HOPE

Helping Others Through Purpose & Engagement

A Handbook for Supervising Volunteers with Brain Injury (BI)

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CRAIG

Each year, **3.5 million people sustain an acquired brain injury (ABI)**, according to the Brain Injury Association of America.

More than **12 million Americans** live with the impact of ABI.

You may know someone – a family member, co-worker or neighbor – who has experienced a brain injury (BI). Or you may have seen a news article or television show about BI. Because of this, you may already have some idea of what it means to have a BI.

This handbook offers an introduction and overview to the common characteristics of life after BI, and offers general strategies and suggestions for successfully engaging individuals with BI as volunteers.

However, it is important to remember that each individual with BI is unique:

- Each had a different personality and life experiences prior to the injury
- Each had a unique brain injury, each had a different course of rehabilitation
- Each individual has his own set of social supports.

We hope that the information in this handbook will help you to successfully work with volunteers who have BI, while remembering that each person is a unique individual volunteer.

Why Consider a Volunteer with BI?

Most individuals with BI developed a work history and set of skills prior to the injury. Many completed schooling, began a career, and held a job before the injury occurred. They may have advanced degrees, military experience, and a vast array of life experiences.

An individual with BI may have worked as the CEO of a company, a physician, or a manager. People with BI bring a wealth of knowledge and experience to volunteering, even though they may no longer be able to fulfill the cognitive or physical demands of a full time job.

UNDERSTANDING BRAIN INJURY (BI)

A brain injury is an injury that affects the way the brain works and can be caused by an external force or internal factor[3]. This can be due to:

- **a blow to the head (i.e., boxing injury);**
- **something penetrating the skull (i.e., gunshot wound);**
- **acceleration/deceleration (i.e., auto accident);**
- **the force from a blast or explosion; or**
- **internal factors like lack of oxygen, disease or stroke.**

BI has been called the “signature injury” of the recent conflicts in the Middle East due to the high number of brain injuries caused by blast explosions and subsequent injuries.

Brain injuries can be classified as mild, moderate or severe and can affect every aspect of an individual’s life including physical, cognitive, emotional, social and vocational functioning. Although symptoms often improve over time, the Brain Injury Association of America reports that 12 million Americans live with some long-term BI disabilities. BI results in an estimated $76.5 billion in direct/indirect costs per year, including the cost of lost productivity[3]. Anyone is at risk for brain injury. However, most individuals who experience BI are children ages 0 to 4, adolescents ages 15 to 19, and adults age 65 and older[1].

TYPES OF BI

MILD TRAUMATIC BRAIN INJURY (TBI):
The majority of TBIs are classified as mild. TBI is often treated in the emergency room and initial symptoms may include:

- dizziness
- vertigo
- headache
- disorientation
- irritability
- sensitivity to light and
- fatigue

Individuals with mild TBI have a loss of consciousness of less than 30 minutes. For many people, symptoms resolve over time. However, at least 15% of these individuals may have persistent symptoms related to the TBI.

MODERATE TO SEVERE TBI:

Individuals with moderate to severe TBI have a loss of consciousness of more than 30 minutes, and may be unconscious for several weeks or months. These individuals usually are treated in a rehabilitation hospital and receive extensive therapy to help them regain functioning in physical, sensory, cognitive, speech, and emotional skills. They may have difficulty returning to their home, work and school environments.

Symptoms improve quickly at first, but later improvement may be slow and may last a lifetime.

ACQUIRED BRAIN INJURY

Individuals with a non-traumatic or acquired brain injury have experienced damage to their brain due to internal factors, such as a stroke, infection or lack of oxygen.

COMMON CHALLENGES FOLLOWING MODERATE/SEVERE BI

An individual with BI may face a variety of challenges. Some may be related to how the person moves and controls his body. The individual may have difficulty planning movements, using one side of the body, or may move very slowly. Some individuals with BI have difficulty speaking. The person may speak slowly or may be difficult to understand. In addition, the individual may have difficulty with communication, not being able to find the right words, or going “on and on” and not getting to the point. Individuals may also experience changes in sensory areas such as hearing, smell, vision, and touch. These problems may include a lowered sense of sensation, or a heightened sense of sensation, so that loud noises, bright lights, or a touch on the arm may be over-stimulating.

Sometimes a person with BI may not have disabilities that can be easily seen, but may have other challenges that are not immediately obvious to others. For example, the person may experience difficulty with cognitive skills. Many people with moderate to severe BI find it challenging to stay attentive to a task, and may be easily distracted.

The person may also find it difficult to learn and remember new information, or to recall information from day to day. In addition, an individual with cognitive deficits may have difficulty solving problems or making decisions. The person may also struggle to understand what someone else is saying. Many individuals with BI fatigue easily. This fatigue can be both physical and cognitive; the person may not be physically tired but rather may feel cognitively "spent" and need a break from cognitive activities and stimulation.

Some of the challenges facing individuals with BI include social, emotional and psychological functioning. Some people after BI find it more difficult to pick up on social cues or social boundaries with other people[4]. They may continue to talk about a subject even though the other person is trying to signal that he is ready to move on. Individuals with BI may find that they give too much information in conversations or ask questions that are too personal or are not in line with the situation. Other individuals with BI may find that they have lost some of their social confidence and may isolate themselves from others. An individual may be more easily frustrated after a BI and may express emotions more easily, including anger, frustration, sadness or excitement.

COMMON SOCIAL, EMOTIONAL, AND PSYCHOLOGICAL CHALLENGES

- Misreading social cues and boundaries
- Talking "on and on" about a subject or not initiating conversation
- Giving too much information
- Loss of confidence in social situations
- Expressing emotions more intensely and quickly

LONG-TERM CHALLENGES WHICH MAY BE PROBLEMATIC IN A WORK/VOLUNTEER SETTING

Several of the challenges that individuals with BI face may be particularly problematic in a work/volunteer environment. These include challenges with:

- **STAYING FOCUSED** - especially when there are distractions
- **REMEMBERING** – particularly new detailed information
- **READING SOCIAL CUES**
- **DISINHIBITION** – doing and saying things “before thinking”
- **CONTROLLING EMOTIONS**
- **ENERGY/ENDURANCE**
- **EXPRESSING ONESELF** – finding the words and getting them out clearly
- **UNDERSTANDING OTHER PEOPLE** – needing instructions to be slow or repetitious
- **TRANSPORTATION**
- **VARIABILITY IN SKILL LEVEL** – may be very skilled in one area, but have great difficulty in other areas

A Special Note about Military Veterans with TBI

TBI has been called the signature injury of the recent conflicts in the Middle East. Many of these injuries are caused by blast concussion or multiple blast injuries. These soldiers and veterans are frequently young men with limited experience in the civilian workforce. Such blast related injuries often result in a combination of mild TBI, chronic pain, and post-traumatic stress disorder (PTSD).

Many of these individuals face a specific cluster of symptoms, including:

- Chronic pain
- Irritability
- Memory problems
- Anxiety and depression
- Feelings of social isolation
- Emotional numbness

SETTING THE STAGE FOR SUCCESSFUL ENGAGEMENT OF VOLUNTEERS WITH BI

DO I ASK ABOUT THE INJURY?

It's important to get a good understanding of the volunteer's skills and abilities, as well as any limitations. Each person is unique - one volunteer with BI is very different from the next volunteer with BI. You cannot assume that the challenges, strategies and supports needed will be the same.

Therefore, it is important to address the topic of the BI. You may do this by saying something like, "I know you had an injury. What would you like to tell me about it that would help this be a successful volunteer experience? For example, what are your skills and strengths and are there any challenges you think I should be aware of?" Some people may be hesitant to tell you very much about the injury and its consequences. Other people may want to tell you too much.

Take a moment with the volunteer to discuss his unique skill set so that you can optimize the positive and strategize the challenges. Ask the person how he wants to handle questions from others (co-workers, clients, etc.) about the injury. If the person seems to want to give too much information about the injury, or continue and go "on and on" discussing it, you may need to set some boundaries as to what is okay to discuss in the workplace.

Make these boundaries clear as soon as possible.

HOW SHOULD I INTERACT WITH SOMEONE WITH A BI?

Even though an individual with a BI may at times have difficulty expressing himself it's important to talk with the individual just as you would talk with anyone else of that age. What a person understands may be very different from what the person can express. The individual may need a little more time to find the right words, or may need you to repeat what you have said more than once. Showing patience may take an extra moment, but will be rewarded in the end with better communication.

Here are several examples of common communication problems related to BI that may require consideration:

- Going on and on – Sometimes after a brain injury, a person may become very tangential. That is, the person may go on and on, when a simple answer might be enough. This may occur for a variety of reasons: the person may be distracted by a thought during conversation and switch topics; the person may forget what he was talking about and start discussing something else; or the person may not pick up non-verbal feedback as you try to let him know that the conversation needs to move on.

STRATEGY

You may want to establish a set "cue" or signal that you will give the person to get back on track, (i.e., holding up your hand, making a "timeout" signal with your hands, etc.) It is helpful to let all of the staff working with the person know to use the same cue.

SETTING THE STAGE FOR SUCCESSFUL ENGAGEMENT OF VOLUNTEERS WITH BI

UNABLE TO EXPRESS HIM/HERSELF –

- Sometimes a person has difficulty finding the right words to get a message across. Or, a person may have difficulty forming the words in a way that is easy for others to understand.

STRATEGY

Be prepared for the conversation to take a little longer. You may ask the person if he would like you to help by filling in the words for them. Asking shows respect and can help eliminate frustration.

CROSSING SOCIAL BOUNDARIES –

- Sometimes a person may say or do things that are too personal or uncomfortable. He may ask personal questions, disclose personal information, stand too close, or touch someone in a way that is too familiar. He may not pick up on social boundaries.

STRATEGY

If you notice that this is a problem for a volunteer, talk to him privately about it right away. Let the volunteer know that you want their experience to be successful and that this behavior will get in the way. Point out kindly what the boundaries are, and let them know that you will give them a subtle cue when a boundary is crossed. Praise the person for adhering to social boundaries.

BECOMING EMOTIONAL –

- A volunteer with BI may become frustrated or anxious when faced with a new or difficult situation. This may also occur when the person is tired or overwhelmed.

STRATEGY

One important strategy for helping an individual with BI stay in control of his emotions is to be aware of the “signs” that show he is about to become upset, and to intervene before there is a problem. These “signs” of impending emotions may include looking tense or tearful, stopping work tasks or “shutting down”, or becoming “hyperactive” – moving or talking quickly. It is also important to follow the general strategies listed on the following pages.

WHAT ARE SOME GENERAL STRATEGIES I CAN USE TO HELP THE VOLUNTEER BE SUCCESSFUL[5]?

STRATEGY

PROVIDE CONSISTENCY, REPETITION AND STRUCTURE –

The more you can keep the job environment and duties consistent, repetitious and structured, the more successful the volunteer will be. There are several strategies for doing this:

1. As much as possible, have the volunteer work in the same setting and with the same coworkers.
2. Keep tools and materials in the same location.
3. Write down a list of job duties and instructions for the volunteer, and consider posting these (on a whiteboard, etc.)
4. Give the volunteer a consistent message regarding duties and expectations, so that he is getting the same message from everyone and does not get confused.
5. Break tasks into smaller steps if they are difficult for the person to understand.
6. Allow the volunteer to take regular breaks to “recharge.”

STRATEGY

PERSONAL ORGANIZATION SYSTEM –

Find out what kind of system the volunteer uses for keeping track of his schedule and responsibilities. Most people after a BI learn to use some type of personal organizer. It may be a phone, a day-planner, etc. Encourage the volunteer to add their volunteer schedule and responsibilities to that system. Realize that this system serves as an extension of the volunteer’s brain and allows him to recall and organize information more successfully. If the person does not have such a system, we have provided a sample in the HOPE Handbook (see Resources below). There are several tools that may be useful to help with organization – for example, clipboards, whiteboard, name tags. Whatever is used needs to work for that particular individual.

STRATEGY

PROVIDE FEEDBACK AND REINFORCEMENT –

We all learn through feedback and reinforcement, allowing us to know when we have done something well. After a BI, a person may not pick up on subtle feedback and may need to get more direct feedback and reinforcement. Giving direct and clear feedback can help the individual understand what is needed.

STRATEGY

BE POSITIVE –

Individuals with BI may have lost self -confidence and self-esteem after the injury. The person may be hyper-aware of every tiny mistake or error, even if it is not their fault or not noticed by others. The person may not always realize when he has done something well. Positive feedback can help the person regain confidence in himself as a worker. Let the person know what you DO want him to do, rather than what you DON'T want done. (i.e., "Could you please put those in the storage room?" rather than "Don't forget to put those away.")

STRATEGY

REDUCE STIMULATION –

The volunteer may be easily distracted by noises, bright lights, or activities in the environment. The person may have difficulty "filtering out" these distractions and may be most productive in a quieter environment. It's best to ask the volunteer about such distractions and, if they are problematic, to figure out a solution together.

STRATEGY

PROVIDE BREAKS –

As mentioned above, many volunteers with BI will be most successful if they are allowed to take scheduled breaks. When fatigued the volunteer with BI may have difficulty focusing, remembering, and controlling emotions. Be aware that the person may not realize he needs a break until he is completely fatigued. It is best to have the breaks scheduled, and encourage the volunteer to take them before he is too fatigued.

SUMMARY OF STRATEGIES FOR A SUCCESSFUL ENVIRONMENT

CONSISTENCY, REPETITION AND STRUCTURE
- Consistent routines; written instructions; to-do lists; break tasks into small steps as needed

FEEDBACK AND REINFORCEMENT
- Subtle feedback may be missed; be direct and straight-forward; point out successes

REDUCED STIMULATION
- Excess noise, bright lights, etc. – as needed

PROVIDE BREAKS
- May need breaks in quiet area for cognitive fatigue

MUTUAL RESPECT
- Keep in mind the individual's age, background and experience

HELPFUL RESOURCES

If you would like more information regarding BI, here are several resources:

- The Brain Injury Association of America: biausa.org
- The Center for Disease Control and Prevention: cdc.gov/traumaticbraininjury
- Craig Hospital: craighospital.org
- The Defense and Veterans Brain Injury Center: dvbic.org

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MY VOLUNTEER PLAN

Name of Agency: _____

Agency Address: _____

Name of Supervisor: _____

Agency Phone Number: _____

Other Important People Involved with my Volunteer Plan: _____
_____
_____

My Role and Duties: _____
_____
_____

Schedule: _____
_____

Notes

THE GIVE INITIATIVE
AT CRAIG HOSPITAL

This handbook was printed in collaboration with Craig Hospital's GIVE Initiative.

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