

NEBRASKA BRAIN INJURY ADVISORY COUNCIL

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Traumatic  
Brain Injury  
Provider Training  
Manual

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ADAPTED WITH PERMISSION FROM THE BIA OF MICHIGAN BY

## Nebraska Brain Injury Advisory Council

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# Welcome

More than 6.5 million Americans live with a disability as a result of a traumatic brain injury (TBI). Many of these individuals and their families are confronted with inadequate or unavailable TBI services and supports. Passage of the Traumatic Brain Injury Act of 1996 (PL 104-166) signaled a national recognition of the need to improve state TBI service systems. The Act authorized the Health Resources and Services Administration to award grants to states for the purpose of planning and implementing needed health and related service systems change. The Act was reauthorized in 2008 (PL 111-36) and most recently in 2014 (PL 113-196), demonstrating the continued need to address state systems and service gaps for individuals with TBI. In 2016 the federal TBI grant program was transferred to the Administration for Community Living (ACL) which is a part of the U.S. Department of Health and Human Services.

This training manual is intended to assist agency and service provider staff in meeting the needs of people with brain injury. It contains resource materials and hands-on tools to equip staff to better serve individuals with brain injuries and their families. It is hoped that this manual will serve as a resource.

This training was originally developed by the Brain Injury Association of Michigan as a project of the Michigan Department of Community Health's Traumatic Brain Injury Implementation Grant, a funded project of the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB). It has been adapted with permission by the Nebraska Brain Injury Advisory Council and Nebraska VR, an office of the Nebraska Department of Education. We are grateful to the Brain Injury Association of Michigan for their time and talents in developing this training and for their generosity in allowing us to adapt it for use in Nebraska.

# Training Materials

It is important to note that nearly all the materials in this training manual were taken directly from other sources, with the authors' permission. These sources were originally written for other works and for a variety of audiences. Applicable materials are cited as resources throughout this manual. The following are the major sources for the material contained within this document:

Black, K, Caregiver College Presentation. Michigan: Detroit Medical Center, Rehabilitation Institute of Michigan, 1998

Beckwith, B, Dimambro, L. TBI Basics. Brain Injury Association of Michigan Annual Conference, 1996-2002.

Brain Injury Association of America. 2003. <http://www.biausa.org/brain-injury>

Brain Injury Association of Michigan, Traumatic Brain Injury Manual – What You Need to Know. Michigan: Brain Injury Association of Michigan, 1996

Braunling-McMorrow D, Davie, C, Ferriera-Bedford, T, et al. Acquired Brain Injury Programs, Preservice Materials Manual. Illinois: Mentor, 2000.

Braunling-McMorrow D, Niemann GW, and Savage RC (eds.), Training Manual for Certified Brain Injury Specialists (CBIS) Level 1. Texas: HDI Publishers, 1998.

Corrigan JD, Relationship between Traumatic Brain Injury and Substance Abuse. Ohio Valley Center, 2003.  
<http://ohiovalley.org/informationeducation/materials/programmer/recovery/>

Rehabilitation of Persons with Traumatic Brain Injury. Consequences of Traumatic Brain Injury, NIH Report of the Consensus Development Panel. 1998 Oct 26-28: 1-3.

Ruff RM, Marshall LF, Klauber MR, Blunt BA, Grant I, Foulkes MA, et al. Alcohol Abuse and Neurological Outcome of the Severely Head Injured, *Journal of Head Trauma Rehabilitation*, 1990; 5:21-31.

# Introduction to Brain Injury

## Brain Injury Definitions

A **brain injury** is any injury that results in brain cell death and loss of function.

**Traumatic Brain Injury** (TBI) is caused by an external trauma to the head or violent movement of the head, such as from a fall, car crash or being shaken. TBI may or may not be combined with loss of consciousness, an open wound or skull fracture.<sup>1</sup>

**Acquired Brain Injury** (ABI) is an injury to the brain that has occurred after birth and includes: TBI, stroke, near suffocation, infections in the brain, etc. (Brain Injury Association of America, 1997)

## Significance of Brain Injury

According to the Centers for Disease Control and Prevention:

- 2.8 million Americans sustain a traumatic brain injury every year<sup>2</sup>.
- Each year, 80,000 Americans experience the onset of long-term disability following TBI<sup>2</sup>.
- Nearly 50,000 people die every year as a result of TBI<sup>2</sup>.
- 6.5 million Americans (2% of the U.S. population) currently live with disabilities resulting from a brain injury<sup>2</sup>.
- After one brain injury, the risk for a second is three times greater; after the second injury, the risk for a third injury is eight times greater<sup>3</sup>.

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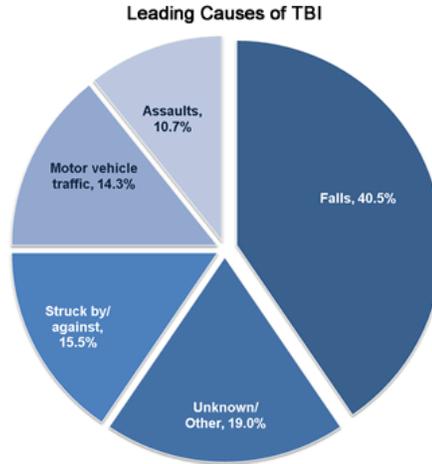
<sup>1</sup> Thurman D.J., Sniezek J.E., Johnson D., Greenspan A, Smith S.M. (1994). Guidelines for Surveillance of Central Nervous System Injury. Centers for Disease Control and Prevention.

<sup>2</sup> Centers for Disease Control and Prevention – TBI & Concussion - [https://www.cdc.gov/traumaticbraininjury/get\\_the\\_facts.html](https://www.cdc.gov/traumaticbraininjury/get_the_facts.html)

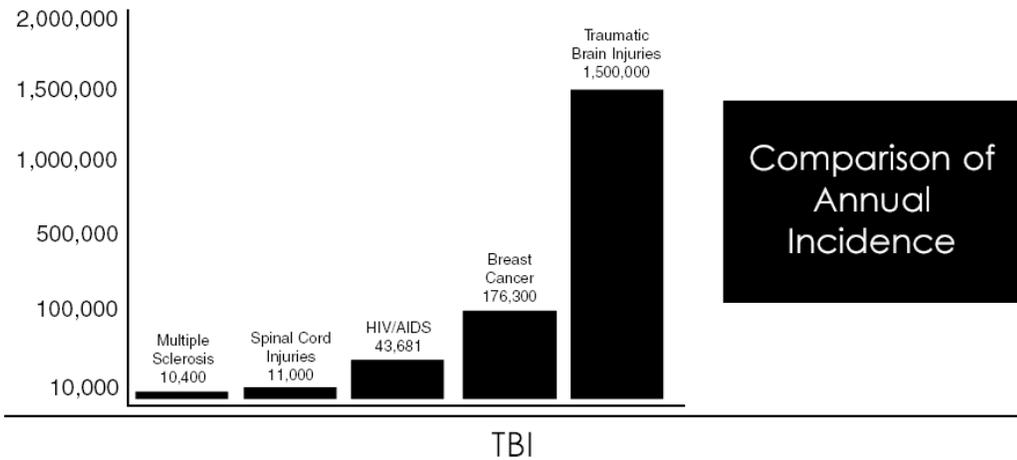
- The risk of TBI is highest among the elderly, adolescents and young adults.<sup>4</sup>
- Males are twice as likely to sustain a brain injury than females.<sup>4</sup>

**Percentage of TBI Causes**

2006-2010: Falls were the leading cause of traumatic brain injury, accounting for 40% of all TBIs in the United States that resulted in an ED visit, hospitalization, or death.



**A Comparison of Traumatic Brain Injury and Leading Injuries or Diseases**



<sup>3</sup> Annegers JF, Garbow JD, Kurtland LT, et al. The Incidence, Causes and Secular Trends of Head Trauma in Olmstead County, Minnesota 1935-1974. Neurology, 1980; 30:912-919

<sup>4</sup> Analysis by the CDC National Center for Injury Prevention and Disease Control, using data obtained from state health departments in Alaska, Arizona, California, Colorado, Louisiana, Maryland, Missouri, New York, Oklahoma, Rhode Island, South Carolina and Utah

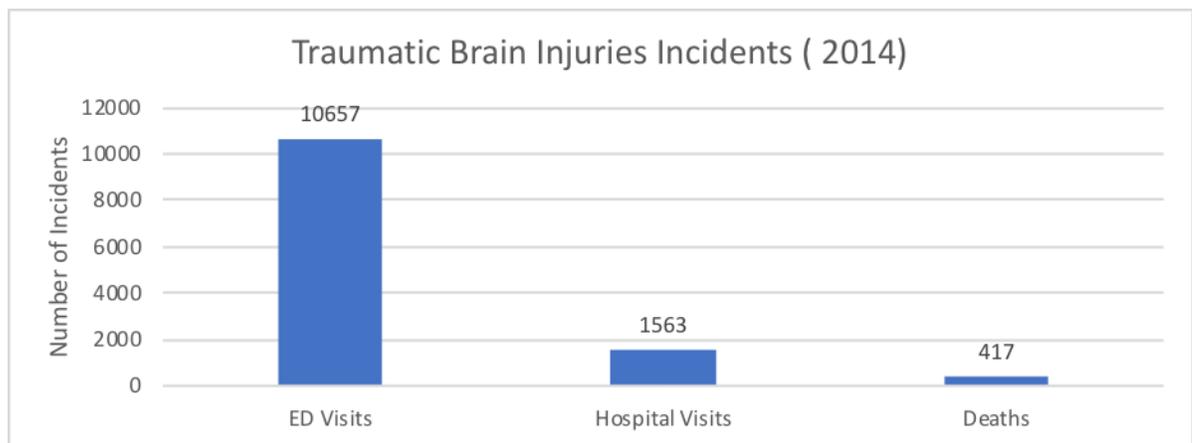
## Traumatic Brain Injuries in Nebraska

Data on the incidence of long-term TBI-related disability is limited, however based on the 2001 CDC estimate that 2% of the US population is currently living with a disability resulting from TBI, it is likely that more than 38,000 Nebraskans are living with permanent physical, cognitive, emotional and/or behavioral challenges due to TBI.<sup>5</sup>

During 2014, a TBI was sustained by 12,637 people in Nebraska. Among those injured:

- 417 died where TBI was reported as a cause of death on the death certificate alone or in combination with other injuries or conditions,
- 1,563 were hospitalized with a TBI alone or in combination with other injuries or conditions, and
- 10,657 were treated and released from emergency departments with a TBI alone or in combination with other injuries or conditions.<sup>6</sup>

An unreported number of individuals also sustained injuries that were treated in other settings or went untreated.



## Age Breakdown and Incidence

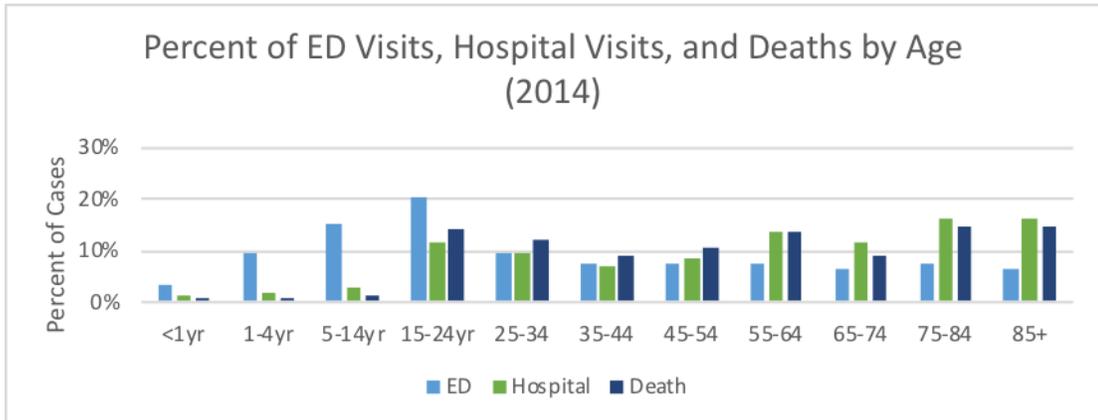
In Nebraska, the age makeup of TBI-related emergency department visits consists of a younger demographic when compared to hospital visits and death for 2014. Persons aged 0-14 years made the most TBI-related emergency department visits. The highest number of TBI-related deaths were among persons aged 65 and over.<sup>7</sup>

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<sup>5</sup> Calculations based on CDC estimates that 2% of the US population is currently living with a disability resulting from a TBI.

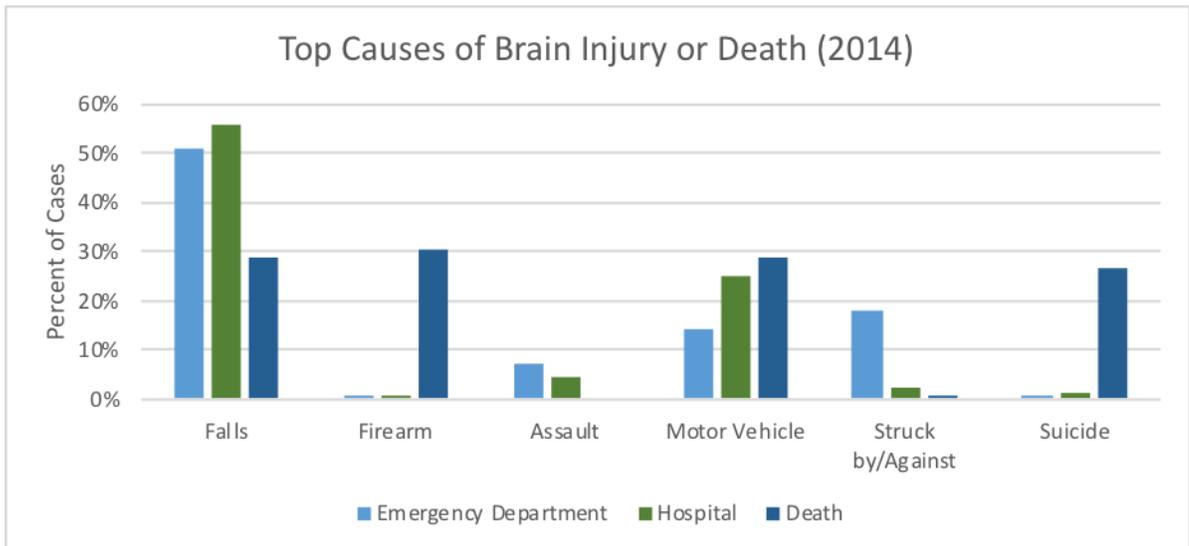
<sup>6</sup> Nebraska TBI Registry and Nebraska Vital Statistics

<sup>7</sup> Nebraska Hospital Discharge – E Code



### Causes of TBI

In 2014, unintentional falls remained the leading cause of injury among those treated and released from an emergency department or hospital in Nebraska. Firearm-related TBIs resulted in the highest number of deaths due to TBI during that year.<sup>8</sup>



<sup>8</sup> Nebraska Hospital Discharge – E Code

In 2010, a statewide Needs and Resources Assessment was conducted to survey individuals with brain injury and their families regarding their ongoing challenges, barriers and service needs.<sup>9</sup>

Significant barriers noted by individuals with TBI, their families and service providers:

- Awareness and advocacy
- Funding sources - financial resources
- Knowledge of services and resources
- Case management/resource facilitation
- Training for service professionals (primary care, therapists)
- Education at all levels: community, service provider staff, families and caregivers
- Geographic barriers - transportation
- Early intervention<sup>9</sup>

Most important needs noted by individuals with TBI and their families:

- Cognitive training
- Sources of funding
- Primary medical care
- Physical therapy
- Counseling (individual and family)
- Information resources
- Occupational therapy<sup>9</sup>

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<sup>9</sup> 2010 Nebraska Traumatic Brain Injury Needs and Resources Assessment

## The Cost of Traumatic Brain Injury:

Based on estimates provided by the WISQARS Cost of Injury Reports application, there is a total cost estimate of over \$800 million associated with TBIs sustained in 2013 in Nebraska. **It is important to note that these costs were not all accrued in 2013.** Over \$600 million of the total estimated cost is associated with work loss, the vast majority which extends into the distant future. In addition, a considerable amount of the over \$200 million in medical costs associated with TBI will be accrued over subsequent years. At the same time, TBIs sustained in the near and distant past continue to have a significant economic impact. (Source: The Cost of Traumatic Brain Injury in Nebraska in 2013)

## Brain Injury Severity

A standardized scale is used to evaluate the degree of impairment and to identify the seriousness of injury in relation to outcome. The Glasgow Coma Scale involves three determinants: eye opening, verbal responses and motor responses. Brain injury may be mild (such as from a concussion), moderate or severe. *See Appendix for Glasgow Coma Scale and Rancho Los Amigos Scale.*

**It is important to note that the severity is determined at the time of injury and does not always predict long-term outcomes**

### Mild

Mild brain injury is also known as a concussion. It can be medically defined as any period of loss of consciousness; any loss of memory for events immediately before or after the accident; any alteration in the mental state at the time of the accident (e.g., feeling dazed, disoriented or confused). It generally does not include posttraumatic amnesia greater than 24 hours<sup>10</sup>. Many people do not seek medical assistance because, at the time, they do not believe the injury is severe. Symptoms may not appear until later. “Post concussive syndrome” can include temporary headaches, dizziness, mild mental slowing and fatigue. Symptoms of mild brain injury usually improve over 1-3 months.

**75% of all  
brain injuries  
are mild**

### Moderate

A moderate brain injury is one that can be medically defined as a loss of consciousness can last minutes or a few hours and is followed by a few days or weeks of confusion. Persons with moderate TBI may have a longer period of impaired consciousness, more impaired verbal memory shortly after the injury and a lower likelihood of achieving a good recovery within 6 months<sup>11</sup>.

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<sup>10</sup> Rehabilitation of Persons with Traumatic Brain Injury. Consequences of Traumatic Brain Injury, NIH Report of the Consensus Development Panel. 1998 Oct 26-28: 1-3.

<sup>11</sup> Rehabilitation of Persons with Traumatic Brain Injury. Consequences of Traumatic Brain Injury, NIH Report of the Consensus Development Panel. 1998 Oct 26-28: 1-3.

## Severe

Severe brain injury is medically defined by a loss of consciousness, or coma, for 6 hours or longer, either immediately after the injury or after an intervening period of clarity. Individuals who suffer a severe TBI are at risk for long-term disability. Their behavior can be inhibited, and at times they may disregard social conventions. Some have difficulty remaining employed, maintaining pre-injury relationships and establishing new social contacts<sup>11</sup>.

## Brain Injury Events<sup>12</sup>

### Primary Event

Destructive events that occur during the initial phase of injury (i.e., contusion, hemorrhaging, shear injuries)

The skull is hard and inflexible. The brain is rather soft, like firm jello. When the skull makes a rapid movement, it moves as a solid object. The brain, encased inside of the skull, moves at a different rate than the skull because it is soft. Also, different parts of the brain move at different speeds because of their relative lightness or heaviness. The differential movement of the skull and brain when the head is struck results in direct brain injury from two main causes: **axonal shearing** and **contusion (bruising)**.

#### Axonal Shearing

When the brain is slammed back and forth inside the skull after a head trauma, it is alternatively compressed and stretched because of its soft, jello-like structure. The long, fragile axons of the neurons that make up the brain are also compressed and stretched. If the impact is severe enough, axons can be stretched until they are torn. This is called axonal shearing. When this happens, the neuron dies. This is a major cause of brain damage after a traumatic brain injury and cannot be directly treated at this time.

#### Contusion

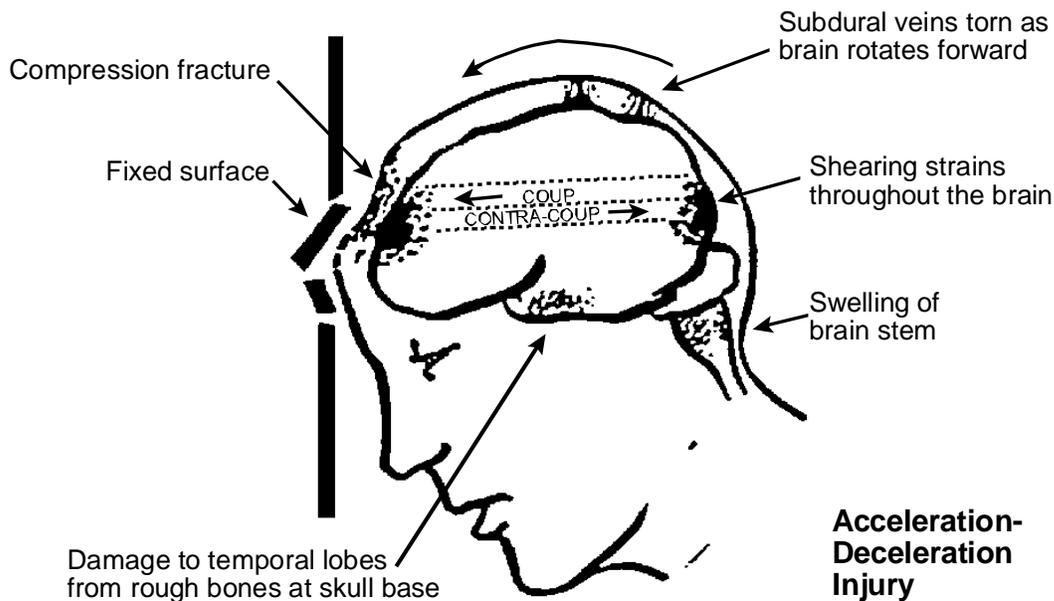
The brain's violent slamming against the bones of the skull can also result in contusion, bruising and bleeding from the impact. This results from tearing of small blood vessels. It can result in the death of neurons and is the second leading cause of neuron death after a traumatic brain injury. Small contusions are usually not treated (concussion) if blood flow is interrupted.

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<sup>11</sup> Rehabilitation of Persons with Traumatic Brain Injury. Consequences of Traumatic Brain Injury, NIH Report of the Consensus Development Panel. 1998 Oct 26-28: 1-3.

<sup>12</sup> Material on pages 6-10 were taken, with permission, from: Braunling-McMorrow D, Niemann GW, and Savage RC(eds.), Training Manual for Certified Brain Injury Specialists (CBIS) Level 1. Texas: HDI Publishers, 1998.

## Types of Damage in Closed Head Injury



### Coup-Contracoup

After a traumatic brain injury, contusion can occur anywhere in the brain. Often, most of the contusions will be on the underside of the frontal and temporal lobes because of the irregular and rough texture of the bones underlying these parts of the brain. In addition, specific sites of bruising and contusion can occur at the site of the blow to the head (“coup”) and the site directly opposite to where the blow was struck on the head (“contracoup”).

### Skull Fracture

Bones of the skull are broken or cracked. Injury severity can range from simple, undisplaced fractures to compound fractures which involve loose bone fragments placing pressure or penetrating injury to the brain.

Damage to the brain may occur at the time of impact or may develop sometime after the injury (due to swelling or bleeding). When the head is hit with sufficient force, the brain turns and twists on its axis (the brainstem) causing a loss of consciousness. If the injury is severe the area of the brain where the impact occurred may be bruised and damaged. It is because of this twisting and rebounding that people with traumatic brain injury usually receive damage to multiple parts of their brain.

If the person remains unconscious for more than a brief period of time he is considered to be in a coma. When in a coma the person is unable to open his eyes, speak or follow commands.

## **Secondary Event**

Additional insult occurring within the first hours or days post-injury (i.e., squeeze from increasing intracranial pressure, glutamate/nitric oxide cytotoxic effects) can include:

### Brain Swelling (Cerebral Edema)

The brain also swells after a severe trauma, just like any other part of the body. This is also a major cause of damage after brain injury. Very severe swelling can cause death by compressing the brain stem. Brain swelling can lead to neuron damage by squeezing the cells or from anoxia caused by disrupting the flow of blood and oxygen to the brain.

### Hematomas

If the blood vessels damaged by the impact inside the skull are large enough, they may bleed enough to create a pool of blood or **hematoma**. A hematoma can cause brain injury by directly damaging the neurons it comes in contact with or by squeezing neurons through increased pressure in the brain due to its volume. The treatment for a hematoma is to surgically drain it, if possible.

### Increased Intracranial Pressure

Intracranial pressure occurs because of a buildup of pressure within the skull. Because the brain, membranes and cerebrospinal fluid are encased with the bones of the skull, the fluid formed as a result of swelling or bleeding “backstop” in the brain causing increased pressure inside the brain which results in further damage to brain tissue.

### Hypovolemic Shock

After injury, loss of blood volume further compromises healthy brain tissue.

### Anoxia

As previously mentioned, anoxia is a lack of oxygen to the brain and subsequent further damage to brain cells.

## Tertiary Event

Late stage events may arise weeks or months post-injury (i.e., seizures, hydrocephalus).

### Seizure Disorders

A secondary effect of brain injury can be a **seizure disorder** caused by a specific injury that leads to a disruption in electrical activity of the brain. Seizure disorders can occur at any point after a brain injury (immediately, soon or much later). Seizures are usually treated with anticonvulsant drugs.

### Hydrocephalus

The flow of cerebrospinal fluid in the ventricles of the brain can sometimes be blocked or disrupted after a brain injury. When this happens, the fluid constantly being made in the ventricles can accumulate in the brain, causing increased pressure. This problem is called **hydrocephalus**, and it can be a serious secondary effect of a brain injury. Hydrocephalus can be treated by inserting a needle valve into the ventricles to draw off the fluid down a tube into the abdominal cavity. This procedure, called a **ventriculo peritoneal shunt**, reduces pressure inside the brain.

## Substance Abuse and Brain Injuries

### Relationship between Traumatic Brain Injury and Substance Abuse<sup>13</sup>

Substance abuse is more prevalent among persons with disabilities than society in general;<sup>14 15 16</sup> yet, research and treatment specific to this segment of the population has been minimal.<sup>17</sup> Among disability groups with unique issues of substance abuse are those individuals who have experienced traumatic brain injury. There has always been acknowledgment of the relationship between intoxication and injury,<sup>18 19</sup> but only more

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<sup>13</sup> Material on pages 10-12 were taken, with permission, from: Corrigan JD, Relationship between Traumatic Brain Injury and Substance Abuse. Ohio Valley Center, 2003. <http://www.ohiovalley.org/abuse>

<sup>14</sup> Moore, D. and L. Polsgrove (1991). "Disabilities, developmental handicaps, and substance misuse: A review." *International Journal of Addictions* 26(1): 65-90.

<sup>15</sup> Moore, D. and L. Li (1994). "Substance abuse among applicants for vocational rehabilitation services." *Journal of Rehabilitation* 60(4): 48-53.

<sup>16</sup> Center for Substance Abuse Treatment (1998). *Substance use disorder treatment for people with physical and cognitive disabilities. Treatment Improvement Protocol (TIP) Series*. Washington, DC, U.S. Government Printing Office. Number 29.

<sup>17</sup> National Association on Alcohol Drugs and Disability (1998). *Access Limited--Substance Abuse Services for People with Disabilities: A National Perspective*. San Mateo, CA, NAADD.

<sup>18</sup> Jernigan, D. H. (1991). "Alcohol and head trauma: Strategies for prevention." *Journal of Head Trauma Rehabilitation* 6(2): 48-59.

<sup>19</sup> Corrigan, J. D. (1995). "Substance abuse as a mediating factor in outcome from traumatic brain injury." *Archives of Physical Medicine and Rehabilitation* 76(4): 302-9.

recently has attention been given to the mediating effects of substance abuse on rehabilitation outcomes following traumatic brain injury.<sup>20-21</sup> Clinicians and researchers have repeatedly observed that cognitive and emotional impairments caused by brain injury present unique problems when addressing co-existing substance abuse problems.<sup>22-23</sup>

There is growing evidence that persons with traumatic brain injury and substance abuse problems have significantly worse problems than persons with traumatic brain injury alone. Among patients with the most severe brain injuries, alcohol or other drug consumption declines in the immediate post-injury period; however, people tend to return to pre-injury levels of use by two years post-injury.<sup>18-24-25</sup> Approximately 20% of persons who abstained or were light drinkers pre-injury, become high volume users after.<sup>22</sup> Persons with traumatic brain injury and substance abuse problems are less likely to be working<sup>26-27-28</sup>, and have lower life satisfaction<sup>26</sup>.

Persons with traumatic brain injuries face several challenges when seeking treatment from substance abuse providers<sup>21</sup>.

- Cognitive impairments may affect a person's learning style, making participation in didactic training and group interventions more difficult.
- Misinterpretation of memory problems as resistance to treatment can undermine a treatment relationship.

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<sup>20</sup> Kreutzer, J., A. Witol, et al. (1996). "Alcohol and drug use among young persons with traumatic brain injury." *Journal of Learning Disabilities* 29(6): 643-51.

<sup>21</sup> Corrigan, J. D., J. A. Bogner, et al. (1999). *Substance abuse and brain injury. Rehabilitation of the adult and child with traumatic brain injury.* M. Rosenthal, E. R. Griffith, J. D. Miller and J. Kreutzer. Philadelphia, PA, F.A. Davis Co. 3rd Edition.

<sup>22</sup> Langley, M. J. (1991). *Preventing post-injury alcohol-related problems: A behavioral approach.* Work Worth Doing: Advances in Brain Injury Rehabilitation. B. T. McMahon and L. R. Shaw. Orlando, FL, Paul M Deutsch Press, Inc.

<sup>23</sup> Center for Substance Abuse Treatment (1998). *Substance use disorder treatment for people with physical and cognitive disabilities.* Treatment Improvement Protocol (TIP) Series. Washington, DC, U.S. Government Printing Office. Number 29.

<sup>24</sup> Corrigan, J. D., E. Rust, et al. (1995). "The nature and extent of substance abuse problems among persons with traumatic brain injuries." *Journal of Head Trauma Rehabilitation* 10(3): 29-45.

<sup>25</sup> Corrigan, J. D., K. Smith-Knapp, et al. (1998). "Outcomes in the first 5 years after traumatic brain injury." *Archives of Physical Medicine and Rehabilitation* 79(3): 298-305.

<sup>26</sup> Sander, A. M., J. S. Kreutzer, et al. (1996). "A multicenter longitudinal investigation of return to work and community integration following traumatic brain injury." *Journal of Head Trauma Rehabilitation* 11: 70-84.

<sup>27</sup> Bogner, J. A., J. D. Corrigan, et al. (1997). "Integrating substance abuse treatment and vocational rehabilitation following traumatic brain injury." *Journal of Head Trauma Rehabilitation* 12(5): 57-71.

<sup>28</sup> Corrigan, J. D., J. A. Bogner, et al. (1997). "Systematic bias in outcome studies of persons with traumatic brain injury." *Archives of Physical Medicine and Rehabilitation* 78(2): 132-7.

- Damage to the frontal lobes affects executive thinking skills and promotes socially inappropriate behavior.
- Environmental cues may not be perceived, creating consternation for fellow clients and staff.

It is easy to interpret these behaviors as intentionally disruptive, particularly when the individual with a brain injury shows no visible signs of disability<sup>29</sup>.

### **Suggestions for Substance Abuse Treatment Providers Working with Persons Who Have Limitations in Cognitive Abilities<sup>30</sup>**

The substance abuse provider should determine a person's unique communication and learning styles.

- Ask how well the person reads and writes; or evaluate via samples.
- Evaluate whether the individual is able to comprehend both written and spoken language.
- If someone is not able to speak (or speak easily), inquire as to alternate methods of expression (e.g., writing or gestures).
- Both ask about and observe a person's attention span; be attuned to whether attention seems to change in busy versus quiet environments.
- Both ask about and observe a person's capacity for new learning; inquire as to strengths and weaknesses or seek consultation to determine optimum approaches.

The substance abuse provider should assist the individual to compensate for a unique learning style.

- Modify written material to make it concise and to the point.
- Paraphrase concepts, use concrete examples, incorporate visual aids, or otherwise present an idea in more than one way.
- If it helps, allow the individual to take notes or at least write down key points for later review and recall.
- Encourage the use of a calendar or planner; if the treatment program includes a daily schedule, make sure a "pocket version" is kept for easy reference.
- Make sure homework assignments are written down.
- After group sessions, meet individually to review main points.

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<sup>29</sup> Center for Substance Abuse Treatment (1998). Substance Use Disorder Treatment for People With Physical and Cognitive Disabilities. Treatment Improvement Protocol (TIP) Series. Washington, DC, U.S. Government Printing Office. Number 29.

<sup>30</sup> Material on pages 12-13 were taken, with permission, from: Corrigan JD, Suggestions for Substance Abuse Treatment Providers Working with Persons Who Have Limitations in Cognitive Abilities. Ohio Valley Center, 2003. <http://www.ohiovalley.org/abuse>

- Provide assistance with homework or worksheets; allow more time and take into account reading or writing abilities.
- Enlist family, friends or other service providers to reinforce goals.
- Do not take for granted that something learned in one situation will be generalized to another.
- Repeat, review, rehearse, repeat, review, rehearse.

The substance abuse provider should provide direct feedback regarding inappropriate behaviors.

- Let a person know a behavior is inappropriate; do not assume the individual knows and is choosing to do so anyway.
- Provide straightforward feedback about when and where behaviors are appropriate.
- Redirect tangential or excessive speech, including a predetermined method of signals for use in groups.

The substance abuse provider should be cautious when making inferences about motivation based on observed behaviors.

- Do not presume that non-compliance arises from lack of motivation or resistance, check it out.
- Be aware that unawareness of deficits can arise as a result of specific damage to the brain and may not always be due to denial.
- Confrontation shuts down thinking and elicits rigidity; roll with resistance.
- Do not just discharge for non-compliance; follow-up and find out why someone has no-showed or otherwise not followed through.

Related articles:

Kolakowsky-Hayner, S. and J. S. Kreutzer (2001). "Pre-injury crime, substance abuse, and neurobehavioral functioning after traumatic brain injury." *Brain Injury* 15(1): 53-63.

Kreutzer, J. S., J. H. Marwitz, et al. (1995). "Interrelationships between crime, substance abuse, and aggressive behaviors among persons with traumatic brain injury." *Brain Injury* 9(8): 757-68.

Kreutzer, J. S., P. H. Wehman, et al. (1991). "Substance abuse and crime patterns among persons with traumatic brain injury referred for supported employment." *Brain Injury* 5(2): 177-87.

# Brain Injury Consequences and Interaction Strategies

## The Brain and How it Works

The brain is a soft gelatin-like organ that weighs approximately 3 pounds in an adult, about the size of a grapefruit. It is protected by a rough and bony thick layer of bone (the skull) and is surrounded by cerebrospinal fluid, which allows the brain to “float” slightly within the skull. This fluid also fills the open areas within the brain (the ventricles). It is the control board for all of the body’s functions, including thinking, moving and breathing. It receives messages, interprets them and then responds to them by enabling the person to speak, move or show emotion. The brain is comprised of the **cerebrum**, where most thinking functions occur; the **cerebellum**, which coordinates movement; and the **brain stem**, which controls consciousness, alertness and basic bodily functions. See functional domain of the brain diagram on page 16.



### Cerebrum<sup>31</sup>

The cerebrum is the largest part of the brain and is divided into the left and right hemispheres. The left hemisphere generally controls movement and receives messages from the right side of the body and the right hemisphere controls movement and receives messages from the left. The dominant hemisphere (usually the left hemisphere) controls verbal functions (speaking, comprehension, writing, reading, calculating), while the right hemisphere generally controls functions that are more abstract in nature (creativity, visual memory, copying, drawing, musical skills).

The cerebral hemispheres are divided into four “lobes” (frontal, temporal, parietal and occipital), each of which specializes in particular functions and skills.

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<sup>31</sup> Material on pages 14-18 were taken, with permission, from: Braunling-McMorrow D, Niemann GW, and Savage RC (eds.), Training Manual for Certified Brain Injury Specialists (CBIS) Level 1. Texas: HDI Publishers, 1998.

### Frontal lobe

The frontal lobe is located in the front of the brain. It is the largest and most evolved of the lobes. The frontal lobe provides “executive” control over much of the brain’s higher functions. The frontal lobe is concerned with the **output** of behavior and contains the neurons connected to the brain stem and spinal cord that control voluntary movement. The **right frontal lobe** controls movements of the left side of the body and the **left frontal lobe** controls movements of the right side of the body. The frontal lobe plans, initiates and controls all purposeful actions.

Through complex connections to all parts of the brain, the frontal lobes are also involved in controlling attention and concentration, abstract and complex thinking, decision-making, mental flexibility, higher judgment and reasoning, and emotional responses. The left frontal lobe also contains an area called **Broca’s area**, which is responsible for producing speech and language output, such as speaking and writing.

When a frontal lobe is injured, weakness (**hemiparesis**) and even total paralysis (**hemiplegia**) can result on the side of the body opposite to that lobe. Injury to the frontal lobes often results in distractibility, difficulty concentrating, inflexible thinking, simplistic or “concrete” thinking, the inability to plan or think ahead, poor judgment and inappropriate emotional behavior.

### Temporal lobe

The temporal lobe is a large, thumb-shaped extension of the cerebral hemispheres located near the temples of the head. In both cerebral hemispheres, the top of the temporal lobe has a small area about the size of a poker chip that is responsible for hearing (the **auditory cortex**). The temporal lobe is also involved in perception and memory.

The two temporal lobes perform different functions. The **left temporal lobe** is primarily specialized in the comprehension of languages, including listening, reading and verbal memory. The **right temporal lobe** is primarily specialized in comprehending music and memory for visual information.

The specific type of disability produced by injury will depend on whether a person is right or left-handed and requires careful evaluation.

### Parietal lobe

The parietal lobe (Latin for “forming the sides”) is located on the upper sides of each cerebral hemisphere, above and in front of the occipital lobe, above the temporal lobe, and behind the frontal lobe.

The parietal lobe is responsible for perceiving, analyzing and assembling touch information from the body. It is also in the parietal lobe where visual, auditory, and touch information combine to make sense of the world. The **left parietal lobe** is also believed to be the area where letters come together to form words and where words are put together in thoughts. The **right parietal lobe** is responsible for understanding the “spatial” nature of the world, including recognizing faces and shapes, being aware of body states and deficiencies, and knowing directions.

When the parietal lobe is injured, the inability to recognize touch sensation from the opposite side of the body can result.

### Occipital lobe

The **occipital lobe** is in the extreme rear of the cerebral hemisphere at the back of the head. The occipital lobe is devoted entirely to vision and is often called the visual cortex. The occipital lobe can be injured by disease or trauma but is most often injured by a stroke causing loss of blood flow or bleeding. Damage to the occipital lobe can result in disorders of perception, called **agnosia** (not knowing), such as impaired color vision or the inability to recognize objects. Even blindness can result if the injury is severe enough.



coordination.

### **Cerebellum**

The cerebellum is a cauliflower shaped structure located beneath the occipital lobe and behind the brain stem. It has a right and left hemisphere and is the size of two large plums. It has two main functions: balance and



### **Brain Stem**

The brain stem has two main functions; basic life and arousal. It connects the cerebrum with the spinal cord. The lower portion (medulla oblongata) controls breathing, heartbeat, and other involuntary muscle activity. The brain stem also controls eye movement through the midbrain.

## **Interacting Parts Of The Brain**

Most higher, complex behavior is the result of the interaction of many different parts of the brain. In particular, the “higher” thought processes of the cortex can powerfully influence functions of the brain done by “lower” brain areas. Below are a couple of common examples:

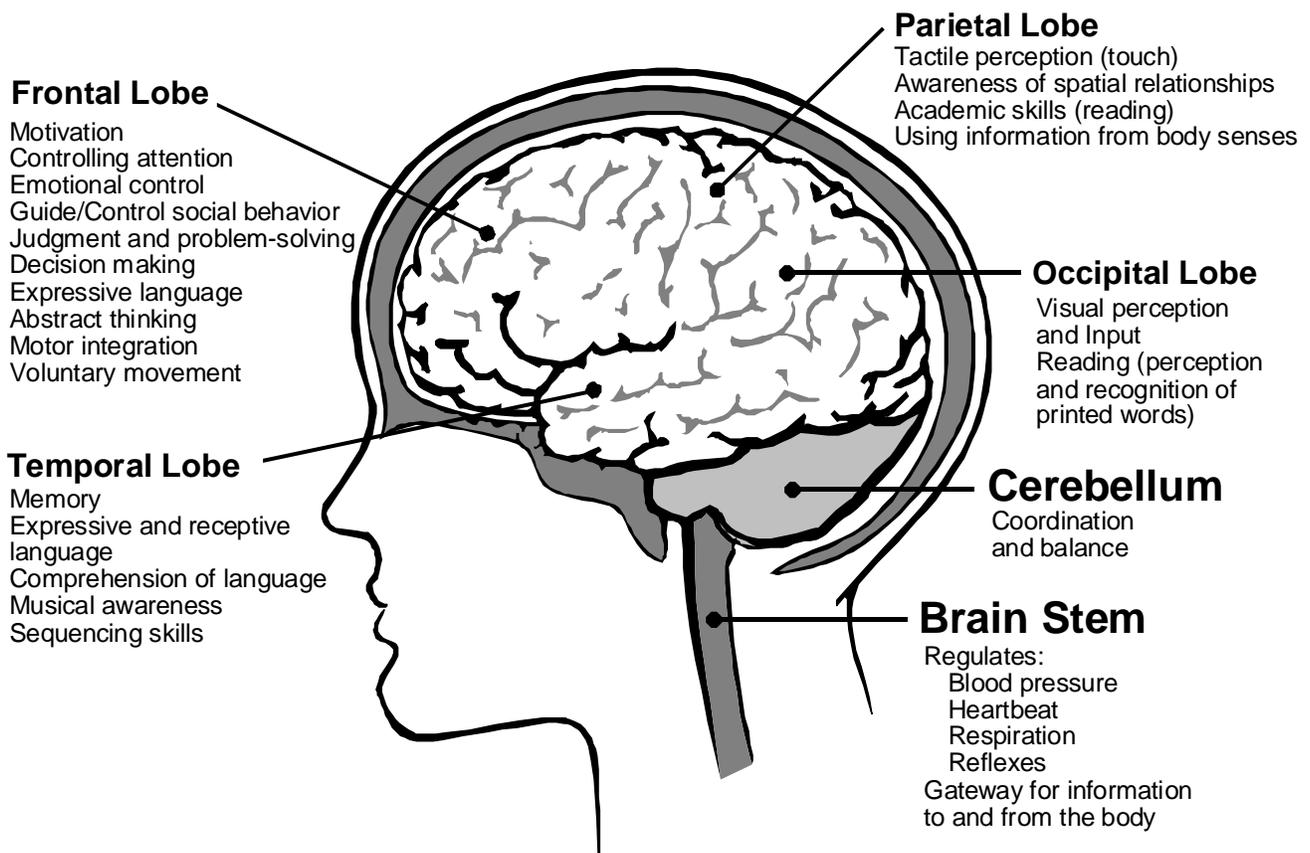
### Frontal-Brain Stem Connections: Thoughts and Arousal

The **frontal lobes** of the brain are responsible for controlling and regulating much of the brain’s activities. The **reticular activating system**, or RAS, of the brain stem is responsible for arousing and alerting the brain. However, these two parts of the brain often interact to regulate alertness. For example, when an individual has been awake for 24 hours without sleeping, the RAS will usually become inactive so that the individual can sleep. However, if the individual is driving home from a long trip and needs to stay awake, the thought processes of the frontal lobes (e.g., “I have to stay awake!”) can influence the RAS to keep functioning and, therefore, keep the individual awake. In this way, thoughts influence arousal.

### Frontal-Limbic Connections: Thoughts and Emotions

Again, the frontal lobes of the brain are responsible for controlling and regulating brain activity. Emotions are complex states or “feelings” that are produced by the **limbic system**. There are direct neuron pathway connections between the frontal lobes and the limbic system. Thoughts generated in the frontal lobe of the cortex travel down to the limbic system to influence the production of emotional states. For example, an individual sees a rattlesnake in front of him and thinks, “This is a rattlesnake – he will bite me – I’m scared!” These thoughts impact the limbic system to produce an emotional state of fear. This, in turn, results in fearful avoidance behavior in the individual.

### Functional Domains of the Brain



## General Patterns of Dysfunction by Location of Injury

### Left Side of Brain

- Difficulties in understanding language (*receptive language*)
- Difficulties in speaking or verbal output (*expressive language*)
- Catastrophic reactions (*depression, anxiety*)
- Verbal memory deficits
- Decreased control over right-sided movements
- Impaired logic
- Sequencing difficulties

### Right Side of Brain

- Impairments in visual-spatial perception
- Left-neglect or inattention to the left side of space or body
- Decreased awareness of deficits
- Altered creativity and music perception
- Loss of the gestalt, or “big picture”
- Visual memory deficits
- Decreased control over left-sided movements

### Diffuse Injury

- Reduced thinking speed
- Increased confusion
- Reduced attention and concentration
- Increased fatigue
- Impaired cognitive functions across all areas

Just as each individual is unique, so is each brain injury. Recovery from a brain injury is often slow and the person may exhibit and have changes, for better or worse, which may affect them the rest of their lives. These difficulties include thinking, attention, motivation and arousal, communication and language, learning, vision and hearing, and understanding. Personality, mood, and emotions are often altered. Physical, cognitive and personality changes may occur following a brain injury. Each person's recovery is unique due to pre-injury personality, learning style, location and severity of injury, time elapsed since the injury and the individual's psychological reaction to the injury. Changes in cognition and behavior may appear years after the initial injury and last a lifetime. Frequently reported problems include the following:

## **Physical Consequences<sup>32</sup>**

### **Motor**

The person may experience paralysis of one side of the body (hemiparesis), paralysis involving both legs and both arms (Quadraparesis), poor balance, lowered endurance, a loss of ability to plan motor movements (ataxia) and abnormal tone and muscle stiffness (spasticity). The individual may also lose the ability to stabilize his trunk even though his limbs are functional (proximal instability). Direct damage to muscular and bony tissue may be sustained.

### **Perceptual**

All senses may be affected, producing changes in hearing, vision, taste, smell and touch. Changes may involve an increase, decrease or loss of sensitivity. This could result in the inability to see items on one side of the visual field, (visual field deficit), sensitivity to movement (vestibular deficits) or difficulty in understanding where his limbs are in relation to his body.

### **Speech and Language**

The person may have difficulty understanding what is said to him (receptive aphasia), or difficulty expressing his thoughts (expressive aphasia). Some people have a specific difficulty recalling nouns or names or pronouncing or articulating words (dysarthria).

### **Regulatory**

The person may become easily fatigued and require rest periods throughout the day. Changes may also occur in the person's ability to regulate his body temperature, consumption of foods and liquids. Loss of bowel and bladder control may also occur.

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<sup>32</sup> Material on pages 19-20 was taken, with permission, from: Black, K, Caregiver College Presentation. Michigan: Detroit Medical Center, Rehabilitation Institute of Michigan, 1998

**Traumatic Epilepsy**

Following a brain injury, a person may experience seizures. Seizures may occur immediately following the injury or may develop months or years later. Two types of seizures may occur. First, a major motor or generalized seizure in which the patient may begin making rapid body movements, lose consciousness, lose bowel and bladder control, and breathe irregularly. After a few minutes the person may regain consciousness on his/her own and express feeling confused and complain of soreness. The second type is focal motor seizures. This type of seizure exhibits twitching or jerking movements. The person usually does not lose consciousness and may not be aware the seizure occurred.

<b>Strategies to Address Physical Consequences<sup>33</sup></b>		
<b>PROBLEM AREA</b>	<b>BEHAVIOR</b>	<b>STRATEGY</b>
Impairment of movement	Poor balance, reduced motor coordination, weakness on one side, jerky walking, reduced endurance, fatigue	Walk slowly, follow instructions of Physical Therapist.
Spasticity of limbs	Muscles that are tight, difficulty walking, stiff legged	Maintenance of Range of Motion and stretching programs to reduce tone. These need to be done under the direction of a Licensed Physical Therapist.
Labored speech	Slow, slurred speed, at times unintelligible	Encourage person to take their time and articulate. Utilize written communication if clarity is poor.
Visual & perceptual difficulties	Double vision, loss of visual fields, blurred vision, depth perception difficulties	Encourage person to turn their head to compensate for loss of field. Cover one eye if seeing double.
Seizure disorder	Staring spells, leg jerks, Grand mal - falling down, loss of bladder control	Maintenance of medical follow up, take medications as prescribed, don't use alcohol or illegal drugs
Swallowing difficulties	Coughing, choking, difficulty chewing, drooling	Video swallow can provide information regarding the problems that occur. There are various diets that can be prescribed. Need to ensure that the patient is getting adequate nutrition. Oral motor exercises may also help.
Apraxia	Inability to perform purposeful movements. May or may not see loss of coordination, motor function, or sensation. May affect oral and speech movements, limb movements, constructional skills	Allow adequate time to initiate and restart. Provide visual or physical cues - gestures, pictures, models, hand guidance.
Sensory	Increased light and sound sensitivity. Impaired smell and taste. Tactile defensiveness. Body temperature and weight fluctuations. Tinnitus.	Increase deficit awareness of how daily tasks may be affected by sensory impairments. Medical follow-up and medications may be necessary.
Pain	Episodic/Continuous. Headaches. Effect on cognitive/emotional status. Exaggerated pain reactions.	Pain management program. Counseling. Rating scales for pain. Medications.

<sup>33</sup> The table on page 21 was taken, with permission, from: Beckwith, B, Dimambro, L. TBI Basics. Brain Injury Association of Michigan Annual Conference, 1996-2002.

## Cognitive Consequences<sup>34</sup>

Many families find that the cognitive deficits and personality changes that occur are the most difficult to accept. When we can see a disability, it is easier for us to understand the limitations of the individual and what we can expect of him. Cognitive and personality changes cannot be easily “seen,” therefore, they are often more difficult to explain, understand, and accept.

People with brain injuries often are confused about the current time, where they are, who they are and who the people around them may be (disorientation). In addition, the person with a brain injury may exhibit an inability to focus on a task without being distracted (attention deficits), an inability to maintain attention on a task over a period of time (concentration), difficulty recalling and “stringing” recent information (memory) and difficulty learning new information. They may also display poor judgment and an inability to plan events or tasks, difficulty drawing conclusions and making decisions (problem-solving), difficulty switching from one topic or task to another (perseveration) and may have difficulty adapting to changes in daily routines (inflexibility). The person may also be unable to understand abstract concepts.

Many people with brain injuries may lack an awareness of or appreciation of, their current situation. This can be caused by both the actual damage to the brain and by the person’s reaction to the injury. Their families may also have this reaction to their loved one’s injury. The person and/or the family may completely deny that a disability is present, refuse treatment, and therefore, unknowingly place them at risk. This is particularly an issue for those persons who appear to function well but may have impaired judgment or problem solving.

### Basic Cognitive Strategies<sup>35</sup>

Damage to the brain can compromise some or all of an individual’s skills or abilities, particularly the execution of cognitive functions as identified in earlier modules. Cognitive limitations must be taken into account when supporting individuals in achieving their targeted outcomes. Also, an individual’s cognition, or the way they think, is a significant factor in analyzing antecedents.

Remember, when providing cognitive support to individuals with brain injury, their cognitive functions worked adequately to support them prior to the injuries. They also probably remember how they used to function, and the present challenges may frustrate them. They should be approached as you would any other person their same age. Do

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<sup>34</sup> Material on page 22 taken, with permission, from: Black, K, Caregiver College Presentation. Michigan: Detroit Medical Center, Rehabilitation Institute of Michigan, 1998

<sup>35</sup> Material on pages 22-28 taken, with permission, from: Braunling-McMorrow D, Davie, C, Ferriera-Bedford, T, et al. Acquired Brain Injury Programs, Preservice Materials Manual. Illinois: Mentor, 2000.

not speak down to a person or “baby” them. Treat people with dignity and respect, as you would want to be treated if you had the same injury.

The following are common cognitive impairments and the basic strategies that can be used as support for each.

- Memory
- Attention/Concentration
- Language – Comprehension/Understanding Difficulties
- Language – Expressive Difficulties
- Sequencing Difficulties
- Planning and Organization Difficulties
- Problem-Solving Difficulties

### Memory

Memory impairment is considered the most common deficit that results from a brain injury. Memory refers to the process of first organizing and storing information, then recalling that information at a later time. Different types of memory have been identified and are affected to different degrees following a brain injury. Memory deficits affect an individual’s ability to acquire new information.

Strategies and support that can be provided to individuals with memory difficulties fall into two broad categories. There are those strategies that help them **store** the new information presented to them if the brain cannot do this effectively. There are also those strategies that assist them in **retrieving** the information that gets stored in their memory. The strategies identified here provide both types of assistance to the individual.

#### Suggested Techniques:

- Use a memory book, date book or journal. It should be personalized to the needs of the individual. The individual should be encouraged to carry it at all times.
- Hang a wall calendar in the individual’s room or residence and note important appointments and dates on the calendar.
- Use cueing systems, such as an alarmed watch, as a reminder of important times during the day like medication times.
- Post a map of the city, residence or home in which the individual lives (if they are not familiar with the area).
- Label cabinets and drawers to aid with locating items in the kitchen and bedroom.

### Attention/Concentration

Attention and concentration difficulties are also common following a brain injury. In order to benefit from any rehabilitation program, the individual must be able to attend to the information and concentrate on the therapy tasks.

The process of attention and concentration has several components. First, the individual must be able to screen out all irrelevant information and activity going on around him/her. For example, this happens when a person has a conversation at home with a family member while the television is on in the same room. During the conversation, the person screens out the television noise in order to attend to what the family member is saying. The second part of attention is the ability to sustain that focus for a period of time without reinforcement.

Individuals with attention and concentration difficulties following their brain injuries will face certain challenges during the rehabilitation process. They will require support and assistance simply to participate in their therapy program. The following techniques will help to structure the environment around the person to maximize attention and concentration abilities.

Suggested techniques:

- Make sure the individual's working environment is clear and quiet.
- Engage the individual in tasks that are shorter in length, initially.
- Designate a space in the residence where the individual can work uninterrupted.
- Assist the individual to keep personal space (e.g., room, bathroom) organized and free of clutter.

### Language – Comprehension/Understanding Difficulties

Comprehension difficulties limit a person's ability to make sense of what is happening in the environment. It affects the ability to understand what is said or even read. Their ability to understand words that were once common may be affected. The speed with which this information is taken into the brain can also be affected. Conversation may now be difficult, especially if it involves more than one person. If the individual once enjoyed reading, this may no longer be a fun activity. Watching a television program or listening to a radio report may be difficult, and the individual may need a lot of explanation for things to make sense.

The following strategies will support the individual and structure the flow of information around them to provide the greatest opportunity for comprehension:

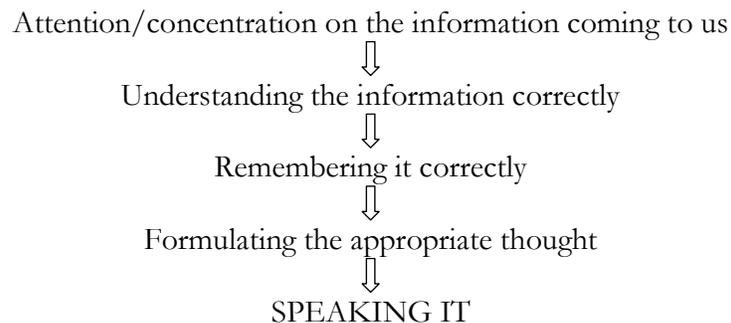
Suggested Techniques:

- Speak to the individual in shorter sentences – *not baby talk or talking down!* Simply make your sentences short – put one thought in each sentence. Instead of saying, "Will you go to the utility room and get my dress out of the dryer – I want to wear it today," say "Will you go to the utility room?" (pause) "Get my dress out of the dryer, please?" (pause) "Bring it to me, thanks!"
- Speak at a slower pace to the individual to allow time for the information to be understood.

- Encourage the individual to ask for clarification if the communication seemed confusing. In the initial stages of rehabilitation, you may need to model and later prompt the questioning. For example, when you deliver a communication, you may simply ask, “Did I make sense to you?” instead of, “Did you get that?” The first type of question may take the edge off and reduces the likelihood of the individual becoming defensive.
- Support any communication you deliver with simple gestures, like pointing to or picking up the object mentioned. Do not make the gestures elaborate – that may only add to the confusion.

### Language – Expressive Difficulties

Expression is the other part of the communication process. We must first take information, process it, AND understand it before we can express our thoughts. Expressing ourselves is the reflection of a number of cognitive processes we have mentioned:



We do this every day without thinking about it. Individuals with brain injuries may have difficulty putting thoughts together to make a complete thought. They may have difficulty coming up with a particular word to make the thought complete, or the production of the communication may be slowed. They may say irrelevant things, ramble on without a clear point to the communication, or speak completely off-topic. The following strategies can support individuals with a brain injury in communicating with clarity.

#### Suggested Techniques:

- Set up a discrete cueing system that will let the person know if she/he is wandering from the topic (a hand signal or finger motion).
- When in private, respectfully let the person know when she/he wanders off topic, yet be direct.
- Avoid lengthy, in-depth discussions. Discuss topics in shorter segments with less detail.
- Use wh- questions (i.e., who, what, when, where, why) as a structure for written and verbal communication.

### Sequencing Difficulties

Sequencing refers to the ability to put the steps of daily activities in the proper order. These skills are directly related to memory. Individuals with brain injuries may have difficulty sequencing daily activities such as laundry, grocery shopping and room cleaning.

#### Suggested Techniques:

- Create a checklist of the steps required to complete a task. Each step can be marked off as it is completed. When creating the checklist, be alert for hidden steps that are often completed automatically without thinking. They will need to be spelled out.
- For grocery shopping, make a checklist that is organized according to the layout of the store. This checklist will help to organize the shopping trip, as well as make sure the necessary items are purchased.
- For cooking tasks, create an individualized cookbook that includes checklists of ingredients required, equipment needed, and checklist for the recipe. By laminating the recipes, they can be wiped off and used again.

### Planning and Organization Difficulties

Planning and organization are among the higher-level thinking processes. To plan and organize requires the ability to look ahead, put things in an order, and consider multiple factors simultaneously. It requires concentration, memory and sequencing. Difficulties in any one of these areas will result in difficulties with planning and organization. For most of us, this is an unconscious activity – we do not realize when we do this on a daily basis.

The following supportive strategies for individuals with brain injuries will provide systems that help this process become more conscious for them:

#### Suggested Techniques:

- A memory or date book can serve as a supportive strategy for difficulties with planning and organization. This book can help to organize important information the individual may need – phone numbers, addresses, goals on which they are working, items to purchase, etc.
- Assist the individual in creating a system for organizing their living space. Label dresser drawers so that clothes are always put in the same area. Desktop organizers are sometimes effective for this purpose. Whatever is developed must be useful for the individual – they must be able to use it. No strategy, however creative, is effective if the individual cannot use it!

### Problem-Solving Difficulties

To problem-solve a situation, individuals must be able to integrate all of the skills identified so far. Attention, concentration, memory, sequencing and planning all come into play when we attempt to solve problems. The steps in which we engage (which are often unconscious and happen in a split second) may now be challenging. Strategies to support them in this area of unconscious problem solving involve cueing the steps required and allowing for a slow and deliberate process.

#### Suggested Techniques:

- Support the use of external cueing systems for problem-solving when they must address each step in order and not skip anything. Key parts include: stating the problem, identifying several possible solutions, identifying the advantages and disadvantages of each possible solution, picking a solution, trying it, and evaluating the solution tried (did it work?).
- Allow people an ample amount of time to work through difficult, challenging situations. This will allow them to process all aspects and arrive at a well-thought-out solution.

<b>Strategies to Address Cognitive Consequences<sup>36</sup></b>		
<b>PROBLEM AREA</b>	<b>BEHAVIOR</b>	<b>STRATEGY</b>
Impaired alertness	Inability to attend to environment. Reduced alertness, may appear sleepy. Very slow processing speed. Slow reaction time to environmental changes.	Stimulation - in correct amounts based on level of injury. Allow time to respond as needed. External cue-timers.
Impaired attention/concentration	Easily distractible (internal and external stimuli). Cannot sustain attention to new target. Cannot pay attention to two things at once.	Control environmental distractions. Notes and lists assist in shifting/dividing attention. Timers to cue to new task. Pacing to avoid "overload." Train person to identify his/her attention level.
Impaired learning and memory	Decreased ability to store/retrieve new information (verbal or visual). Forgets details easily. Decreased rate of new learning.	Repetition - overlearn new skills. Notes, lists, tape recorders, timers, planners as memory aids. Avoid learning multiple new things.
Impaired abstraction	Gets "stuck" on one view or situation. Misinterprets - especially hidden meanings. Difficulty understanding abstract concepts. Concrete thinking style.	Cues to direct alternate viewpoints and speak more concrete terms. Give examples.
Impaired conceptualization	Difficulty seeing links between situations or events. Difficulty applying behavior to new situations (generalization).	Written/verbal cues to assist comparing and contrasting ideas. Practice new skills in different environments.
Impaired problem solving	"Stubborn!" Decreased flexibility - can only see one alternative. Difficulty seeing cause/effect, prioritizing, and organizing tasks. Hard time handling the unexpected.	Don't get angry. Explain alternate solutions and assist evaluating. Minimize change. Establish routines.
Perseveration	Repetitive phrases. Decreased ability to switch to new tasks.	Increase awareness of behaviors. Direct intervention to break pattern.
Impaired communication skills	Receptive or expressive deficits. Impaired word finding. Disorganized communication. Impaired social language (pragmatics)	Give extra time for processing and expression. Verbal cues/feedback to assist pragmatics. Group/peer activities excellent way to facilitate appropriate behaviors.
Impaired orientation	Confusion in new environments. Disoriented to person, place, and time. Gets lost easily.	Planners and calendars. Prepare for new changes in environment. Daily environment orientation by caregivers.

<sup>36</sup> Table on page 28 was taken, with permission, from: Beckwith, B, Dimambro, L. TBI Basics. Brain Injury Association of Michigan Annual Conference, 1996-2002.

<b>Strategies to Address Executive Consequences<sup>37</sup></b>		
<b>PROBLEM AREA</b>	<b>BEHAVIOR</b>	<b>STRATEGY</b>
Impaired ability to plan/organize/follow through on goals	Low motivation. Cannot maintain skills (jobs, social relationships). “Going nowhere.” Unfinished tasks.	Written/verbal cues to set specific goals with timelines and evaluate progress. List steps in a goal - break things down. Reinforce small successes.
Impaired ability to initiate	Looks “lazy.” No forward action on tasks (simple or complex). Needs constant prompts to start.	Checklists to cue tasks, broken into steps. Timers to cue when to begin tasks. Verbal cues as needed.
Impaired ability to self-evaluate, monitor and self-correct ongoing behavior	Inappropriate behavior to situation. Cannot correct mistake even when given feedback.	Provide consistent direct feedback to correct inappropriate responses. Videotape or peer review to increase self-awareness. Troubleshooting - anticipate potential problems and script possible responses.

## **Behavioral/Emotional Consequences<sup>38</sup>**

Individuals with brain injury may show a lack of interest in the world around them (apathy) and a decrease in motivation. They may exhibit extreme and rapid changes in emotion (emotional lability), irritability, depression and a lack of initiative. Difficulty controlling impulses and emotions (disinhibition), resulting in temper flare-ups, aggression, cursing, and generally lowered frustration tolerance may be exhibited. This may cause some to act upon sexual impulses inappropriately. Such persons may also exhibit social immaturity by making “overly friendly” or “silly” comments.

### **Basic Behavior Strategies<sup>39</sup>**

Human behavior is very complex. Researchers have been studying our behavior for centuries – what we do, why we do it and how we do it. Team members should have an understanding of basic behavior principles and how support provided to individuals will reinforce behaviors.

<sup>37</sup> Table on page 29 taken, with permission, from: Beckwith, B, Dimambro, L. TBI Basics. Brain Injury Association of Michigan Annual Conference, 1996-2002.

<sup>38</sup> Material on page 29 taken, with permission, from: Black, K, Caregiver College Presentation. Michigan: Detroit Medical Center, Rehabilitation Institute of Michigan, 1998

<sup>39</sup> Material on pages 29-35 taken, with permission, from: Braunling-McMorrow D, Davie, C, Ferriera-Bedford, T, et al. Acquired Brain Injury Programs, Preservice Materials Manual. Illinois: Mentor, 2000.

Because every interaction with individuals with brain injuries may have a direct impact on their behavior, **active treatment** is a key part of the treatment philosophy. Active treatment is defined as:

“Any interaction between a staff member and another person that is intended to result in greater autonomy for the other person (McMorrow, 1994).”

You should become alert to your behavior, make sure that both your responses and interactions support the individual and the outcomes she/he desires.

Following is a discussion of several basic behavior principles that can help guide your behavior in working with an individual:

### Predispositions

Any discussion of behavior principles should begin with a mention of predispositions. This refers to the principle that there are conditions that individuals bring to any situation that reduce the chance of the individual responding in a desired manner at that time (McMorrow, 1997). For example, if an individual is in pain, she/he may be more likely to be irritable or resistant to touch in a particular area. Or, if an individual did not sleep well the night before, she/he may have difficulty performing job tasks satisfactorily the next day. The following predispositions frequently affect all individuals:

- Medication side effects
- Relationship issues
- Disappointment related to visits
- Sleep irregularity
- Sexual deprivation
- Addictions
- Seizure activity
- Pain

Issues related to any of these predispositions can increase the likelihood that an individual may have problems handling difficult like situations. You should be alert to the presence of these conditions for all people you support. While not directly responsible for producing unwanted behaviors, they may be a factor. Your attention to predispositions may provide the support the person needs to avoid unwanted behaviors during a challenging life moment.

### A – B – C’s of Behavior

As you begin to observe a specific behavior and understand the factors that may contribute to it, you should observe more than the behavior itself. That is, when discussing behavior, you should refer to all behaviors (e.g., eating, walking, social interactions) and not just unwanted behavior (e.g., verbal aggression, physical aggression, property destruction). You need to look at what is occurring both before and after the behavior of interest. The A – B – C method of observation will help you do this. This method is explained as:

A = Antecedents: events that occur prior to a behavior  
B = Behavior of interest  
C = Consequences or results of the behavior

Two paths impact the behavior – focus on the antecedent or focus on the consequence. **Antecedents**, again, are events that occur prior to a targeted behavior. For example, you are in the house with the windows open on a warm day. A thunderstorm blows up; it starts raining, and the storm blows rain in the house. You immediately close your windows. The antecedent to closing the windows was the rain blowing inside the house, since it occurred before the behavior of closing the windows.

Antecedents set the condition for the behaviors that follow them by serving as a signal that the behavior will be reinforced. For example, when the weather alert sirens sound in a community, most residents will hurry to a place of safety. The antecedent (the sounding of the weather alert sirens) sets the condition for the targeted behavior (moving to a place of safety) because in the past this behavior has had a reinforcing consequence (protection from a tornado or damaging storm).

People learn from the consequences of their past behaviors how to act in different situations; that is, they learn how to respond to different antecedents. The ability to discriminate between different antecedents and the behaviors appropriate to them enables an individual to behave in ways that will obtain reinforcers and avoid negative consequences.

Antecedents may be many different things, including the presence of a certain person, a specific event or action, a place, or even a thought.

Questions to ask when identifying antecedents include:

- Where was the individual?
- Who else was around?
- What were they doing?
- What time of day did the behavior occur?

As a provider, be aware of behaviors you exhibit that may serve as antecedents for an unwanted behavior. Often we are unaware of the effect we are having, which is why we should analyze our behavior to determine antecedents. The PEARL scale is another guideline for structuring our interactions in a positive manner, reinforcing desired behaviors.

Identifying the targeted **behavior** is critically important. You should be careful to describe the behavior that was observed and not your interpretation of how someone felt or the attitude displayed. This will allow team members to key into the exact actions that occurred following the antecedent. Which of the following are behavioral observations?

1. Jan gets angry and threatens her sister every time she takes things from her room.
2. Juan answered all three questions correctly after reading the paragraph.
3. Carl is happy and enjoys being with his dog after school.
4. Terry clenched his teeth, shook his fist and yelled at his friend after he found out that he took his CD.
5. Sherry smiled and laughed when she played fetch with her dog.
6. Jeff understands most of what people say to him.
7. Brad was depressed after the movie.

Behavioral terms are accurate, objective words that give specific information about actions. Statements 2, 4 and 5 above provide the most accurate, objective description of the behavior that was observed. Words like “gets angry”, “is happy”, “understands”, and “was depressed” do not describe what the individuals were doing in those particular moments. Rather, those words represent someone’s interpretation of behavior that was observed. When describing a behavior, ask yourself: If another person observed the same situation, would his or her observation of the behavior be the same as yours?

**Consequences** of a behavior affect whether that behavior will be repeated in the future under the same conditions. If the consequence of the behavior resulted in something good happening (positive reinforcement), and we observe the behavior being repeated to achieve the same consequence, that behavior was probably reinforced and is likely to continue. If the consequence of the behavior resulted in the individual’s getting out of an unpleasant situation and helped him to avoid the situation altogether (negative reinforcement), the behavior, again, will likely occur in the future. Finally, some behaviors lead to unwanted consequences (punishment) that make it less likely for the behavior to be repeated.

Taking the time to analyze the behavior sequence of a targeted behavior is a critical step in understanding why a behavior is occurring and helps point to effective treatment planning. As a provider, you can support the rehabilitation team by providing input on predispositions and A – B – C observations for targeted unwanted behaviors or desirable behaviors that may occur in the residential setting. These observations will help the team to design effective treatment plans.

### **Methods for Reinforcing Behavior**

As a provider, you will be expected to support individuals as they practice strategies for increased autonomy and independence. The following methods can be used to help them experience success as they work to achieve their targeted goals:

- Shaping
- Fading
- Redirection

### Shaping

You should not expect people with brain injuries to perform desired tasks completely without assistance from beginning to end, before they are praised or positively reinforced. In many cases, the tasks are multi-stepped and require increasing levels of endurance that the person may not have. **Shaping** can be used in these instances. It is a procedure where reinforcement is provided based upon an individual's getting repeatedly closer to the final target behavior.

For example, if one of the objectives for an individual with limited range of motion is to learn to put his shirt on independently, you should not expect that he will be able to perform the entire task right after the objective was targeted. The physical mobility required might be challenging for him, and he may have cognitive difficulties with sequencing the task. Shaping could be used in this situation.

The person with a brain injury might be provided with a checklist that identifies the steps in putting on a shirt, and he may need guidance or help as he learns each step. In the beginning of the training, the person may take the shirt out of the closet and lay it out on the bed. This would be the first successful step that is reinforced. The next training step would require him to pick up the shirt from the bed and put his head through the neck opening. As he experiences success, other steps on the checklist can be added until he has learned the entire sequence. Remember, if you move too fast using a shaping strategy, the activity of working on personal care tasks may no longer be reinforcing at all.

### Fading

In some cases, following a brain injury, an individual is unable to respond to environmental cues as effectively as she/he once could. **Fading** uses a gradual change from artificial cues to more natural cues.

For example, sometimes after a brain injury an individual can have difficulty reading any kind of printed material because their eyes do not track back to the beginning of a line of print. They are unable to use the natural cue of the margin to find the beginning of the next line. It may be necessary to use a thick, bold red line placed on the left margin of the desired reading material as the cue for the individual to find the left-hand margin. This line may be necessary on all reading material initially. As their eyes respond to the thick, bold red line, the thickness of the line may be narrowed. Then, the color may be faded to pink; the line may then become a set of dashes until it disappears completely. The individual can use the blank margin as a cue for the beginning of the next line.

The same principle holds true when we gradually withdraw our verbal prompts or praise statements as persons become more autonomous in other activities of daily living. It will then make the person less dependent on praise to perform more independently and may more simulate real life.

### Redirection

There may be instances during the rehabilitation process where you will be faced with supporting an individual who is exhibiting unwanted behaviors. Many factors affect individuals with brain injuries during the rehabilitation process including confusion, overstimulation, impulsivity and limited awareness of the challenges. Individuals who exhibit behavioral issues following brain injury simply may not possess the problem-solving skills to deal with difficult life situations any other way. Confronting the individual who is exhibiting unwanted behaviors is usually not therapeutically indicated, since it may produce more intense emotional responding.

Regardless of the type of unwanted behavior – whether it is yelling, striking themselves, or property destruction – attempting to resolve the situation in the crisis moment may lead to further escalation. **Redirection** is a strategy that may be used in these situations. Redirection is actually directing the individual away from whatever is causing the unwanted behavior in order to bring about de-escalation of the behavior.

For example, if an individual has become verbally aggressive about a CD that is missing from her room, attempting to problem-solve the situation in that crisis moment may not be effective. Rather, you should redirect the individual to discuss a topic of interest – plans for attending an upcoming concert, a sporting event, or a favorite movie. In this case, the change in focus, away from the cause of the aggression – the missing CD – will often result in the reduction of the verbal aggression. Once the individual has been calm for a while, discussing the incident and other ways of responding to frustration can then be therapeutic. We all know that solving through problems in our lives is difficult when we are in emotional upset.

### **Environmental Factors**

Our environment consists of everyone with whom we come in contact, and everything that happens around us. The environment's responses to our behaviors profoundly affect how we act, through reinforcement and punishment. Before we provide more explanation as to the application of these factors in daily life, we will provide further clarification.

### Reinforcement

When we attempt to identify reinforcers for individuals, one fact is clear. Items, actions or events that reinforce one individual do not necessarily have the same effect on another individual. We are individual human beings with different likes and dislikes, and this applies to reinforcers as well. You should be aware of, explore and clarify with the individual what things they desire and what things they avoid. This will also help you to monitor your own behavior so that your responses to the individuals are truly reinforcing.

For example, receiving a box of expensive chocolates as a thank you gift for watching a neighbor's house may be a positive reinforcement gesture. However, if you are allergic to chocolate, don't like the taste, or are trying to diet, it would not reinforce your actions. The individual nature of reinforcers will definitely impact your successful support of the persons you serve.

Rewards (Positive Reinforcement) - As was indicated earlier, when good things happen following a behavior and that behavior is repeated in the future in order to achieve that result, the behavior is likely to continue. The behavior has been strengthened or reinforced, hence the name positive reinforcement.

For example, if you work hard to make a special meal for a friend and that friend is surprised and very thankful, you will likely do other things to surprise or please that friend. However, if that friend grumbles and complains about not liking the choice of food, you will not be as eager to do other things to please your friend.

Unwanted behaviors may also be maintained by this same reward/positive reinforcement principle. Reinforcement can happen unintentionally. We may be unaware of the effect we are having on maintaining a behavior – even though we may think we are working very hard to decrease it. As an example, unwanted behaviors are often followed by attention from others in the environment – other staff, family or even other people in the community. The attention given to the individual in the moment of upset may be enough to reinforce him or her and strengthen the behavior. As a provider, you should try to ensure that your responses to unwanted behavior do not inadvertently reinforce the unwanted behavior in the person.

Escape and Avoidance (Negative Reinforcement) - When behavior stops an unpleasant situation – or removes the threat of one – that behavior becomes strengthened. It is more likely to occur in the future. As with positive reinforcement, negative reinforcement strengthens many behaviors that allow us to escape or avoid unpleasant situations. The rehabilitation process can be very unpleasant and certainly painful at times. Cognitive activities can be difficult and confusing. Physical therapy and occupational therapy is demanding and can be physically painful – stretching contracted muscles certainly creates pain. If speech is slow and laborious, communicating with others can cause frustration. The individuals in these situations may discover that having an outburst or complaining of illness will get them out of these unpleasant situations.

As a member of the team, you should watch for this type of reinforcement occurring with unwanted behaviors during therapy times and in other daily activities.

### Punishment

Behaviors that lead to unpleasant or negative consequences are less likely to happen again. This can complicate the rehabilitation process, where therapeutic interventions may result in unpleasant consequences such as pain, confusion or failure.

Most of us have learned what activities we do well, and what situations are troublesome. The same is true for individuals in rehabilitation. When the skills that are most important to an individual's recovery are followed by some type of punishment, those behaviors are weakened. An individual's ability to obtain positive reinforcement is then limited. The individual is likely to find other behaviors that are effective for him/her – even if the behaviors are undesirable.

Punishment does not teach anything. Its long-term effects often tend to be adverse. The individual does not learn what she/he should do, or what behavior is desirable. In addition, the side effects of punishment can be quite alarming (e.g., withdrawal, illness and anxiety). You should try to do whatever possible to diminish the unpleasant consequences that occur without intent. For example, tasks can be designed in such a way that the individual is more likely to succeed than to fail.

When unwanted behaviors develop as a result of any of these environmental factors, or due to the neurological challenges faced by an individual, you should stress that these are not the fault of the individual. The “fault” lies with the injury or with the environment's accidental strengthening of unwanted behaviors instead of the desired responses. The individual is probably not aware of the reasons for the behavior problems and probably does not want to exhibit these behaviors.

<b>Strategies to Address Behavioral/Psychosocial Consequences<sup>40</sup></b>		
<b>PROBLEM AREA</b>	<b>BEHAVIOR</b>	<b>STRATEGY</b>
Impairments in social appropriateness	Rude and selfish, childlike behavior. Does not respond to social cues.	Group activities to utilize peer criticism/approval -vs.- professional criticism/approval, praise positive behaviors, model appropriate behaviors.
Inability to control emotions	Overreacts to situations, laughs too much, becomes angry easily, appears to be moody, apathetic, anxious, depressed, talking about suicide. Frustration tolerance reduced.	Focus on progress made, remain calm, give suggestions for getting in control, don't compare to how they were before.
Sexual dysfunction	Wanting to hug everyone, making sexual statements, inappropriate touching. Reduced sexual drive.	Let them know actions are inappropriate and you feel uncomfortable, give suggestions for appropriate behavior. Counseling and/or medications.
Temper Outbursts	Impatient, becomes irritable when trying to do tasks, using obscenities, yelling, hitting. Self-injurious behaviors.	Redirect person from cause of frustration, get their attention, present alternative and help guide them, review consequences of behavior/action, praise patient once in control, don't leave patient alone, keep surprises to a minimum, be consistent, keep a routine, model calm behavior, reduce stimulation, reorient.
Inability to form and maintain relationships	Boastful, fails to express empathy, fails to respect rights of others.	Redirect disrespectful behavior, encourage cooperative behavior, use role-playing.
Physical	Hyperactivity, drowsiness, insomnia.	Medical monitoring. Medications may be used. Counseling.
Behavioral	Anxiety, depression, paranoia, mania.	Monitoring by psychiatrist, social worker, counselor. May need medications and/or counseling.

<sup>40</sup> Table on page 36 was taken, with permission, from: Beckwith, B, Dimambro, L. TBI Basics. Brain Injury Association of Michigan Annual Conference, 1996-2002.

## Communication Style

### Family Involvement<sup>41</sup>

Services of mental health programs are needed by both people with brain injury and their families. It does no good to remind the survivor how “lucky” he/she is to have recovered physically, when that person is unable to work, friends have fled, and family relations are stretched to the limit.

Psychological disabilities affect not only the person with a brain injury but have an impact on family members as well.

Family problems may not be apparent until several months after the injured member is discharged from the hospital or in-patient rehabilitation program. Because the family often has the responsibility of carrying out the follow-up program, they become partners in the long-term rehabilitation of the person with brain injury. It

can be up to the community mental health professionals who see the person regularly over an extended period of time, to recognize and begin to assist the family learning to deal with prolonged difficulties.

Adjustment problems, which occur as a result of changes in the behavior and personality of a family member, can be more difficult for the family and the survivor to deal with than physical disability. These problems include role changes within the family, relations with friends and relatives outside the immediate family, changes in occupational status, and economic changes.

Dramatic role changes can occur within the family. A strong highly motivated person may now be dependent and apathetic. A reliable breadwinner may be childish and impulsive. Relationships between husbands and wives are

It can be extremely difficult for the family of a person with brain injury to accept the fact that their loved one may never again be that same person as before.

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<sup>41</sup> Material on pages 37-39 were taken, with permission, from: Brain Injury Association of Michigan, Traumatic Brain Injury Manual – What You Need to Know. Michigan: Brain Injury Association of Michigan, 1996

not the only ones to change. Siblings and children of people with brain injury may also be affected, with feelings of guilt over the injured family member, or feelings of being neglected or ignored because of the needs of that person.

It is important to recognize the individual with brain injury in the context of his/her various relationships with family, friends, and society in general. Interviews can be helpful.

- Does the person go out of the house?
- Does the person do any cleaning, grocery shopping, cooking, watch the kids, drive a car, or see relatives outside the immediate family?
- What are the prospects for returning to work, and at what job?
- Does the person have any hobbies or belong to any organizations?
- What resources are available in the local community?
- Do people seem accommodating, or are they “turned off” by the characteristics shown by the person with a brain injury?
- Are they frightened by the term “brain damage”, and will they respond positively to information offered?

People often expect that when someone is sick, or injured, he/she will recover and be the same as before. What the family is told in the beginning stages of brain injury rehabilitation is frequently general and vague and is not adequate preparation for dealing with problems of long duration or disabilities, which may be permanent. Information about specific deficits, their severity, and expected duration can be most reassuring to the families of people with brain injury.

The family is the one constant, on-going factor in the rehabilitation process. Because this process may be long and the outcome unpredictable, it is important that families receive the support they need to help sustain them.

Services of mental health programs are needed by both the person with brain injury and family members, who may be confused and uncertain about appropriate ways of dealing with an injured family member and confused by their own emotional reactions. Families may become focused on the injured person, and contacts with people outside the family may decrease. They may encourage dependency and try to avoid potentially difficult social situations.

A goal of family counseling may be to overcome this denial, with an acceptance of the situation as realistic, and the provision, whenever possible, of adaptive coping mechanisms for dealing with conflict and stress.

Family members, particularly spouses, may feel trapped, even when the changes in the injured person are considered to be “mild”. Those changes which might be categorized as “moderate” present even greater difficulty. The person with brain injury is considered well enough to function at home and in the community, but once there, his/her behavior

may become disruptive and unsettling to those in close proximity. For those family members who deny the existence of obvious personality problems, the contact with an injured family member who manifests behavior and personality changes can be a source of conflict and stress which can lead to depression. Denial can be a needed coping mechanism in the early stages of recovery, but in the long run can prevent family members from accepting and dealing with problems.

Some families may be over-optimistic, with expectation for the injured person unrealistically high. This can do more harm than good for the person with brain injury who is unable (or unwilling) to recognize the changes, which have occurred as a result of the brain injury, or, if aware of the changes, who may feel rejected by the family because of the fact that such changes exist. Factual, realistic information should be provided to family members, who may need to overcome their sense of loss, and learn to live with a “different” person than the one they knew before.

The emotional needs and feelings of a family which has been torn apart by a brain injury must be carefully considered, whatever the specific counseling techniques you choose to employ.

## Key components to building a successful relationship

Once a person can address and accommodate their disability through their own courage, determination and hard work, they have a depth of spirit few know little about. The way in which we interact is primarily influenced by how we view each person whom we serve. If we believe that someone who experienced an injury is helpless, we may approach him as helpless. If we view someone as defiant or non-compliant, rather than someone who may be confused, overwhelmed and in need of assistance, we may treat that person in ways that may be undignified. All people have the right to be treated with respect and dignity.

### General Guidelines for Maintaining a Positive and Supportive Environment<sup>42</sup>

The success of any effort provided will be directly related to the relationship that exists between all members. The amount of support you provide and the degree to which that support is accepted by the individual will be proportional to the relationship that the individual has with you.

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<sup>42</sup> Material on pages 39-51 were taken, with permission, from: Braunling-McMorrow D, Niemann GW, and Savage RC (eds.), Training Manual for Certified Brain Injury Specialists (CBIS) Level 1. Texas: HDI Publishers, 1998.

Relationship development will make a difference in the outcomes of services. The following are other guidelines and suggestions for enhancing the relationship that you have with the individual to create a positive and supportive environment:

- Empathic Listening
- Use of Tone, Volume and Cadence
- Communication Do's and Don'ts

#### Empathic Listening

This strategy employs the thinking that in order to really understand what the person is experiencing, you must “put yourself in their shoes.” Through your communication with them, you try to feel what they are feeling, experience events as they experience them, and understand their responses. This is accomplished in the following manner:

1. Don't be judgmental. When you judge a person's actions or responses, you will be unable to gain an understanding of the origin. You cannot have a sense of what she/he is experiencing that led to that response, if you are judgmental.
2. Don't ignore. Communicate and try to make sense of the individuals' way of responding.
3. Carefully listen to messages.
4. Use silence. Stay with the individual, but do not always respond or fill the silence with talking.
5. Use reflective listening. Repeat back to the person what you think you are hearing.

#### Monitor the Tone, Volume and Cadence of your voice

These nonverbal components of communication will also send messages to the person despite the content of your message. Make sure the nonverbal components match the verbal components.

1. Tone. Make your tone smooth and supportive. Try to avoid inflections of impatience, condescension and inattention.
2. Volume. Keep the volume of your voice at a moderate level. Avoid shouting or whispering.
3. Cadence. Deliver your message at an even cadence or rhythm. Avoid jumpy or excited patterns.

### **Communication Do's and Don'ts**

Following is a list of recommendations for communication that will further enhance a positive and supportive environment:

#### **DO**

DO be accepting  
DO take every issue seriously  
DO address people age appropriately  
DO convey respect  
DO assist them in problem solving  
DO state relevant facts to those that need to know  
DO remember that you don't know how they feel  
DO get all the facts  
DO be their equal  
DO be sincere

#### **DON'T**

DON'T be blame/fault finding  
DON'T ignore an issue  
DON'T talk down to anyone  
DON'T patronize  
DON'T take responsibility for their situations  
DON'T gossip  
AVOID saying things like "I know," "I know how you feel."  
DON'T make promises you can't keep  
AVOID domination

All staff must work together in order for these components to come together; all members have a part to play and a responsibility for the outcomes. People with brain injuries and their families have unique roles to play – they must be clear about the outcomes they desire. Individuals must try the strategies and programs identified to see if they are successful and then practice them in functional settings.

## **A Word about Labels**

Language reflects and reinforces both our perceptions and misperceptions of others. All too frequently the terms used for people with disabilities perpetuate stereotypes and false ideas.

Often people with disabilities feel they are not treated with respect or dignity. Using respectful language can improve the manner in which people with disabilities are treated. When referring to a person with a disability remember to make reference to the **person first**, then the disability (for example: A "person with a brain injury" rather than "brain injured person").

<b>Objectionable</b>	<b>Explanation</b>	<b>Preferable</b>
(The) disabled	Sees people only in terms of their disabilities	People with disabilities
Invalid	Inaccurate, most people with disabilities are not sickly	None is needed
Wheelchair bound	Creates a false impression; wheelchairs liberate, not confine or bind; they are mobility tools from which people transfer to sleep, sit in chairs, drive cars, etc.	Uses a wheelchair
Physically Challenged	Euphemisms avoid reality and rob people of dignity	A person has a physical, cognitive or mental disability
Inspirational	People with disabilities are not collectively inspirational or courageous	Acknowledge the person's abilities and individuality

When referring to yourself, your family or the people you serve, please use words that reflect dignity.

#### **From Harvard Medical School**

...The words and images you use can create either a straightforward, positive view of people with disabilities or an insensitive portrayal that reinforces common myths and is a form of discrimination... Listed below are preferred words that reflect a positive attitude in portraying disabilities:

#### Nondisabled

Appropriate term for people without disabilities. Normal, able-bodied, healthy, or whole are inappropriate.

#### Psychiatric disability

Words such as crazy, maniac, lunatic, demented, and psycho are offensive and should never be applied to people with mental health problems... Acceptable terms are people with psychiatric disabilities, psychiatric illnesses, emotional disorders, or mental disabilities.

#### Stroke

Stroke survivor is preferred over stroke victim.

—*Guidelines for Reporting and Writing About People with Disabilities. Research and Training Center on Independent Living for Underserved Population. Fifth Edition, 1996.*

## Suggestions for Working with Individuals with Brain Injury<sup>43</sup>

### 1. Consistency is important

If all those who work with individuals with brain injury get together regularly, common strategies can be developed for use by all. It helps to try to see the person from all aspects. Changes for people with brain injury are difficult to deal with.

### 2. Treat the individual as an adult

Although behavior may be immature at times, the individual is easily embarrassed and will resent being talked “down to.” The individual may be acutely suffering awareness of being “different” (even if denying problems).

### 3. Recovery from brain injury is a learning process

One who understands and practices behavior and learning theories can greatly help. However, any behavior technique must fit the cognitive and emotional deficits. For example, over-stimulation or techniques requiring little repetition will generally not be useful.

### 4. Be patient

Change is slow. Not all problem areas can be addressed at once. Try to develop small steps, which can reinforce progress.

### 5. Over stimulation can hinder progress

The person with a brain injury often takes information more slowly and takes longer to process it. The “normal” pace of conversation and activity may be too much to follow or understand. Watch for overload and signs of frustration.

### 6. Model calm and controlled behavior yourself

The individual with a brain injury may pick up on non-verbal cues better than verbal ones. An individual may have a keen perception of those who really are concerned. Body language conveys a lot . . . try to be calm and friendly. This is especially important when an individual is agitated or irritable. Your calm behavior will also help reduce their fear and anxiety.

### 7. Expect the unexpected

People with brain injuries are more subject to “ups and downs,” mood changes, differences in alertness and attention span. Ability to cope may vary day-to-day or minute-to-minute. Helping the person regain control and be steady is important.

### 8. People with brain injuries are more sensitive to stress

Changes in routines, sleep patterns, colds, minor illnesses, fatigue, unexpected events such as disagreements with others, unkept appointments, etc., can drastically affect function. The individual must concentrate 100% on a task. Any distraction or interruption may produce the inability to perform. These persons need structure, guidance, reasonable demands, and more frequent breaks for mental rest.

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<sup>43</sup> Material on pages 43-44 were taken, with permission, from: Brain Injury Association of Michigan, Traumatic Brain Injury Manual – What You Need to Know. Michigan: Brain Injury Association of Michigan, 1996.

## **9. Individual may get worse before getting better**

As the recovery period lengthens, the person may become more aware of limitations, more frustrated at inability to deal with day-to-day demands. Behavior may worsen. If not recognized and treated appropriately this stage can become a block to further progress.

## **10. Redirect the person**

People with brain injury are usually very suggestible. If agitated, confused, frustrated or otherwise behaving inappropriately, getting the person's attention and introducing another topic, stimulus, or person may be very effective.

## **Adjustment to Disability**

- Brain injury can be a catastrophic event, which dramatically changes a person and their family. A host of emotional responses may result. Over time, people often find that they adjust to the changes created by the brain injury. Adjustment doesn't mean that people are happy about the changes. Adjustment means they recognize that they cannot be changed, and rather than struggle toward the impossible, begin to set goals and make decisions based on the new self.
- The person who has sustained the brain injury often must develop a new sense of self, and the family must develop a new vision of who the person is. This is a gradual evolutionary process, which can be different for each individual and for each family.
- For the person with a brain injury, learning what a brain injury is, identifying the changes the injury has caused and, ultimately, adjusting to the new limitations resulting from the brain injury can be a challenging and difficult, but often necessary process.
- Family members often experience a similar process. They have the dual challenge of changing their vision of the person with a brain injury while the family is redefined and their role in it changes, too.
- Three general types of individual and family intervention have been identified and may prove to be helpful at different stages of recovery: Information and education; support, problem solving, and restructuring; and formal therapy.

## **How to Help**

Things you need to remember:

1. Reinforce the behaviors you would like to see increase. Like a garden, "water the behaviors you'd like to grow."
2. When safety is not an issue, ignore the behaviors you would like to decrease.
3. Model the behaviors you would like to see.
4. Avoid situations that provoke behaviors you are trying to reduce.
5. Structure the environment; use cues for positive behaviors. Plan rest periods.
6. Redirect the person rather than challenge them.
7. Seek professional help sooner rather than later.

# Appendix

## GLASGOW COMA SCALE (GCS)

### Assessment of Conscious Level

#### Eye Opening

Spontaneous	Opens eyes on own	E 4
Speech	Opens eyes when asked to in a loud voice	3
Pain	Opens eyes upon pressure	2
Pain	Does not open eyes	1

#### Best Motor Response

Commands	Follows simple commands	M 6
Pain	Pulls examiner's hand away upon pressure	5
Pain	Pulls a part of body away upon pressure	4
Pain	Flexes body inappropriately to pain (decorticate posturing)	3
Pain	Body becomes rigid in an extended position upon pressure (decerebrate posturing)	2
Pain	Has no motor response	1

#### Verbal Response (Talking)

Speech	Carries on a conversation correctly and tells examiner where he/she is, who he/she is and the month and year	V 5
Speech	Seems confused or disoriented	4
Speech	Talks so examiner can understand victim but makes no sense	3
Speech	Makes sounds that examiner cannot understand	2
Speech	Makes no noise	1

### Classifying the Severity of Traumatic Brain Injury

<b>Mild</b>	Loss of Consciousness <20 minutes Post-Traumatic Amnesia <24 hours GCS = 13-15
<b>Moderate</b>	Loss of Consciousness $\geq$ 20 minutes and $\leq$ 36 hours Post-Traumatic Amnesia $\geq$ 24 hours and $\leq$ 7 days GCS = 9-12
<b>Severe</b>	Loss of Consciousness > 36 hours Post-Traumatic Amnesia > 7 days GCS = 3-8

# **RANCHO LOS AMIGOS**

## **Levels Of Cognitive Functioning**

To assist all those involved with the treatment and rehabilitation of the Closed Head Injured, a “Levels of Cognitive Functioning Scale” was developed by the Head Injury Treatment Team at Rancho Los Amigos Hospital in Downey, California. This scale depicts certain characteristics of each phase of the recovery process following a head injury.

### **LEVEL I: No Response**

No observable wake/sleep cycle, eye opening or purposeful movement. There is a complete absence of observable change in behavior when the patient is presented with visual, auditory, tactile, proprioceptive, vestibular or painful stimuli.

### **LEVEL II: Generalized Response**

Demonstrates generalized reflex response to painful stimuli. Responds to external stimuli with physiological changes, generalized gross body movement and/or no purposeful vocalization (i.e. eye opening, pupillary dilation, etc.) Responds to repeated auditory stimuli with increased or decreased activity. Responses to stimuli may be the same regardless of type and location of stimuli and they may be significantly delayed.

### **LEVEL III: Localized Response**

Demonstrates withdrawal or vocalization to painful stimuli. Turns towards or away from auditory stimuli. Blinks when a strong light crosses the visual field. Follows moving object, which is passed within the visual field. Responds to discomfort by pulling tubes or restraints. Inconsistent responses are noted to simple commands. May respond to some persons (especially family and friends) but not to others.

### **LEVEL IV: Agitated and Confused Response**

The individual is alert and in a heightened state of activity. They will make purposeful attempts to remove restraints or tubes and crawl out of bed. May perform motor activities such as sitting, reaching and walking but without any apparent purpose or upon another’s request. Hypersensitivity to external and internal stimuli. May cry out or scream out to stimulus even after its removal. May exhibit aggressive or flight behavior. Moods may swing from euphoric to hostile with no apparent relationship to environmental events. Unable to cooperate with treatment efforts. Verbalizations are frequently incoherent and/or inappropriate to activity or environment. Short-term memory is impaired. Goal directed, problem solving, and self-monitoring behaviors are absent.

**LEVEL V: Inappropriate and Confused, Non-agitated Response**

Alert, not agitated but may wander randomly or with a vague intention of going home. May become agitated in response to external stimulation and/or lack of environmental structure rather than internal confusion. Not oriented to person, place or time. The patient is highly distractible, their memory is severely impaired and they may confuse the past and present. May be able to perform previously learned tasks when structure and cues provided. Difficulty learning new information. Goal directed, problem solving, and self-monitoring behaviors are absent. Able to respond appropriately to simple commands fairly consistently with external structure and cues. The patient appears more calm and alert, and responds to simple, familiar commands like “brush your teeth”. Responses to simple commands without external structure are random and non-purposeful. At this stage, the patient can monitor self-care activities with assistance but is unable to learn new information. Verbalizations are often inappropriate and confabulation may exist in this level.

**LEVEL VI: Appropriate and Confused Response**

Marked signs of recovery noted at this level. Consistently able to follow simple commands and actively participate in their therapy program. Memory for past events shows improvement but recent memory remains impaired. Able to use memory aide with maximum assist. With supervision, structure, and cues, goal directed behavior is demonstrated. External cues are required for task completion. Decreased ability to process information. Limited ability to identify consequences to actions. Beginning to show awareness of their impairments, disabilities and safety risks.

**LEVEL VII: Automatic and Appropriate Response**

Able to go through their daily routine automatically often demonstrating a robot-like appearance. Consistently oriented to familiar surroundings but memory may be impaired for specifics. Able to attend to highly familiar tasks for at least 5 minutes in a non-distracting environment. Demonstrates initiative and carry-over for new learning and participates in recreational and social activities. Requires supervision due to lack of judgment, problem solving and planning skills. Sometimes unrealistic regarding future plans. They lack insight into and demonstrate superficial awareness of their disability, even though they can recognize their physical disabilities. They may overestimate their abilities and be unaware of others’ needs and feelings. May be uncooperative. Unable to recognize inappropriate social interaction behavior.

**LEVEL VIII: Purposeful and Appropriate Response**

Patient is alert and fully oriented. Able to integrate and recall past and recent information. Able to independently complete familiar tasks when working in a distracting environment for at least 1 hour. Able to initiate familiar activities with intermittent assistance. Able to use assistive memory devices to recall schedule. Records critical information for later use with intermittent assistance. Aware of their disability but unable to self-monitor and recognize a problem while it is happening. Able to think about consequences of a decision or action with minimal assistance. May be depressed, irritable, and argumentative. Some deficits that still persist are, decreased abstract reasoning, slow rate of processing new information/learning, low frustration tolerance and poor judgment in stressful or unfamiliar situations.

**LEVEL IX: Purposeful and Appropriate Response; Stand-by Assistance on Request**

Able to independently shift back and forth between tasks for at least two consecutive hours. Requires assistance with unfamiliar personal, household, work and leisure tasks. Aware of and acknowledges impairments and disabilities when they interfere with task completion and takes appropriate corrective action but requires stand-by assist to anticipate a problem before it occurs and take action to avoid it. Accurately estimates abilities but requires stand-by assistance to adjust to task demands. Acknowledges other's needs and feelings and responds appropriately with stand-by assistance.

**LEVEL X: Purposeful and Appropriate; Modified Independent**

Able to handle multiple tasks simultaneously in all environments but may require periodic breaks. Able to independently procure, create and maintain own assistive memory devices. Independently initiates and carries out steps to complete familiar and unfamiliar personal tasks but may require more than the usual amount of time and/or compensatory strategies to complete them. Anticipates impact of impairments and disabilities on ability to complete daily living tasks and takes action to avoid problems before they occur. Able to independently think about consequences of decisions or actions but may require more than the usual amount of time and/or compensatory strategies to select the appropriate decision or action. Accurately estimates abilities and independently adjusts to task demands. Able to recognize the needs and feelings of others and automatically respond in appropriate manner. Irritable and low frustration tolerance noted when ill, fatigued and/or under emotional stress.

*Information on the Cognitive Stages of Recovery was taken from a study guide called "Cognitive Treatment of the Closed Head Injured Patient". Copyright, 1983. Cardinal Hill Hospital, Lexington, Kentucky and from "TBI Rehabilitation: An Interdisciplinary Approach Based Upon The Revised Rancho Levels of Cognitive Functioning", a presentation by Chris Hagen in June 2001 in Detroit, Michigan.*

## Identifying a Possible Brain Injury<sup>44</sup>

A history of physical abuse, a fall, or an accident resulting in any of the following issues help to identify an individual with a brain injury.

### Verbal Issues

- Poor speech
- Monotone
- Vulgarity/swearing
- Talks too loud or too soft
- Difficulty “finding” words
- Broken speech

### Personality Issues

- Denies deficits
- Appears unmotivated
- Egotistical
- Doesn’t listen
- Asks a lot of questions
- Argumentative
- Manipulative
- Irritable
- Moody – laughs or cries easily

### Social Issues

- Poor eye contact
- Inappropriate social interaction (overly formal, overly friendly)
- Interrupts conversation
- Goes off on tangents
- Doesn’t recognize “personal space”
- Inappropriate conversation (sex, drugs, alcohol abuse, etc.)
- Fabricates stories/lies

### Behavioral Issues

- Wanders off/runs away
- Impulsive (acts without thinking)
- Repeated invasion of personal space
- Short fuse

### Thinking Issues

- Easily distracted
- Seems to “space out”
- Difficulty understanding
- Difficulty with reality
- Seems confused
- Poor memory
- Decreased safety awareness
- Slow to answer questions
- Difficulty organizing (time, etc.)

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<sup>44</sup> Material on page 50 was taken, with permission, from: Brain Injury Association of Michigan, Traumatic Brain Injury Manual – What You Need to Know. Michigan: Brain Injury Association of Michigan, 1996.

## TBI Model Systems

The TBI Model Systems are funded through the National Institute on Disability and Rehabilitation Research (NIDRR). There were five TBI Model Systems originally established in 1987. There were 12 new centers named in 1998. As of 2015 there are 16 active centers. The focus of the Model Systems is the comprehensive delivery of care to individuals with brain injury, from acute neurological care through community integration. Model systems were established to demonstrate and evaluate the cost/benefit and outcomes of a comprehensive system of service delivery for individuals with brain injury. For more information about the TBI Model Systems, visit their web site at: <http://www.tbindsc.org>

### **University of Alabama at Birmingham Traumatic Brain Injury Care System**

Spain Rehabilitation Center  
1717 6<sup>th</sup> Avenue South  
Birmingham, AL 35233-7330  
Thomas Novack, Ph.D., Project Director  
205.934.3454  
[www.uab.edu/tbi](http://www.uab.edu/tbi)

### **Rocky Mountain Regional Brain Injury System**

Craig Hospital  
3425 S. Clarkson Street  
Englewood, CO 80110  
Gale G. Whiteneck, Ph.D., Project  
Director  
303.789.8204  
[www.craighospital.org](http://www.craighospital.org)

### **South Florida Traumatic Brain Injury Model System**

University of Miami, Miller School of  
Medicine  
Healthsouth Rehabilitation Hospital  
20601 Old Cutler Rd  
Miami, FL 33189  
David S. Kushner, M.D., Project Director  
305.243.3887  
[www.umpmr.med.miami.edu](http://www.umpmr.med.miami.edu)

### **Indiana University School of Medicine Rehabilitation Hospital of Indiana TBI Model System**

4141 Shore Drive  
Indianapolis, IN 46254

Flora Hammond, M.D., Project Director  
317.329.2000  
[www.rhin.com](http://www.rhin.com)

### **Spaulding/Partners Traumatic Brain Injury Model System at Harvard Medical School**

Spaulding Rehabilitation Hospital  
125 Nashua Street  
Boston, MA 02114

Mel Glenn, M.D., Project Director  
617.573.2625  
[www.sh-tbi.org](http://www.sh-tbi.org)

### **Mayo Medical Center**

Department of Physical Medicine and  
Rehabilitation  
St. Marys Hospital  
1 Domitilla  
Rochester, MN 55905

Allen W. Brown, M.D., Project Director  
507.255.5123  
[www.mayoclinic.org](http://www.mayoclinic.org)

### **Northern New Jersey Traumatic Brain Injury System**

Kessler Medical Rehabilitation Research and  
Education Corporation  
1199 Pleasant Valley Way  
West Orange, NJ 07052

Nancy D. Chiaravalloti, Ph.D., Project  
Director  
973.324.8440

[www.kesslerfoundation.org/researchcenter/tbi/modelsystems.php](http://www.kesslerfoundation.org/researchcenter/tbi/modelsystems.php)

**New York Traumatic Brain Injury Model System**

Icahn School of Medicine at Mount Sinai  
Department of Rehabilitation Medicine  
3 East 101<sup>st</sup> Street, Room 118

New York, NY 10029  
Wayne Gordon, PhD., Project Director  
212.824.8372

[www.icahn.mssm.edu/research/programs/new-york-traumatic-brain-injury-model-system](http://www.icahn.mssm.edu/research/programs/new-york-traumatic-brain-injury-model-system)

**Rusk Rehabilitation Traumatic Brain Injury Model System**

Rusk Rehabilitation, Ambulatory Care Center  
New York University School of Medicine  
240 East 38<sup>th</sup> Street

New York, NY 10016  
Steven R. Flanagan, M.D., Project Director

212.263.6033  
[www.rusk.med.nyu.edu/brain-injury-rehabilitation-program](http://www.rusk.med.nyu.edu/brain-injury-rehabilitation-program)

**The Ohio Regional TBI Model System Department of Physical Medicine and Rehabilitation**

Wexner Medical Center at Ohio State University  
2145 Dodd Hall, 480 West 9<sup>th</sup> Avenue  
Columbus, OH 43210  
John D. Corrigan, Ph.D., Project Director  
614.293.3830

[www.ohiovalley.org](http://www.ohiovalley.org)

**TBI Model System of Pennsylvania at Moss Rehabilitation/MRRI**

Korman Suite 213  
1200 West Tabor Road  
Philadelphia, PA 19141  
Tessa Hart, M.D., Ph.D., Project Director  
215.456.5925

[www.einstein.edu/mossrehab/rehab\\_2.html](http://www.einstein.edu/mossrehab/rehab_2.html)

**University of Pittsburgh Traumatic Brain Injury Model System**

Department of Physical Medicine & Rehabilitation  
Kaufmann Medical Building, Suite 202  
Pittsburgh, PA 15213

Lauren Kessler, M.D., Project Director  
412.692.4354

[www.rehabilomics.pitt.edu](http://www.rehabilomics.pitt.edu)

**TBI Model System of TIRR**

Brain Injury Research Center  
2455 South Braeswood  
Houston, TX 77030-4305  
Mark Sherer, Ph.D., Project Director  
713.799.7007

[www.tirr.memorialhermann.org/research/traumatic-brain-injury-model-system/](http://www.tirr.memorialhermann.org/research/traumatic-brain-injury-model-system/)

**Baylor Institute for Rehabilitation**

Univ. of Texas Southwestern Medical Center  
909 N. Washington  
Dallas, TX 75246  
Caryn Harper, Ph.D., Project Director  
[www.baylorhealth.com/BIR/](http://www.baylorhealth.com/BIR/)

**The Virginia Commonwealth TBI Model System**

Virginia Commonwealth University/Medical College of Virginia Campus  
Box 980542  
1200 E. Broad Street  
Room 3-102  
Richmond, VA 23298-0542  
Jeffrey Kreutzer, Ph.D., Project Director  
804.828.3704  
[www.tbinrc.com](http://www.tbinrc.com)

**University of Washington Traumatic Brain Injury Model System**

University of Washington  
Department of Rehabilitation Medicine  
Box 356490  
Seattle, WA 98195  
Jeanne Hoffman, Ph.D., Project Director  
206.543.0219  
[www.tbi.washington.edu](http://www.tbi.washington.edu)

## Rehabilitation Research and Training Centers

Rehabilitation Research and Training Centers (RRTCs) are supported and funded by the National Institute on Disability and Rehabilitation Research (NIDRR). There are two RRTCs which specifically address traumatic brain injury and the needs of persons with brain injury.

### **RRTC on Community Integration of Persons with Traumatic Brain Injury**

Mt. Sinai Medical Center  
Department of Rehabilitation Medicine  
One Gustave L. Levy, Box 1240  
New York, NY 10029  
(212) 348-7917  
(212) 348-5901 Fax

### **RRTC on Rehabilitation Interventions in Traumatic Brain Injury**

The Institute for Rehabilitation and Research  
133 Moursund Avenue  
Houston, TX 77030  
(713) 666-9550  
(713) 668-5210 Fax

## Regional Traumatic Brain Injury Rehabilitation and Prevention Centers

There are currently two Regional Traumatic Brain Injury Rehabilitation and Prevention Centers. Each TBI center undertakes a number of specific projects to accomplish its goals. Activities of these centers include projects to: eliminate the barriers to the provision of services; develop innovative vocational rehabilitation programs for people with brain injury; conduct programs aimed at both primary and secondary prevention of brain injury; and develop models of community re-entry and substance abuse treatment. The two TBI Centers are:

### **Southeastern Comprehensive Head Injury Center**

University of Alabama at Birmingham  
1521 11<sup>th</sup> Avenue, South  
Birmingham, AL 35294-4551  
(205) 934-2442

### **Ohio Valley Center for Brain Injury Prevention and Rehabilitation**

1335 Dublin Road, Suite 50-A  
Columbus, OH 43215-1000  
(614) 293-3802