



Resource Coordination for Individuals with Traumatic Brain Injury A Handbook for Human Service Professionals

This Publication prepared by:

**Maryland Department of Health and Mental Hygiene
The Maryland TBI Post Demonstration Project**

&

The Mental Health Management Agency of Frederick County, Inc.

**Anastasia B. Edmonston M.S. CRC
Project Director**

**Robert L. Ehrlich, Jr., Governor
Michael S. Steele, Lt. Governor
S. Anthony McCann, Secretary**

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Introduction: This handbook is intended for use by human service professionals including; mental health professionals, case managers, clinicians, therapists, special educators and transitioning specialists. Much of the material covered in this handbook is an expanded version of the training conducted by the Maryland Traumatic Brain Injury Post Demonstration Project with mental health professionals and other human service providers in Frederick and Anne Arundel counties. In addition to training, the Project provided case management and resource coordination to individuals with brain injuries in those counties. Lessons learned and examples from the Project are also incorporated throughout this handbook.

Purpose: Many individuals with brain injury receive treatment and rehabilitation through a variety of service delivery systems. Some of these individuals may never have received specific brain injury related treatment and remediation. Perhaps their brain injury occurred at a very early age and the long-term affects of that injury are not recognized as impacting their current status and needs. It seemed clear from the feedback provided to the Maryland Traumatic Brain Injury Post Demonstration Project by community mental health providers and other human service professionals that many individuals they serve have a history of a brain injury. Unfortunately, these professionals do not always feel informed about brain injury and its sequela, nor how to support individuals who are experiencing challenges related to a history of a brain injury.

This handbook is intended to educate and increase the comfort level of professionals when working with individuals with brain injury. In doing so, it is hoped that service capacity to individuals with brain injury can be expanded and enhanced at the local level to better serve the unique needs of this population. Towards this end this handbook will aid professionals by:

- Defining traumatic brain injury and describe its major physical, cognitive and behavioral sequela.
- Providing an overview of the incidence of traumatic brain injury and the lack of recognition of this major public health issue.
- Identifying the medical and rehabilitation pathways of treatment following a traumatic brain injury.
- Introducing a specific screening tool to help professionals identify when an individual has a history of a brain injury.
- Providing professionals with an intake interview format that they can use to identify service gaps and treatment needs of individuals who have a history or suspected history of a brain injury.
- Supplying examples of common information and resource referral needs of individuals with traumatic brain injury and how these needs can be met through resource coordination.
- Offering strategies and techniques professionals can apply in their work with individuals with traumatic brain injuries.
- Providing a biography of resources and additional readings regarding traumatic brain injury.

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Chapter 1

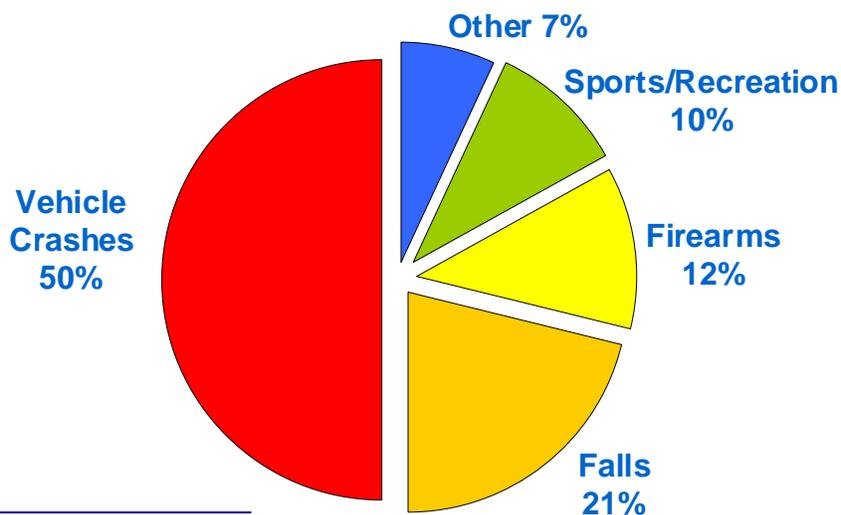
What is Brain Injury?

According to the Brain Injury Association of America, a "**Traumatic brain injury** (TBI) is an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment (1986)." TBI can be the result of a motor vehicle, motorcycle, or biking accident. Gunshot wounds, falls, sport injury and assaults are other modes of injury. (see chart below)

In 1999, the Centers for Disease Control (CDC) reported at least 5.3 million children and adults in the United States were living with a permanent disability as the result of a traumatic brain injury. In comparison to a TBI, an **acquired brain injury (ABI)**, according to the Brain Injury Association of America, "is an injury to the brain, which is not hereditary, congenital, degenerative or induced by birth trauma.

An acquired brain injury commonly results in a change in neuronal activity, which effects the physical integrity, the metabolic activity, or the functional ability of the cell. An acquired brain injury may result in mild, moderate, or severe impairments in one or more areas, including cognition, speech-language communication; memory; attention and concentration; reasoning; abstract thinking; physical functions; psychosocial behavior; and information processing (1997)." Examples of acquired brain injury include the following: stroke; brain tumor; aneurysm; brain infections (such as meningitis or encephalitis); anoxia caused by heart attack, near suffocation, drug overdose or carbon monoxide poisoning.

Causes of Traumatic Brain Injury



The numbers noted in the chart are derived from the ongoing Centers for Disease Control (CDC) Traumatic Brain Injury Surveillance Grant. The CDC reports that vehicle crashes are the leading cause of traumatic brain injury in the United States. Falls are the second leading cause (1999). The elderly and young children are very vulnerable to fall-related traumatic brain injury. The National Center for Injury Prevention and Control analyzed data regarding deaths from traumatic brain injury for the period of 1989-1998. Researchers looked at the cause of death data. They found traumatic brain injury related deaths from motor vehicle accidents had declined by 22% and traumatic brain injury (TBI) related deaths from firearms had declined by 14%. The mortality rate for falls conversely rose during this period by 25%. According to the CDC, firearm use causes about 10% of all traumatic brain injuries but accounts for 44% of traumatic brain injury-related deaths. Nine out of 10 individuals with a firearm-related TBI die and nearly two thirds of firearm-related traumatic brain injuries are classified as suicidal in intent. (CDC 1999)

Types of Brain Injuries

Traumatic brain injuries are commonly categorized according to severity. When reviewing the medical records of an individual with a brain injury, injuries are defined as mild, moderate or severe. These commonly used definitions are explained as follows:

Mild Traumatic Brain Injury

- 75%-85% of all brain injuries are mild and are the most common type of brain injury.
- Individuals experience a brief (<15 minutes) or NO loss of consciousness.
- Neurological exam is usually normal.
- 90% of individuals recover within 6-8 weeks, often within hours or days.

Typically, an individual will receive a blow to the head in a minor car accident or during a sports or recreational activity. He/she will feel dazed but may not necessarily "black out". If individuals are seen in the emergency room they tend to be treated and released due to the CAT scan, MRI and EEG, (if given), being normal. Most individuals who incur a mild brain injury resume normal activities without any long-term ramifications of the injury. However, approximately 10% of individuals who have a mild traumatic brain injury do experience functional difficulties. Experts attribute this to the stretching and tearing of the brain's microscopic axons and dendrites that occurs when the head is struck or shaken with great force. The brain's physical density resembles Jell-O or cooked cauliflower, and if it is shaken and jarred within the sharp and bony skull, damage can occur that disrupts the electrochemical functioning of the cells. Thomas Kay Ph.D. neuropsychologist and former director of the Research and Training Center at New York University has written extensively about the impact of mild brain injury on functioning. In his 1986 paper, *Minor Head Injury: An Introduction for Professionals*, he describes the mechanism of such injury. The harder the force applied or if an individual suffers several mild brain injuries over time (as sometimes happens to athletes or victims of domestic abuse or repeated assault), the more severe the possible brain injury.

Individuals with mild traumatic brain injury often do not receive medical follow-up because the injury was deemed "mild". The functional problems they might experience in their thinking, emotional or physical skills in the weeks, months and sometimes years after their

injury, therefore, may not be attributed to their brain injury. The difficulties resulting from their injuries and lack of medical explanation may result in anxiety, depression, emotional lability, and interpersonal difficulties with family, friends, co-workers or employers. Kay termed this sequela of complications the "psychological overlay" that develops in a subgroup of those who incur a traumatic brain injury. It is not uncommon for an individual with a mild brain injury to be treated inappropriately for depression and/or anxiety, or even to be thought of as a malingerer. Problems related to a mild brain injury are especially hard to detect in individuals who are very bright and function at a very high level. An interesting case in point regarding the frequent disconnect between the medical professionals' diagnosis and the individual with a mild brain injury's experience was reported in the September 4, 2003 edition of the Baltimore Sun.

"Veteran 60 Minutes newsman Mike Wallace is on the mend after slipping on a jetty, falling and hitting his head while on vacation.

Wallace walked away from the accident, which took place mid-August in Martha's Vineyard, but was later checked into a hospital for a few days for observation, CBS News spokesman Kevin Tedesco said yesterday.

*Doctors pronounced Wallace healthy, but the correspondent said that **"my hearing, memory and sight have suffered."***

Moderate Brain Injury

- Loss of Consciousness /Coma between 20-30 minutes to 24 hours, followed by a few days or weeks of confusion.
- EEG/CAT/MRI are positive for brain injury.
- A total of 33-50% of individuals with moderate brain injury have long-term difficulties in one or more areas of functioning.

For individuals with a moderate brain injury, there is clear evidence that an injury has occurred. They more than likely received treatment in a hospital/trauma center, and are unable to work/attend school for a period of time. The nature and extent of their injuries may have necessitated a stay in a rehabilitation hospital or outpatient rehabilitation following discharge from the hospital for physical, speech and occupational therapy. Long-term deficits may be obvious to the observer. For example, the individual may now use a cane or have a noticeable speech impairment. However, many individuals who have a history of a moderate brain injury appear "normal". These individuals fill the ranks of what is often referred to as the "walking wounded". Individuals with moderate traumatic brain injury may experience life-long impairments in their physical, emotional and cognitive skills leading to diminished productivity in work, as well as a loss of interpersonal relationships with family, friends and community.

Severe Traumatic Brain Injury

- Almost always results in prolonged loss of consciousness or coma of days, weeks, or longer.
- 80% of individuals with severe brain injury have multiple impairments in functioning.

Individuals with severe brain injuries commonly require weeks, months and years of therapy to regain skills and/or regain the function lost as a result of injury. Many never recover to pre-injury levels. Progress may be very slow, and individuals with severe brain injury often require life-long care and support.

Due to lack of appropriate services and supports in the community, individuals with severe traumatic brain injury, (who are often young), tend to be discharged from the hospital or rehabilitation center to a nursing home. If they are discharged to home and community, frequently the burden of care falls on family members. An example of someone who has sustained a severe brain injury is James Brady, who was President Reagan's press secretary when he was shot in the head during John Hickley's assassination attempt on the President.

Traumatic Brain Injury A Serious and Under Recognized Public Health Problem

Who is Affected?

- Brain injury affects 1.5 million Americans a year.
- Approximately 80,000 each year experience long-term disability following a brain injury.
- Traumatic brain injury is the leading cause of death and disability for Americans under 45.
- The risk of traumatic brain injury is higher for men than for women.
- Traumatic brain injury results in one and a half times more deaths each year than AIDS.
- More Americans died as a result of traumatic brain injury between 1981 and 1993 than were killed in all the wars in our history combined (up until the first Gulf War).

In Maryland in 2000...

- There were over 5,229 traumatic brain injuries.
- 5% of all hospitalizations were traumatic brain injury related.
- 25% of all injury-related deaths for ages 15-24 were related to a traumatic brain injury.
- 11% of all injuries to children age 14 and under were related to a traumatic brain injury.

Despite the high incidence of traumatic brain injury as indicated by the CDC's data above, public awareness of brain injury and its long-term deficits is very low. The Brain Injury Association of America commissioned a Harris poll that was conducted in 2000. The purpose of the poll was to survey public perceptions and knowledge of brain and head injuries. Over 1,000 adults were interviewed. The major findings of the poll found:

- 1 in 3 Americans are not familiar with the term "brain injury".
- 2 in 3 (66%) believe that brain injury happens less frequently than breast cancer.
- 50% believe brain injuries happen less frequently than AIDS.

The chart below illustrates dramatically the gap between public awareness and the reality of the incidence of Traumatic Brain Injury when compared with more recognized disabling diseases and conditions.

Injury and Disability Prevalence Rates



Perhaps the gap between incidence and awareness is so wide because there is no recognizable face of brain injury. The brain injury community does not have someone like Christopher Reeve or Michael J. Fox. These two men so eloquently speak to the ravages of spinal cord injury and Parkinson's disease, and as a result, have increased not only public awareness of these disabling conditions but their advocacy has led to increased funding for research and treatment.

Another factor in the lack of public awareness is that brain injury is often misdiagnosed. For example, the academic and behavior difficulties a child experiences at age 12 may not be attributed to the head injury he sustained in a fall at age 3. The diagnosis on the child's Individual Education Plan (IEP) or 504 Plan may be read rather as Learning Disabled (LD) or Autism Spectrum Disorder, Emotionally Disturbed, Mentally Retarded or Attention Deficit with Hyperactivity Disorder (ADHD) rather than traumatic brain injury. As a father of a son with a traumatic brain injury put it, brain injury, "is the only disability that can mimic or replicate any other disability".

Chapter 2

Common Functional Disabilities Experienced After Brain Injury

It is often said that no two individuals experience the consequences of brain injury in the same manner. How the presence of a brain injury is expressed varies and can depend not only on the location and severity of the injury and length of coma, but also on the individual's age at time of injury, as well as educational and vocational history and social supports. Described below are some deficits commonly found across physical, cognitive and personality/behavior domains that are associated with brain injury.

Possible Physical Changes Following a Brain Injury

- **Motor Skills and Balance**

Due to injury to those parts of the brain that control movement (such as the cerebellum and frontal lobe), individuals may suffer paralysis on either side of their body depending on the side of the brain affected. (Damage to the right side affects left side balance, gait and coordination and visa versa.)

- **Hearing Loss**

Injury to the temporal bone and temporal area can result in varying degrees of hearing loss. Categories of hearing loss that are often associated with brain injury include: conductive hearing loss, peripheral sensorineural hearing loss, (or a combination of both), or an individual may have hearing impairment associated with a central auditory processing disorder. The American Speech-Language-Hearing Association defines these disorders in the following way: A conductive hearing loss occurs when sound is not conducted efficiently through the outer and middle ear. Causes of conductive hearing loss can include malformation of the ear canal or impacted earwax. Such causes can frequently be treated by surgery. A sensorineural hearing loss can be traced to a variety of causes such as birth injury, noise exposure and brain injury. It occurs when there is damage to the inner ear or to the nerve pathways from the inner ear to the brain. When there is damage to the auditory centers of the brain (found in the temporal lobe) either through disease, tumor or injury, individuals cannot process and comprehend auditory information.

If an a professional notices that an individual with a TBI is having trouble following conversations or misses pieces of information that is conveyed to them verbally, a hearing screening should be done. If a hearing impairment is ruled out, then the observed problems may be due to injury related attention and comprehension problems.

- **Vision**

There are many ways that vision can be impacted following a traumatic brain injury. Individuals may suffer from a visual field cut. For example, their brain may not process any visual information from their left visual field so when reading they will miss the words on the left. Perceptual skills are also common too many individuals post a traumatic brain injury. Visual perceptual difficulties can lead to impaired depth perception and a reduced ability to judge distances and the location of objects in space. Double vision can also be an issue. As a result of visual problems an individual can have difficulty driving, reading and or physically navigating their environment. Problems with vision and visual perceptual

skills reflect damage to the occipital and/or parietal lobes.

- **Spasticity/Tremors**

Damage to the frontal lobe and cerebellum can lead to intention tremors, which is often referred to as ataxia. An individual with this type of movement disorder will shake and tremble when making the intentional movements needed to pick up objects such as a fork or pencil, or to use a keyboard. In severe cases, ataxia can be present in all four limbs, trunk, head and neck making ambulation next to impossible. Other important activities of daily living such as dressing, bathing and toileting can also be impacted.

- **Speech Disorders**

Apraxia and dysarthria are common speech disorders following traumatic brain injury. Both of these conditions affect an individual's ability to coordinate the movements of his or her tongue, teeth and jaw in order to clearly communicate. In some cases eating, drinking and swallowing are negatively affected. For those who have apraxia, the impairment of speech is the result of damage to the portion of the brain that programs the positioning of speech muscles and the sequencing of muscle movements for the volitional production of speech. Dysarthria is the result of disturbances in muscular control-weakness, slowness, or incoordination of the speech mechanism due to damage to the central or peripheral nervous system or both. The term encompasses co-existing neurogenic disorders of several or all the basic processes of speech: respiration, phonation, resonance, articulation and prosody. It is not uncommon for an individual with brain injury to have both apraxia and dysarthria. (Darley, F.L. 1969 and Wertz, R.I. 1985)

Apraxia and dysarthria make communication a very difficult and often exhausting activity. Speech therapists can coach individuals to utilize a variety of exercises and strategies to aid in intelligibility. For example individuals may compensate by speaking very slowly and deliberately, finger spelling or sign language or they may utilize various devices such as a speech synthesizer.

- **Fatigue/Weakness**

Although common in the early stages following brain injury, fatigue and general feeling of weakness can be chronic and life long for some. Careful structuring of daily activities with the incorporation of "down" or rest times is critical.

- **Seizures**

Traumatic Brain Injury is a common cause of epileptic seizures. A 2003 review of the epidemiology of posttraumatic epilepsy conducted at the University of Colorado Health Science Center found that the risk of seizures is anywhere between 4% to 53% after a brain injury. Risk factors associated with a higher incidence of seizure activity include: acute intracerebral hematoma, younger age at the time of the injury, increased injury severity, chronic alcoholism and an initial seizure within the first week following injury.

- **Taste and Smell**

Impairment in the senses of taste and smell is usually indicative of a severe brain injury. (Green et. al 2003)

Possible Changes in Cognition and Thinking Following a Brain Injury

- **Memory, Attention and Speed of Information Processing**

Many individuals who experience a traumatic brain injury will cite poor memory as a major deficit; typically, information in long-term memory is more easily retrievable. For example, most individuals with traumatic brain injury can recall events from their childhood and identify friends and family members. What tends to be impacted by injury is the ability to remember more recent information and events. Thomas McAllister, MD., as part of New Hampshire's Project Response (funded by the HRSA Traumatic Brain Injury State Grants Program), has provided training to professionals regarding the neurological sequela of traumatic brain injury. In his trainings, he describes how memory can be affected by a traumatic brain injury.

For example, some may have difficulty with what is referred to as working memory. (The ability to keep something in mind while retrieving or processing other relevant information.) Functional working memory can also be affected by attention, another common area of deficit after injury. Attentional problems, may include the ability to focus one's attention on relevant information, (referred to as selective attention), the ability to sustain ones attention as the situation demands, and the ability to shift and divide ones attention according to the demands of internal and external stimuli. If an individual cannot attend to what is being said or read, or is not observant of their environment, he or she will not be able to process and respond appropriately. Consequently, the ability to place the information in working memory and ultimately store it in short and long-term memory is compromised. Reduced speed of information processing refers to how efficiently one can comprehend information. Deficits in this area result in poor results on timed tests and tasks, and difficulty absorbing verbal and/or written information. Interestingly, these deficits may not be evident upon first meeting with an individual. For example, a clinician may complete an intake interview with a prospective client who is eager and interested in receiving services. The next appointment is set, but at the appointed date, the individual simply does not show up for the appointment. A subsequent phone call to the person reveals that they forgot not only the appointment, but also most of the content of the initial interview. Obviously, memory, attention and speed of processing deficits have wide reaching social, educational and vocational implications.

- **Receptive and Expressive Aphasia**

The inability either to understand what is being said or what is read is thought to be associated with damage to language centers located in the temporal lobe of the brain. Sometimes, comprehension is possible but information is processed at a much slower rate, making it difficult for those with receptive aphasia to follow conversations. Expressive aphasia impacts on what is often referred to as one's "naming ability" and can be due to damage to the frontal lobe. As a result, conversation is conducted in a halting manner, as the individual tries to retrieve the desired word or words.

- **Executive Skills**

The set of cognitive skills associated with executive skill functioning includes, **problem solving, organizational skills, self-perception, cognitive flexibility, and task persistence.** Among other things, executive skills allow us to plan and organize solutions to problems as well as form steps to achieve goals. Executive skills allow us to "think on our feet" and multitask. They enable us to generate alternative solutions to problems or

situations as the need arises. Those with impaired executive skills often act impulsively either in words or action. Not being able to adequately respond in an appropriate and thoughtful way to the demands of the workplace and community, as well as the nuances of interpersonal interactions, can be highly debilitating.

- **Decreased Awareness**

This is a common aspect of brain injury and difficult to remediate. Research suggests that up to 45% of individuals with moderate to severe traumatic brain injury demonstrate a reduced awareness or complete lack of awareness regarding their deficits (Flashman & McCallister 2002). As awareness is the key to sustained functional gains, a lack of awareness can impede rehabilitation efforts. For families and untrained professionals, the lack of awareness can be misinterpreted as oppositional or unmotivated behavior. In fact a lack of awareness, commonly seen in those with frontal lobe and executive skill damage, is a syndrome referred to as anosognosia. Laura Flashman, M.D. of Dartmouth College describes anosognosia as a neurological syndrome involving complete unawareness of disability and the resulting deficits. It is associated with damage to the right hemisphere of the brain. Friends, family and professionals may observe the individual fabricates stories or information to explain limitations or gaps in memory. This is referred to as confabulation and is common in those with anosognosia. It is important for clinicians to understand that this neurologically-based denial is different from the type of denial associated with a psychodynamic defense mechanism.

Possible Changes in Personality and Behavior after a Brain Injury

The psychosocial sequela following a traumatic brain injury varies from individual to individual. The functional impact can depend on such factors as age at time of injury, level of education, premorbid and post injury substance use and abuse, work history, family and community supports, and the severity of the injury. Common behavior and personality changes seen after brain injury include the following:

- **Depression**

The incidence of depression following traumatic brain injury is well documented in the literature. Researchers in Finland conducted a 30-year follow-up of 60 individuals with Traumatic Brain Injury. Of these individuals, 48.3% had an Axis I disorder during their lifetime that was diagnosed after the brain injury. The most common of the Axis I disorders were Major Depression, alcohol abuse dependence, panic disorder, specific phobia and psychotic disorders (Koponen et al 2002).

Duke University researchers published their 50-year follow-up of World War II veterans in 2002. A total of 1,198 veterans participated in the study. Of those, 520 had incurred a brain injury. They found those individuals with a history of brain injury had a lifetime prevalence of major depression of 18.5%, in contrast to the 13.4% rate of depression for non-brain injured veterans. Kreutzer and Steel of the Defense and Veterans Brain Injury Center in Richmond VA, found that of 172 outpatients at a brain injury clinic who were assessed using the Minnesota Multiphasic Personality Inventory, Neurobehavioral Inventory and the Beck Depression Scale, 30-38% were found to be clinically depressed.

- **Substance Use and Abuse**

John Corrigan and his colleagues at the Ohio Valley Center have done extensive work in the area of traumatic brain injury and substance use and abuse. He reports that:

1. Almost two-thirds of adults participating in brain injury rehabilitation have a history of substance abuse prior to their injury.
2. Persons who have sustained brain injuries test positive for alcohol in two-thirds of moving vehicle crashes and 60% of assaults.
3. Approximately 20% of persons who did not have substance abuse problems before their injury develop them after their injury (1998).

- **Social and Emotional Problems**

It is not uncommon for individuals following a brain injury to experience difficulty controlling or regulating their behavior and/or mood. Family members may be surprised to see a formerly emotionally stoic individual break into tears at the slightest provocation, or conversely, laugh hysterically at what others perceive as a mildly amusing joke. Out of context aggression, and impulsivity in words and actions are also not uncommon.

For professionals working with individuals who experience emotional or behavioral disinhibition, it is important to keep in mind that the origin of many of these behaviors or moods are directly related to their brain injury. Frontal lobe lesions common to traumatic brain injuries can lead to behaviors that are disruptive and result in consequences ranging from loss of friends and employment to criminal behavior, domestic violence and incarceration, (Kim E. 2001, Tateno A., Robinson RG 2003, Timonen M, et. al. 2002 and Cohen RA, 1999).

Young adults who incurred their injuries as children or teenagers appear to be very vulnerable to social isolation as a result of their injuries. Frequently they lose a year or more of school due to a brain injury and subsequent rehabilitation efforts. Returning to school they are behind their peer group and this loss can be compounded by injury imposed behavioral and cognitive difficulties that result in reduced social skills and or maturity. Such circumstances can leave individuals at risk for depression, anxiety and substance abuse. Carefully orchestrated school reentry, vocational transitional planning and psychosocial support services are crucial for both the individual and their families.

Chapter 3

Where are Individuals with TBI Being Served?

Individuals who experience a disability as a result of a traumatic brain injury (TBI) receive services and supports within many different service delivery systems. Few states have a comprehensive and fluid system of services that are specifically designed for individuals with TBI. This is not surprising since the needs of individuals with TBI vary greatly based on the type and severity of the injury the individual incurred, the individual's age and level of functioning at the time of the injury, and the individual's natural support network. Individuals who have sustained a TBI and are in need of services and supports may be eligible for services offered through many different private or public organizations. For instance, depending on their needs and other criteria, individuals with brain injury may be eligible for public services from several different entities, such as: the Developmental Disabilities System, the State Department of Education, the Division of Rehabilitation Services, Alcohol and Drug Abuse Administration, the Public Mental Health System, and/or Medicaid. The points of entry into each of these differ, as does the eligibility criteria, application procedure, and the scope of services. Individuals with brain injury and families need support to navigate the complexities of the service systems.

The age at which a brain injury is sustained is significant. Life-long supports do exist for some individuals who are under the age of 22 at the time of their injury. These individuals may be eligible for funding through the Developmental Disabilities System. The Developmental Disabilities System can provide residential and/or day treatment, as well as vocational services. Those injured after the age of 22, they may be eligible for some support services through the Developmental Disabilities System, but often options and services are limited.

Those who sustain their brain injury when over the age of 22, and whose injury imposed deficits are not resolved adequately through the rehabilitation services that they are able to access, either through private insurance, Medicaid or state vocational rehabilitation agencies, are often left isolated and without supports. As a result, these individuals are vulnerable and can experience mental health problems that can exacerbate cognitive and behavioral deficits. An individual, often years post injury, may receive services through the mental health system and may receive a diagnosis of a major mental illness. This does not mean that there are not mental health issues independent of a brain injury; however, knowing that there is a history of a brain injury can help guide providers of services in their treatment.

As part of the training activities of the Maryland Traumatic Brain Injury Post Demonstration Project, mental health workers in two Maryland detention centers received training on brain injury and its physical, cognitive and behavioral sequela. The feedback provided to the Project included the observations made by the detention center mental health workers that many incarcerated individuals have a history of brain injury. Within one Maryland Detention Center in Frederick County, mental health workers reviewed the histories of 80 individuals who were part of their target population of inmates with serious mental illness. Out of the 80 individuals, 20 individuals had a documented history of TBI. Of those 20 individuals, 18 had a documented history of substance abuse. Mental health workers also report that individuals with TBI seem to cycle back through the detention

centers on a regular basis. The typical scenario for individuals with TBI, reported by the mental health workers, is that the inmate with TBI uses substances, commits a crime while under the influence (such as assault), and is incarcerated for no longer than eighteen months at the detention center. The individuals often receive treatment and counseling while incarcerated but they are unable to follow through with recommended community supports upon release. The result is a high rate of recidivism to jail because they abuse substances and/or commit crimes. This may be due to the individual's poor memory, poor organizational skills and inability to follow through as a result of the injury. Other contributing factors may be the fact that many of these individuals have little to no family support, have exhausted their family's ability to advocate for them, or their families are also struggling with addiction or other issues. For these reasons, they are not always able to connect with recommended substance abuse treatment programs, or brain injury rehabilitation and community mental health services.

Chapter 4

Suggested Rehabilitation Pathways

When working with individuals with a history of traumatic brain injury it is important to obtain a thorough medical and rehabilitation history. In doing so, treatment needs and gaps in services can be identified and referrals made to those services. Before that can be done, it is important to be familiar with what are considered the standards of care and best practices for individuals who incur a mild, moderate or severe brain injury.

Mild Brain Injury

The majority of individuals who incur a mild brain injury may experience fatigue and headaches following the injury. After rest and time off from work or school they often resume activities without residual effects. As mentioned earlier, a minority will suffer cognitive and physical problems that do not resolve quickly.

To avoid what Thomas Kay termed the “psychosocial overlay” associated with those with mild brain injury who do not recover quickly or completely, benefit can be gained through; reassurance, education, evaluation, treatment and support. These interventions can be broken down in the following manner:

- Reassurance that some physical or cognitive difficulties are normal after a mild brain injury is critical both immediately after the injury and over time if issues do not resolve.
- Ideally, written educational materials and resources should be offered to the individual and their family regarding the symptoms associated with mild brain injury.
- Evaluation by a neuropsychologist familiar with mild traumatic brain injury is recommended if the individual is not able to resume normal activities within a few months following the injury. A neuropsychological evaluation can assess any diminishment in cognitive functioning as well as assess the individual’s level of depression and anxiety.
- Treatment may be recommended by the neuropsychologist in the form of cognitive therapy that can be done by a speech therapist, occupational therapist, neuropsychologist, or cognitive therapist.
- Support to the individual as they are undergoing evaluation and treatment can be accessed through individual and/or family psychotherapy, and/or participation in a Brain Injury Support Group.

Moderate to Severe Brain Injury

The development of a system of medical and rehabilitation care and treatment has evolved rather quickly in recent decades to meet the needs of a relatively new segment of the disabled population in this country. Thirty years ago, 50% of all people who sustained a brain injury died from their injuries. That number has now been reduced to 22%. Survival has been enhanced through the development of our nation’s emergency response network including the “911” system and quick transportation of the injured to trauma centers. Also

contributing to a decrease in fatalities are the improved safety features in cars such as child safety seats, air bags and seatbelts. (Brain Injury Association of America, 2000). Management and ultimate survival of those with moderate to severe injuries has improved thanks to technology and the development of best practice guidelines by trauma experts and neurosurgeons. (Brain Trauma Foundation, 2003)

In 1999, the Agency for Health Care Policy and Research published *Rehabilitation for Traumatic Brain Injury*. The Oregon Health Sciences University was contracted and charged with identifying and assessing the evidence on traumatic brain injury rehabilitation. The panel of experts, family members and individuals with brain injuries reviewed over 3,000 abstracts and articles related to traumatic brain injury rehabilitation in order to determine what interventions aid in recovery and return to function. Unfortunately, the resulting report created more questions than answers. This was primarily due to the lack of studies conducted utilizing well-designed randomized controlled trials, the gold standard of research methodology. However there is some evidence to suggest that cognitive rehabilitation, supported employment and long-term care coordination have a beneficial effect on the outcomes of individuals with traumatic brain injuries. The report offers many valuable suggestions for future research efforts.

Fortunately, there is a general consensus among rehabilitation professionals, developed by clinical experience and research over time, regarding what medical and rehabilitation interventions and strategies are beneficial. The Brain Injury Association of America stresses that each brain injury is unique, as are the rehabilitation needs of each individual. However, there are generally acknowledged specialized medical and rehabilitation programs that address the physical, cognitive and behavioral needs of those with moderate to severe traumatic brain injury. Ideally, an individual with a traumatic brain injury has access to the following services as needed:

- Intensive care delivered at a hospital and/or trauma center;
- Inpatient acute brain injury rehabilitation services provided by a facility accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) and/or the Joint Commission on Accreditation of Health Care Organizations (JCAHO). Programs that have been reviewed and accredited by these independent review commissions conform to nationally and internationally recognized levels of care. Programs who maintain their CARF and JCAHO accreditation undergo an accreditation review every three years;
- Outpatient rehabilitation at a CARF and or JCAHO accredited brain injury rehabilitation program offering a community re-entry program and individual therapies and treatments that can include; neuropsychological evaluation, speech, occupational and physical therapy, vocational services and psychotherapy;
- Referral to a state vocational rehabilitation counselor with knowledge and expertise on traumatic brain injury;
- Vocational services, if necessary can include: vocational evaluation, work adjustment training, vocational training, job placement and job coaching; and
- Support services in the community (case management services, support group, individual/family therapy, attendant care services, ongoing neuropsychiatric supports and perhaps residential and or in-home or day rehabilitation or medical day care services).

It is important to note that an individual's ability to access what they need, when they need it varies. The delivery of appropriate services depends on a complex interaction of individual and family resources, insurance coverage, and state and local funding streams. Many individuals can easily "fall through the cracks". As a result, individuals with TBI, their families and state and national advocates continue to work towards filling in the service gaps and the creation of a continuum of care. Until this goal is achieved, there are and will continue to be individuals with TBI who do not receive the services they need to maximize their recovery and independence.

Chapter 5

Suggested Strategies to Support Cognitive, Communicative, and Behavioral Functioning

We all have individual strengths and weaknesses. Some of us learn better when information is conveyed to us verbally, some if information is given visually. Some of us are very laid back, others possess a quick triggered temper. These traits may reverse, stay constant or become exaggerated after a traumatic brain injury. Bottom-line, no two brains are alike, and therefore, no one package of strategies and supports fits all individuals after a brain injury. If an individual has participated in a specialized brain injury rehabilitation program, the treating therapists have evaluated the individual's strength's and weaknesses and has provided the individual the opportunity for practice and mastery of compensatory strategies in the therapeutic setting. The goal of rehabilitation is to carry over the use of strategies at home, work and in the community.

For some, the ability to use and generalize strategies outside of the rehabilitation setting is difficult without long-term support at home and in the community. Some individuals may not have the opportunity to consistently employ the strategies they have learned post-discharge for a myriad of reasons. These can include difficulty returning to work, ongoing medical issues or concurring mental health and substance abuse issues. Unemployment is a major factor in the social isolation many individuals feel following a traumatic brain injury. The National Association of State Head Injury Administrators (NASHA) reports that without supports, 75% of individuals who return to work lose their jobs within 90 days.

For human service professionals who work with individuals who have a history of brain injury, it is important to be familiar with some of the common strategies recommended to support cognitive, communicative and behavioral skills. Reinforcement of strategies can enhance independence, competency and the ability to participate fully in services. Keep in mind that strategies and clusters of strategies can be helpful across deficit areas. For example, using memory strategies successfully can reduce anxiety and as a result help circumvent behavioral outbursts.

Strategies to aid in memory & organizational skills

- Use of a journal/calendar
- Use of a daily schedule
- "To Do" lists
- Labeling items (useful for someone with language as well as memory deficits)
- Use of a tape recorder (to record "to do" items, counseling sessions or key points of sessions)
- Break tasks into small manageable steps
- Use of a highlighter to highlight key information on written material
- Use of an alarm watch (helpful for cueing transitions throughout the day, and with medication compliance)
- Encourage review of daily schedule
- Post signs on the wall (in home, for example a written reminder above the stove to "turn off")
- Encourage routine in the daily schedule as much as is feasible

Strategies to aid in communication skills

- Encourage the individual to paraphrase conversational key points, instructions etc., back to the speaker. This will ensure that the individual has comprehended what was said and the act of repeating will reinforce the information in memory.
- For those whose injury has caused them to react impulsively in words and/or action, the professional can encourage the use of breaks and pauses in conversations. Role-playing and coaching (video or audio taping role-playing can be very helpful) are good tools to enhance awareness of this tendency.
- If the professional suspects that the individual he or she is interacting with has a reduced rate of processing verbal information secondary to a brain injury, the professional needs to be mindful to speak in short sentences and phrases. This will allow the individual to process more efficiently what is being said. Building in pauses will allow the individual with a brain injury to ask clarifying questions of the speaker. **This is particularly true if the information is novel, complex or emotionally laden.**
- Where possible, when giving instructions, do so verbally and in writing and when feasible, physically model the task.
- Request that the individual jot down notes regarding discussions that he/she has with others and other important information into a journal or date book for future reference.

Strategies to Enhance Behavior and Social Skills

- The professional should ask early on in the relationship for permission to "coach" the individual. That is, to obtain the individual's permission to provide them with feedback regarding their behavior and/or use of strategies.
- Always address individuals professionally and respectfully in context, tone and body language.
- When giving feedback be specific, direct and timely. Giving feedback regarding an incident that happened a week ago is not helpful to someone who may not remember the incident.
- Be clear on your expectations of the individual and his/her behavior.
- Utilize positive reinforcement/feedback.
- Formalize your expectations by negotiating a written plan of action signed by both parties. The plan should lay out expectations on both sides (e.g. the individual with a brain injury will gather all their financial paperwork, the professional will help with completing application for entitlements such as SSDI/SSI). The plan can act as a support for the individual's memory and something they can reference between contacts with the professional.
- The plan can become a focal point of subsequent meetings and updated as needed.

Chapter 6

Screening for Traumatic Brain Injury and Gathering Data via a Structured Interview

Human service professionals should screen the individuals that they see for a history of a traumatic brain injury. Knowing that an individual has had an injury can help human service professionals tailor interventions to help accommodate for such injury imposed deficits as impaired memory and organizational skills. If a consumer has a reduced ability to process and recall information, the human service professional can summarize main points and vital information in writing. Knowledge of the presence of a brain injury can also document the need for, and support, referrals to rehabilitation and medical services directed at remediation of specific deficits. Data collection also drives funding and can be used to support TBI research and service funding.

John Corrigan Ph.D. and his colleagues at the Ohio Valley Center for Brain Injury Prevention and Rehabilitation have developed the Traumatic Brain Injury (TBI) Screening, originally designed for use by substance abuse counselors and other human service providers. A shorter version of Corrigan's screening was created for use during the Maryland TBI Post Demonstration Project. This version consists of six questions. The six questions and follow-up questions for the interviewers are below. The TBI Screening forms in both English and Spanish can be found in the Appendix.

Traumatic Brain Injury Screening Questions and Interview Prompts

Question 1:

Have you ever been injured following a blow to the head?

Ask the individual about any serious falls or sports accidents incurred as an adult or child.

Question 2:

Have you ever been hospitalized or treated in an emergency room following an injury?

Ask the individual if they have ever been treated and released from the emergency room, evaluated by a neurologist, had a CAT scan, MRI or EEG done while in the emergency room.

Question 3:

Have you ever been unconscious following an accident or injury?

If yes, do you have any memory for the event? Felt dazed and confused following the event? Experienced a headache, fatigue, dizziness, or changes in vision?

Question 4:

Have you ever been injured in a fight?

Taken a direct blow to the head or experienced a violent shaking of the head and neck?

Question 5:

Have you ever been injured by a spouse or family member?

Has anyone ever severely pushed, punched, shaken, or choked you?

Question 6:

Have you ever had any major surgeries?

Such as heart bypass, transplant or brain surgery.

Illnesses?

Such as toxic shock syndrome, meningitis, encephalitis, hydrocephalous, drug overdose, seizure disorder, or lead poisoning.

Additional things to look and listen for when assessing a possible history of brain injury can include,

- Does the individual have any visible scars?*
- Do they walk with a limp?*
- Use a cane or walker?*
- Wear a foot brace?*
- Appear to have limited use of one hand and/or one side of their body?*
- Have difficulty answering questions?*
- Are their answers unorganized and/or rambling?*
- Do they become easily distracted, agitated or are they emotionally labile?*
- Do they report a difficulty keeping jobs, interpersonal conflicts with supervisors or co-workers?*
- Are they unemployed or underemployed given their level of education or nature of jobs held in the past?*
- Are their personal papers and documents including applications for entitlements, etc. unorganized or incorrectly or incompletely filled out?*
- If this is someone with whom you have worked with for some time, are they chronically late for appointments or frequently "forget" appointments?*

If a History of a Brain Injury is Suspected....

If an individual's response to the screening confirms that there is indeed a history or suspected history of a brain injury, the next step is to obtain specific information regarding what if any services the individual has received. One way to determine this is a structured interview and a review of an individual's medical records. The Structured Interview Form is a modified version of the Intake Interview utilized by the Resource Coordinators of the Maryland Traumatic Brain Injury Post Demonstration Project.

Structured Interview Form

Name_____

DOB_____

Social Security #_____

Address_____

Telephone_____

County_____

Are you currently living; Alone_____, In a Residential Setting_____,

With Family or Friends_____

Date of Interview_____

Name of Interviewer _____

Medical/Rehabilitation History

Date of Injury_____

Type of Injury_____

Mechanism of Injury_____

Age at Injury_____

Were you in a coma? _____

If yes, for how long? _____

Where were you treated immediately after the injury? _____

What was your length of stay?_____

Did you receive inpatient rehabilitation services?_____

Where did you receive inpatient services?_____

What was your length of stay?_____

What were the recommendations/referrals of your treating therapists upon discharge?

Did you receive outpatient rehabilitation services? _____

For how long did you receive outpatient services? _____

What were the recommendations/referrals of your treating therapists upon discharge.

Are you a client of the Developmental Disabilities Administration? _____

If yes, can you describe any services you have received or are receiving from the Developmental Disabilities Administration? _____

Are you currently under the care of a neurologist, physiatrist, psychiatrist or neuropsychiatrist?

If yes, please tell me the name of your doctor(s) _____

Have you ever undergone testing by a neuropsychologist? _____

If yes, please tell me the name of your neuropsychologist and when was the testing done.

Educational History

Are you a high school graduate or did you obtain a GED? Yes _____, No _____

Did you receive any special education services while in school? Yes _____, No _____

Have you taken any college classes? Yes _____, No _____

If yes, please list the classes taken. _____

Did you graduate from college? Yes _____, No _____ Year _____

What was your degree? _____ Field of study? _____

Any postgraduate experience? _____

Current Income Sources

Are you receiving Social Security Disability Insurance (SSDI) or Supplemental Security Income? _____

Are you receiving Workers Compensation? _____

Insurance Status

Are you receiving Medicaid or Medicare? _____

Are you receiving Pharmacy Assistance? _____

Do you have private insurance? (e.g. Blue Cross/Blue Shield) _____

Vocational History

Have you worked since your injury? _____

Have you had any difficulty getting and keeping a job since your injury? _____

If you are having difficulty, can you describe the problems you are having? _____

Are you currently employed? _____

If yes, tell me about your job: _____

Title _____

How long have you held this job? _____

What are your duties and responsibilities?

Can you tell me about any other jobs you have held:

Title _____

How long did you hold this job? _____

What were your duties and responsibilities?

Title _____

How long did you hold this job? _____

What were your duties and responsibilities?

Title _____

How long did you hold this job? _____

What were your duties and responsibilities?

Are you a past or present client of the state Division of Rehabilitation Services? _____

If yes, who is/was your counselor and what kind of services have you received/are receiving?

Counselor name _____

Services received _____

Current Needs

What are the services you feel you need at this time to become more independent in the community.

- Rehabilitation services (physical, occupational, speech therapy)
- Medical (primary care, medication monitoring, seizure control)
- Psychological/psychiatric services (individual or family counseling, medication monitoring)
- Housing
- Transportation
- Educational
- Vocational
- Access to benefits and entitlements (SSDI, SSI, Medicaid, Pharmacy Assistance, Food Stamps etc.)
- Other _____

If an individual has received services related to a brain injury, the next step is to ask them to sign a release of information to be sent to all past and present service providers in order to confirm what services have been delivered. Also the professional can gain a better understanding regarding that individual's brain-injury related deficits as well as the individual's strengths and ability to utilize strategies to compensate for deficits. Another source of information regarding the services, treatment and supports utilized in the past are family members. With the individual's permission, it can be very helpful to include at least one family member in the process.

Once the information has been gathered and reviewed, the professional is better able to ask specific questions of the individual in order to get a more comprehensive understanding of what it is they have received in terms of services. It is recommended to get permission to speak to or obtain records from all human service providers that have worked with the individual whether or not the services they provide or provided are specific to brain injury rehabilitation.

If the individual is currently being seen by multiple agencies in the community, it is recommended that the professional coordinate regular interagency meetings to review the services that are being provided, how effective they are, and to ensure that services are not being fragmented or unnecessarily duplicated.

Often an individual's recall of services provided might be incomplete due to the passage of time and the nature of head injury and its impact on memory. The professional can incorporate the feedback provided by other agencies and providers into their plan of care. With a comprehensive history in hand, they can then fill in any gaps. Gaps can take the form of services needed, entitlements to which the individual is eligible, but never applied for, referrals to appropriate professionals for re-evaluation or evaluation of skills and or/ any treatment needs.

Chapter 7

Below are some examples of what human services providers and agencies may encounter when working with an individual who has a history of a traumatic brain injury. The type of referrals and recommendations made will depend in part on the resources available in the individual's community and the experience and familiarity of the professional with what is locally available. Additional factors include the limitations and strengths of the individual being served, as well as what services may already have occurred or are in process. Some individuals may just require a phone number of a local resource, or they may require very structured hands-on assistance to successfully access needed supports and services.

Case Study 1

Background Information

An individual has recently been discharged from the local inpatient psychiatric unit. He was taken to the emergency room two weeks ago because his family was concerned about his depression and excessive drinking. The psychiatrist diagnosed him with a bipolar disorder and he is currently stabilized medically and behaviorally. He has been referred to a local community mental health provider for follow-up mental health services and counseling, and has been attending regular Alcoholics Anonymous meetings. The staff reports that his affect is fairly flat and he appears to be cooperative with the recommended treatment; however, he consistently misses appointments unless a family member accompanies him.

He is 37 years old and until two years ago was a successful pharmaceutical sales representative. He is currently separated from his wife and two sons and is living with his parents. According to the information he shared at intake, he was functioning at a high level until he was in a car accident three years ago while traveling on business. He reports he was treated and released from the emergency room but was not hospitalized. He has seen a lot of doctors because of "whiplash" and chronic pain in his back, neck and head. He reported he felt "foggy" and had difficulty managing his work duties and eventually filed a worker's compensation claim. That claim was denied by the company and is currently in litigation. He left work two years ago because he felt he just couldn't do the job. At about the same time, his wife asked him to move out. Following the separation he continued to pursue his workman's compensation claim. He also reports that he began using alcohol excessively because the pain medication "was useless". According to both he and his mother, he did not suffer from depression or substance abuse prior to his accident.

Steps the mental health professional can take to investigate whether or not this individual has suffered a "mild"traumatic brain injury.

- Conduct the Traumatic Brain Injury Screening (in appendix I).
- Conduct the Structured Interview (see above).
- Obtain the emergency room records. Is the term "concussion" used? Was confusion, poor orientation or slurred speech noted in either the physician's or paramedic's comments?
- Has a neurologist treated the individual? If yes, obtain and review records.
- Does the individual or the family report trouble with attention or concentration since the accident? For example, can he read and recall newspaper articles or books? Can he

remember the main events of a movie or TV show?

- Has there been a marked change in his ability to manage stress and frustration?

If the results of the screening and recommended steps indicate there has been a "mild" brain injury, the following are some information and referral recommendations:

- Review the results of the records review and provide brain injury education information.
- Suggest that he undergo a neuropsychological evaluation. Explain that a neuropsychological evaluation can help pinpoint any cognitive (thinking) deficits that maybe a result of his injury and provide guidelines for any future cognitive remediation. Let him know that a neuropsychologist is a psychologist with expertise in the interrelationships between the brain and behavior. Based on the results of the neuropsychologist's testing, he or she may recommend some kind of therapy such as speech or occupational therapy.
- The individual and his family can make application to the Social Security Administration for Social Security Disability Insurance (SSDI).
- Provide the number of the Brain Injury Association, both the national and state offices. Suggest if they have access to the Internet to search the BIA website, www.biausa.org for information about traumatic brain injury and mild brain injury.
- Explore with the individual and his family the availability of brain injury support groups in their area (contact the state brain injury association for the places and times support groups are held in around the state).
- Suggest he contact the local Centers for Independent Living for peer support and available community living resources.
- Describe the services of the state vocational rehabilitation agency. Vocational services are provided in each state specifically to aid individuals with disabilities return to work. The timing of a referral to state vocational rehabilitation depends on a variety of factors. If an individual is not yet medically stable or is spending the majority of their time on medical or rehabilitation issues, the vocational agency may not feel they are vocationally ready and therefore will not activate the application. However, the case can be made when approaching the vocational rehabilitation agency that the individual is in need of prevocational services such as a trial work period that can include: work adjustment training, vocational evaluation and/or what is known as a extended evaluation which can include a **neuropsychological evaluation**. If there is no other mechanism for funding a neuropsychological evaluation, the state vocational rehabilitation agency may be able to pay for it as part of their determination of eligibility process. The mental health professional can explain to the individual and his family what a neuropsychological evaluation entails. (The neuropsychologist administers a series of tests that will evaluate attention, concentration, new learning capacity, and the ability to recall information as well as assessment of personality functioning. The testing can take 3 to 4 hours and can be broken up into several sessions if necessary.) The testing results should indicate his cognitive strengths, deficits and what strategies may work for him to support his cognitive and behavioral skills. To locate your local office of vocational rehabilitation, check the blue pages in the phone book or contact your state Brain Injury Association affiliate for a referral to the vocational rehabilitation office closest to where the individual resides.
- Results of any testing may be shared with the individual's attorney who is addressing the worker's compensation case if it supports the presence of a disability.

Example 2

A young woman has come to the attention of the Disability Support Office at a local community college. She has been taking classes at the college for the past two semesters and has been struggling academically. Recently her business administration professor has taken an interest in her progress and suspects that perhaps she has a learning disorder. Her professor suggests she make an appointment with a counselor at the Disability Support Office. The counselor at the Disability Support Office interviews the young woman and discovers that she had been an honors student all the way through her junior year of high school. During the summer before her senior year she was the passenger in a car that was involved in an accident. She incurred a moderate brain injury and spent the majority of what would have been her senior year in rehabilitation. She made an excellent physical recovery; however she still reports trouble with her memory. She returned to school and, with the help of her parents, an outside tutor, and speech and occupational therapy, she completed high school and graduated a year late. She is no longer receiving therapy and expresses to the counselor that she had wanted to succeed in college "without any crutches". She acknowledges she may not achieve this goal and will need to seek help, but she is feeling sad about needing assistance.

Steps the disability support counselor can take to determine what residual deficits the student may still be experiencing

- Conduct the intake interview (see above).
- Ask the student to sign a release of information so the counselor can obtain the therapy and assessment records.
- Ask the student what were the strategies she had used in high school to help her learn the material.
- Ask the student if fatigue is an issue.
- Ask for permission to speak to the teachers of the courses she has taken so far at the community college.

If the response to the above indicates the continued interference of brain injury related difficulties on academic performance, the following are commonly used strategies and referral recommendations:

- Assure her that using strategies is not an indication of "failure" on her part but just they can be an insurance policy towards ensuring academic success.
- The use of a tape recorder to record lectures so the student does not have to continually divide (and drain) her attention between listening and note-taking.
- Customized use of a personal/academic organizer based on the data gathered. This can take the low-tech form of a calendar or date book, or utilize more technological devices such as a palm pilot, or laptop/personal computer.
- Advocacy for untimed tests.
- Strategic scheduling, scheduling classes to maximize periods of optimum alertness and/or allow for a daily rest period or nap.
- Cut back course load to one or two classes with the emphasis on mastering academic strategies before increasing the course load.
- Encouraging the use of resource and study labs.
- Identifying a Disability Support Staff person who will be the student's central point of contact.

- That central point of contact should get permission to have ongoing contact with any other service providers, e.g. any off campus tutors to ensure the interventions are consistent and continuous.
 - The Disability Support counselor can outline in a formal plan the recommended strategies suggested for academic success, and outline the responsibilities of both the student and the Disability Support Staff.
 - The plan can act as a central point of regular meetings between the student and the staff with these being updated each semester.
 - The student can be referred to the local Brain Injury Support Group.
 - If the student appears to be or admits to being depressed, the Disability Support Staff counselor should contact the state Brain Injury Association affiliate for names of psychotherapists and psychiatrists who have experience working with individuals with traumatic brain injury.
- Additional resources and suggestions for academic support can be obtained from: The George Washington University HEATH Resource Center

2121 K. St. NW
 Suite 220
 Washington D.C. 20037
 Voice/TTU: 202-973-0904
 Toll free: 1-800-544-3284
 Email: AskHeath@Heath.gwu.edu
 Website: www.gwu.edu

Example 3

An attorney has referred a 22-year old man to a local mental health services provider. According to the attorney, his client has recently been released from the local detention center after being held on an assault charge. According to the young man's mother, he incurred a traumatic brain injury in a car accident at the age of 9. He received rehabilitation at a local pediatric rehabilitation center, and returned to his elementary school after discharge. The accident has left him with a slight weakness on his left side and, due to learning difficulties caused by the accident, he was provided with special education services. The mother reports that his behavior was good before the accident and became problematic afterwards. The school psychologist diagnosed him with ADHD and a conduct disorder. He had been seen by a psychiatrist intermittently over the years and had taken a variety of medications that the mother could not accurately recall. He dropped out of high school in 11th grade and worked day labor jobs. She reports that he hangs out with a "bad crowd" and is easily influenced by others. She claims that he was with this crowd when he got into a fight in a bar, and was subsequently arrested. Because it was a first offense and the attorney argued his client's traumatic brain injury related mental health issues had been undertreated, he was released to his mother with the understanding he would seek treatment.

Steps the mental health counselor can take to document the presence of a traumatic brain injury

- Conduct the Traumatic Brain Injury Screening (in Appendix I).
- Interview (see Structured Interview above) the young man and his mother to determine

where and when he received any medical, rehabilitation and psychiatric treatment.

- Ask for a release to obtain the medical records from treating facilities.

If the results of the screening and recommended steps indicate there has been a brain injury, the following are some information and referral recommendations:

- Refer the young man to a neuropsychiatrist. A neuropsychiatrist is a medical doctor who specializes in the relationship between the brain and disturbances of mood, behavior and cognition. Treatment can involve the use of specific medications as well as behavior management, counseling, family education and support. A neuropsychiatrist has the abilities of both a neurologist and a psychiatrist and as a result can prescribe medicine most appropriate for someone who has psychiatric difficulties and an injury to the brain.
- Explore with the mother if an application has ever been made to the Developmental Disabilities Administration. Explain that this agency can provide services and supports over the lifetime of an individual who becomes disabled before the age of 22 and meets the Administration criteria.
- Suggest that the young man may be entitled to certain benefits because of his disability. Explore his eligibility for Supplemental Security Income (SSI) and Medicaid.
- Once the young man is behaviorally stabilized, recommend that he have an evaluation at a specialized brain injury rehabilitation program that specializes in serving individuals with traumatic brain injury.
- Explore with the family how the young man can reconnect with his peer group in a positive manner through recreation, social and volunteer opportunities. A referral to his local recreation department is a good first step.
- Consider a referral to the local state vocational rehabilitation office for vocational counseling and services.

Example 4

A fifty-eight year old woman has come to the attention of the local housing coalition. Her church referred her after she told her pastor that her apartment building where she had lived for 20 years was being converted to condos, and she has to move within three months. She has been successfully employed as a housekeeper at a local hospital for many years.

She incurred a traumatic brain injury when she was in her 20's. She received rehabilitation and then vocational services through the state vocational rehabilitation agency. It was her vocational rehabilitation counselor who placed her in her job at the hospital. Her job appears to be very routine in nature; she cleans the medical staff offices from 4:00 p.m. to midnight. She reports she receives good yearly reviews and loves her job. She fears she will never be able to afford the rent for a new apartment on the salary she receives. She tells the counselor assigned to her that she has no idea how to go about finding a new apartment. Friends have told her that she would qualify for subsidized housing because of her age and her disability. She feels overwhelmed, and doesn't know how to organize her "paperwork". She brings with her a variety of forms, including: a few pay stubs, her eviction notice, bills from a number of credit cards, several bank statements, her check book as well as newspaper real estate ads. Her paperwork is very unorganized, and her financial records incomplete. The counselor realizes after reviewing her financial situation that this individual is in severe debt. The counselor is concerned regarding the amount of money the individual sends to various charities, and also the amount of

purchases made on the home-shopping network.

Steps the housing counselor can take to determine what are the functional limitations imposed by this individual's brain injury that impact on her ability live successfully in the community

- Conduct the intake interview (see above).
- Obtain a release to receive medical records.
- Ask the individual how she organizes her finances and makes decisions regarding spending.

If the results of the screening and recommended steps indicate if there is evidence that the individual's brain injury is impacting negatively on her ability to function independently, the counselor can:

- Counsel the individual on how to set up a budget.
- Review her current bills and if necessary, contact her creditors to arrange for a payment plan.
- If necessary, seek documentation from the individual's physician attesting to her disability. This can, with the individual's permission, then be shared with her creditors by the counselor so they can better understand her circumstances. Provided with such evidence, creditors have been known to stop applying interest to the debt, or to forgive it wholly.
- If the documentation and the information shared with the counselor indicates the individual has injury-imposed judgment, organization and/or impulsivity issues, the counselor can work with the individual using various budgeting strategies. These can include: cutting down the number of credit cards she holds, coming to an agreement on how much and to whom she directs her charitable giving, and putting a hold on purchases made through the home shopping network.
- Encourage her to write down her expenses and spending.
- Suggest that if she really wants to purchase something other than a necessity, she should take a few days to think about it before she acts.
- Assist her in organizing her paperwork in labeled files.
- Given the documentation of a disability, begin to assist the individual in applying for any subsidized and or Section 8 Housing of which she may be eligible.
- Be aware that she may require assistance in correctly filing out any housing applications, and need the counselor to act as an advocate on her behalf to landlords and other housing authorities.
- Suggest she contact the local Centers for Independent Living for peer support and available community living resources.
- Throughout the process, provide the individual with concrete "homework" assignments with deadlines to help her stay focused and accomplish her goals in a organized and thorough manner.

Keep In Mind

Whenever a human service professional suspects that an individual, he or she is working with, has a history of traumatic brain injury with related cognitive, physical or psychosocial impairments, it is vital that a thorough review be made of any entitlements or benefits for which an individual maybe eligible.

- ✓ Is the individual eligible for SSI or SSDI?
- ✓ Has the individual applied for social security, been denied but never appealed the denial?
- ✓ Was the individual injured while under the age of 22? If so, has an application been made to the state Developmental Disability Administration
- ✓ If application has been made to DDA, what is the status? Has there been a service coordinator assigned to the case?
- ✓ Has a case been opened with the state vocational rehabilitation agency?
- ✓ Is the individual eligible for food stamps, temporary income benefits, pharmacy assistance, and/or do they qualify for paratransit services?
- ✓ Is there a pending worker's compensation case?
- ✓ Is there pending litigation regarding the circumstances of the individual's injury?

In Summary

This handbook is intended to be an overview and a starting point for professionals who are employed in a variety of human service programs and agencies. Because of the inconsistency in the provision of brain-injury related specific services in many states, individuals with TBI are served in a variety of settings. Often the presenting diagnosis does not account for a history of a brain injury and as a result services provided may not be as comprehensive as they need to be to support individuals in their home, community, academic and vocational endeavors. It is hoped that if the human service community better understands TBI and its consequences, individuals with TBI will be better served. It is recommended that the reading and dissemination of this handbook be augmented through staff in-services and trainings and attendance at local, regional and where feasible, national TBI conferences and workshops. Anyone interested in trainings, conferences and workshops can contact the Brain Injury Association of America and their state Brain Injury Association affiliate.

Appendix I

Brief Traumatic Brain Injury Screening

Name

Date

Date of Birth: _____

Sex: M F

**Interviewer's
Name**

For the Interviewer

You are trying to determine if a trauma or injury to the brain has possibly occurred. A positive response would be identified by a blow to the head, a fall, etc., which resulted in loss of consciousness. Be sure to ask about visible scars or marks. Greater than momentary loss of consciousness is felt to be a significant injury, although multiple mild injuries such as fights can also have additive effects over time without significant loss of consciousness. To get an indication of any history of a traumatic brain injury, ask the following questions:

1. Have you ever been injured following a blow to your head?

Yes

No

If yes, when was this? _____

2. Have you ever been hospitalized or treated in an emergency room following an injury?

Yes

No

If yes, when were you hospitalized or treated? _____

3. Have you ever been unconscious following an accident or injury?

Yes

No

If yes, for how long? _____

4. Have you ever been injured in a fight?

Yes

No

5. Have you ever been injured by a spouse or a family member?

Yes

No

6. Have you ever had any Major surgeries?

Yes

No

If yes, list them _____

Illnesses?

Yes

No

If yes, list them _____

Strokes?

Yes

No

Heart Attack?

Yes

No

Additional comments and observations of the interviewer

For the Interviewer:

If you suspect a brain injury is impacting on the individual's functioning at home, work or in the community, please refer them to a local brain injury professional or program. For information and referral information regarding brain injury resources, contact the Brain Injury Association of America at 703-761-0750 or www.biausa.org.

*Adapted from the TBI Screening by John Corrigan Ph.D and his colleagues at the Ohio Valley Center for Brain Injury Prevention and Rehabilitation www.ohiovalley.org. Product of The Maryland TBI Post Demonstration Project 2003

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Appendix II

Examen Abreviado de la Lesión de Trauma Cerebral (Traumatic Brain Injury TBI por su nombre en Inglés)

Nombre _____ **Fecha** _____

Edad _____ Pais de Origen _____

Sexo: M F

**Nombre del
Entrevistador** _____

Para el entrevistador

Su objetivo es tratar de determinar si la persona entrevistada ha sufrido de un trauma o lesión cerebral. Una respuesta positiva le ayudará a identificar una lesión o golpe sufrido en la cabeza ocasionado por caídas, etc..., y como resultado de estos golpes ha sufrido la pérdida del conocimiento. Asegúrese de preguntar si hay evidencia de cicatrices o marcas visibles. Una pérdida momentánea del conocimiento podrá ser considerada una lesión significativa, las peleas ocasionan múltiples lesiones leves, registrando signos de complicaciones a largo plazo sin que haya tenido necesariamente la pérdida del conocimiento. Mediante las siguientes preguntas usted podrá encontrar si hay antecedentes de un Trauma Cerebral.

1. Alguna vez ha sido usted lesionado después de un golpe en la cabeza?

Sí

No

Si es sí, cuando ocurrió? _____

2. Ha estado usted hospitalizado o ha recibido tratamiento en una sala de emergencia después de una lesión cerebral?

Sí

No

Si es sí, cuando fué hospitalizado o cuando recibió tratamiento? _____

3. Alguna vez ha estado usted inconsciente después de un accidente o lesión cerebral?

Sí

No

Si es sí, por cuanto tiempo? _____

4. Ha sido usted lesionado en la cabeza durante una pelea?

Sí

No

5. Alguna vez ha sido usted lesionado en su cabeza por su esposo(a) o algún otro miembro de su familia?

Sí

No

6. Ha sido usted sometido a una cirugía mayor?

Sí

No

Si es sí, menciónela(s) _____

Ha sufrido usted de alguna enfermedad?

Sí

No

Si es sí, menciónela(s) _____

Ha sufrido usted de un derrame cerebral?

Sí

No

Ha tenido usted un ataque cardiaco?

Sí

No

Comentarios adicionales y observaciones del entrevistador

Para el entrevistador:

Si usted sospecha que la Lesión del Trauma Cerebral está limitando las funciones del individuo en su casa, en el trabajo o en la comunidad, por favor llame a la Asociación Americana de Trauma Cerebral (Brain Injury Association of America), 703-761-0750, www.biausa.org.

*Este formato ha sido adaptado de la Prueba / Batería para la Lesión de Trauma Cerebral (Traumatic Brain Injury TBI por su nombre en Inglés) realizado por John Corrigan PhD y sus colegas del Centro para Trauma Cerebral / Prevención y Rehabilitación del Valle de Ohio. www.ohiovalley.org Product of Maryland TBI Post Demonstration Project 2003

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Appendix III

Guide to the Professionals who Provide Services to Individuals with Traumatic Brain Injuries

Neurologist: A medical doctor who specializes in disorders of the nervous system. The neurologist may be involved in diagnosis and treatment recommendations. Neurologists are often consulted in the treatment of seizure disorders and chronic headaches.

Physiatrist: A physician who is board certified in physical and rehabilitation medicine. They supervise an individual's short and long-term rehabilitation plans and prescribe the therapies and adaptive equipment that are needed to assure maximum functioning. May follow an individual many years post injury and can prescribe medications for mood, attention and motor functions.

Neuropsychiatrist: A medical doctor who specializes in the relationship between the brain and disturbances of mood, behavior and cognition. Treatment can involve the use of specific medications, as well as behavioral management, counseling, family education and support. A neuropsychiatrist has the abilities of both a neurologist and psychiatrist. For example, they are aware of what kind of medications will help with behavior management but will negatively impact on an individual's cognition. (e.g., make sleepy)

Neuropsychologist: A neuropsychologist is a psychologist with the expertise in the interrelationships between the brain and behavior. He or she administers a series of tests that evaluate an individual's attention, concentration, new learning capacity, the ability to recall information as well as assessment of personality functioning. The testing can take 3 to 4 hours and can be broken up into several sessions if necessary. The testing results should indicate the individual's cognitive strengths, deficits and what strategies may work for each individual. Some neuropsychologists just do testing, others will work with individuals to learn and implement strategies that will help them capitalize on their residual strengths and help them to compensate for any injury-imposed deficits.

Speech Therapist: Speech therapists are trained in the evaluation and treatment of deficits in attention, organization, sequencing, thinking, problem solving, judgment, memory, writing and talking. They can teach and help individuals implement compensatory strategies. It is important to note that speech therapists working with individuals with brain injuries can and do address the mechanics of speech, e.g., breath control, volume and pitch, but also play a big role in addressing cognitive and functional skills. They can make visits to the home, community and workplace to help design and implement strategies.

Occupational Therapist: Occupational therapists address skills of daily living to enhance independence to include those skills necessary to bathe, cook, and run a household. Occupational therapists address functional memory and problem-solving skills. Occupational therapists work to maintain flexibility of the arms and hands through exercise and custom made splints. They can make visits to the home, community and workplace to help individuals with the design and use of strategies to improve independence. Over the last few years, occupational therapists have been key in the

development and implementation of a new technique called *constraint induced therapy*. This technique is designed to assist those individuals who have lost motor movement in their hands and arms, due to stroke or traumatic brain injury, retrain essentially the motor pathways to encourage use of the affected limb. The unaffected or "good" limb is bound for often many hours a day and the individual is encouraged to use the affected limb in a variety of ways during functional tasks and exercises. Research has shown that with consistent use of this technique, some individuals experience an improvement in functioning of the affected limb. At this time the number of therapists certified in this technique is limited.

Physical Therapist: A physical therapist addresses motor skills, strength, range of motion and positioning. They facilitate the highest level of physical independence and make recommendations regarding the use and fit of assistive devices such as canes, walkers and wheelchairs. If an individual is returning to work after a brain injury, the physical therapist can make recommendations regarding physical tolerance and endurance and their capacity to lift, bend and carry.

Vocational Rehabilitation Counselor: This professional facilitates the assessment of an individual's ability and potential to work. The vocational rehabilitation counselor works with the individual, his/her family, therapists and employer to ensure a smooth transition into the workplace. He or she may provide job coaching. With job coaching, the individual is accompanied to the workplace to ensure they are implementing the memory, attention, and learning strategies and supports that will enable them to be productive, independent workers.

Therapeutic Recreation Specialist: The recreational professional evaluates leisure skills and interests. Activities such as games, arts and crafts, exercise, shopping, attending community events and using community resources can greatly enhance the quality of life for individuals following a traumatic brain injury.

Psychologist/Social Worker: These mental health professionals offer psychotherapy and counseling to individuals and their families to help them adjust and cope with the sequela of brain injury.

Appendix IV

Essentials of an In-House Traumatic Brain Injury Resource Library

The books and resources below are merely suggestions and starting points. There is a wealth of information available to anyone who is interested. A good library should have materials that are not only research and clinically based, but also include materials that put a human face on the personal experience of brain injury. A human service agency should also have available fact sheets and TBI educational materials geared towards non-professionals including those with low literacy levels. The library should provide appropriate and accessible information to its constituents.

Clinical Issues:

Books

Principles of Neuropsychological Rehabilitation, by George Prigatano, Ph.D. 1999.

Awareness of Deficit After Brain Injury: Clinical and Theoretical Issues, George Prigatano, editor 1991.

Staff Development and Clinical Intervention in Brain Injury Rehabilitation, Charles J. Durgin, Nancy D. Schmidt, and L. Jeanne Fryer, editors 1993.

The University of Alabama Traumatic Brain Injury Model System has created the UAB Home Stimulation Program. This free program offers many activities for use by individuals with brain injuries, their families and the professionals who work with them. The activities are designed to help support cognitive skills and can be done in the home setting. The Home Stimulation Program can be accessed from the Internet at <http://main.uab.edu/show.asp?durki=49377>. For further information contact: Research Services, Dept. of Physical Medicine and Rehabilitation, University of Alabama at Birmingham, 619 19th St. S SRC 529, Birmingham, AL 35249-7330/ 206-934-3283. Tbi@uab.edu.

Journals

Agencies or professionals interested in pursuing more in-depth research regarding the field of brain injury rehabilitation and treatment is directed to the National Library of Medicine's PubMed website at www.ncbi.nlm.gov. Abstracts of recent and past journal articles can be obtained free of charge.

Personal Stories:

First Person Accounts of Life after Traumatic Brain Injury

I am the Central Park Jogger: A Story of Hope and Possibility by Trisha Meili, 2003.

Over My Head: A Doctor's Own Story of Head Injury from the Inside Looking Out by Claudia L. Osborn, 2000.

I'll Carry the Fork, recovering from brain injury by Kara L. Swanson, 1999.

From a Spouses' Perspective

Where is the Mango Princess? A Journey Back from Brain Injury by Cathy Crimmins, 2000.

Fictionalized Telling of Life from the Perspective of a Severely Disabled Brain Injured Man

Every Good Boy Does Fine: A Novel by Tim Laskowski, 2003.

Brain Injury Related Pamphlets, Fact Sheets and Resources

There are many brain injury awareness, education and prevention, and resource materials available at either low cost or for free via the Internet and advocacy groups. To obtain these materials contact:

The Brain Injury Association of America (BIAA)

www.biausa.org

1-800-444-6443

The location and contact information regarding your state Brain Injury Association Affiliate can be accessed via the BIAA website. Your state affiliate should be able to provide you with free or low cost educational materials appropriate for the clients your agency serves and their families. Many state affiliates have created directories of local and state resources and programs for individuals with TBI. Such directories can be an invaluable tool when searching for appropriate supports and services. The BIAA website also has links to other sites such as the Model TBI System Demonstration Projects, and the Rehabilitation Research and Training Centers on Brain Injury. These organizations and projects publish various informational and resource materials that can be included in a TBI resource library.

National Association of State Head Injury Administrators

www.nashia.org

301-656-3500

The National Association of State Head Injury Administrators has published a number of TBI fact sheets on a variety of topics. They can be downloaded free of charge from the website.

The Mayo Clinic

www.mayo.edu

507-255-5109

The Mayo Clinic houses one of the TBI Model Systems programs and their TBI guides for families and employer are very informative. These guides can be obtained by calling the above number or they can be downloaded free of charge from the Mayo website. (above)

Lash and Associates Publishing/Training

www.lapublishing.com.

Information and referral regarding brain injury in children and adults.

Appendix V

Opportunities for Staff Training Regarding Brain Injury

- Most BIA affiliates hold educational conferences for professionals, individuals with brain injuries and their families. Contact your local BIA affiliate regarding continuing education opportunities.
- Interested staff members can pursue certification by the American Academy for the Certification of Brain Injury Specialists. The certification program provides recognition of knowledge and studies in brain injury. For those interested in pursuing the course of study and taking the certification exam, contact the Brain Injury Association of America.
- As of April 2004, the Defense and Veterans Brain Injury Center at Walter Reed Army Medical Center is offering an online learning course on traumatic brain injury through the Veterans Health Initiative. For more information contact: http://www1.va.gov/vhi/docs/TBIfinal_www.pdf.

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