dianne King Akers, (512) 369-5944
DKing@austin-safeplace.org
or
- Cema Mastroleo, (512) 356-1588
Cmastroleo@austin-safeplace.org

**SafePlace is the Travis County
Domestic Violence
and Sexual Assault Survival Center**