

Meeting the Needs of Persons Living with Brain Injury



New York Association on Independent Living

Margo B. Singer, CBIS

Brain Injury Association of NYS

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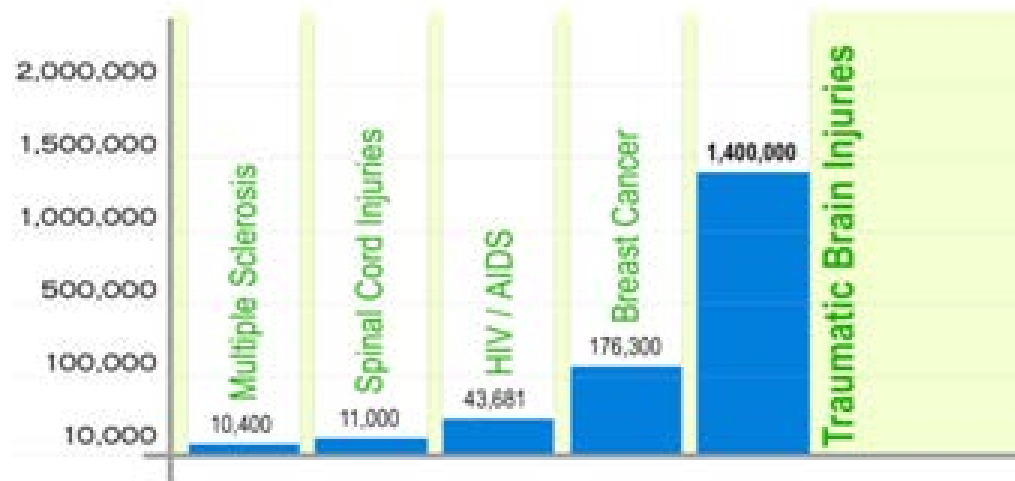
Epidemiology

- Every **13.1 seconds**, one person in the United States sustains a traumatic brain injury.
- An estimated **10 million Americans** are affected by stroke and TBI . . . which makes brain injury the second most prevalent injury and disability in the United States.
- **1.5 million** Americans survive traumatic brain injuries each year.
- More than **52,000 people die** every year as a result of traumatic brain injury.
- An estimated **\$60 Billion** in direct medical costs & lost productivity

Comparative Incidence

Comparison of Annual Incidence

A Comparison of Traumatic Brain Injury and Leading Injuries or Diseases



Brain Injury Association of America, 2005

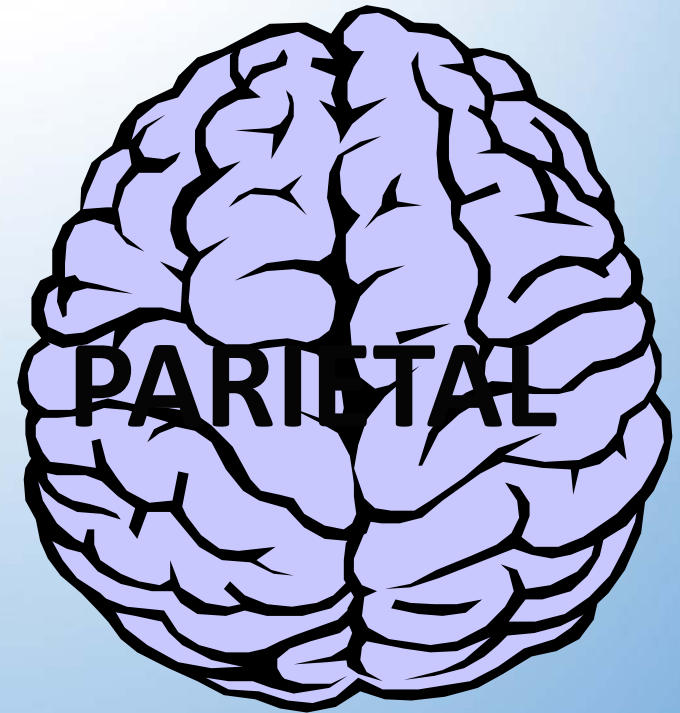
The Brain

Controls everything we do:

- ...breathing
- ...walking
- ...talking
- ...thinking
- ...behaving
- ...feeling

FRONTAL

TEMPORAL



OCCIPITAL

Acquired Brain Injury

Injury to the brain that has occurred after birth and is not hereditary, congenital or degenerative. The injury commonly results in a change in neuronal activity, which affects the physical, metabolic or the functional ability of the cell.

It does not refer to brain injuries induced by birth trauma.

It also excludes: Congenital Disorders, Intellectual Disability, Cerebral Palsy, Birth Injuries, Progressive Disorders (such as Alzheimer's Disease), and Psychiatric Disorders

Causes of Acquired Brain Injury:

- Aneurysm
- Tumors
- Stroke
- Encephalitis or meningitis
- Anoxia
- Insulin shock, liver and kidney disease
- Strangulation, airway obstruction
- Traumatic brain injury
 - Gunshot wound
 - Concussion blast injuries
 - Head hitting windshield
 - Severe whiplash
 - Shaken Baby Syndrome
- Toxic exposure (CO, lead paint, neurotoxins)

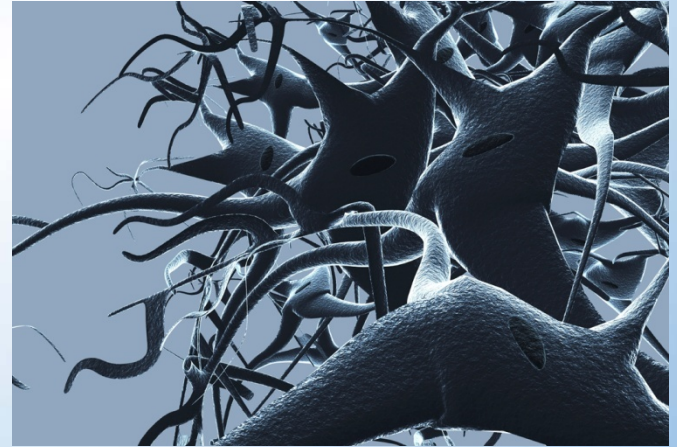
Traumatic Brain Injury

Traumatic Brain Injury is an insult to the brain caused by an external physical force, when the head:

- hits a stationary object (e.g., windshield in a car crash)
- is hit (e.g., mugging)
- is penetrated (e.g., gunshot wound)
- is violently shaken by external force (e.g., Shaken Baby Syndrome, severe whiplash)

How Brain Damage Occurs

The brain is a very complicated organ, with millions of cells and connections.



While specific areas of the brain may be related to specific functions, in reality each function (walking, lifting an arm, speaking, etc.) involves many areas of the brain communicating and interacting with each other.

How Brain Damage Occurs

- Focal Damage
 - Skull Fracture
 - Contusion or bruises under the location of a particular area of impact
- Fronto-Temporal Contusions/Lacerations
 - Bruising of brain or tearing of blood vessels in the frontal and temporal lobes of the brain caused by brain hitting or rotating across ridges inside skull
- Diffuse Axonal Injury
 - Shifting and rotation of brain inside skull will result in tearing and shearing injuries to the brain's long connecting nerve fibers or axons

How Brain Damage Occurs

Some time after the injury, the following may affect the brain:

- Hematoma (Blood Vessel Damage)
- Brain Swelling
- Increased Intracranial Pressure
- Intracranial Infection
- Seizures

Common Problems after Brain Injury

Can be categorized into the following broad functional areas:

- PHYSICAL
- COGNITIVE
- EXECUTIVE FUNCTIONING
- AFFECTIVE/BEHAVIORAL
- PSYCHOSOCIAL

Common Problems After Brain Injury

Physical

Loss of Smell and Taste
Hearing Difficulties
Visual Difficulties
Balance Difficulties
Speech Difficulties
Motor Control and Coordination
Fatigue
Seizures
Decreased Tolerance for Drugs and Alcohol
Headaches
Sleep Disturbances

Common Problems After Brain Injury

Cognitive

Short Term/Working Memory

Attention

Concentration

Distractibility

Decreased Verbal Fluency/Comprehension

Information Processing speed/slowed reaction time

System Arousal

Problem Solving

Changed Intellectual Functioning

Abstraction and Conceptualization

“Flooding”

Common Problems After Brain Injury

Executive Functioning

Goal Setting

Self-Monitoring

Planning

Initiating

Modifying

Bringing to Completion

Time Management

Common Problems After Brain Injury

Affective/Behavioral

Impulsivity

Emotional Lability

Irritability

Decrease Frustration Tolerance

Impaired Judgment

Tension/Anxiety

Depression

Aggressive Behaviors

Disinhibition

Changed Sexual Drive

Changed Personality

Common Problems After Brain Injury

Psychosocial

- Educational/Vocational Problems
- Family Issues
- Interpersonal Difficulties
 - Sexuality
 - Alcohol/Drugs
- Intra-Personal Difficulties
 - Loss of Self Esteem
 - Depression/Frustration
 - Shaken Sense of Self
 - Profound Sense of Loss

Further Challenges

- Community Resources
- Environment of Care
- Adaptive Equipment
- Informal Supports
- Vulnerability to Abuse/Neglect
- Socialization
- Medication Management/Compliance
- General Safety
- Dietary Compliance
- Behavior

Don't Assume

- Don't be misled by what looks like a personality trait or a willful decision, that may be a behavior related to the brain injury.
- Think outside the box, sometimes things are not what they seem.
- **Don't underestimate...** there are still many strengths and abilities to utilize.

Working with Brain Injury

It is very important to understand the people you work with so that you know what they are capable of doing for themselves and what they need help with (e.g., the type and level of support).

Don't Overestimate: they also have areas of need and a lack of self-awareness that may not be readily visible.

Working with Brain Injury

- **ROAD** to help and support an individual with a brain injury:
 - **R**ead/Review
 - **O**bserve
 - **A**sk Questions
 - **D**on't Assume

Understanding the Person

The use of a neuropsychological evaluation is helpful for determining what strategies will be useful to the person.

The neuropsychological evaluation shows us how the person learns best.

It is important to understand how the neuropsychological evaluation translates into the daily experience of the person.

Strategies

- Monitor for fatigue/pain, allow rest breaks in the day
- Present information in slow format, break big projects into manageable pieces, chunk information
- Use a multisensory approach
- Extra time to process and form response
- Repeat, assess, repeat, assess comprehension
- Scripts: “Goal, plan, do, review” or “stop, think, do”
- Increased supervision without increasing dependency
- Communication should be clear & concise

Strategies

Attention/Concentration

- Reduce distractions in the person's work area
- Divide work into small sections – have person complete one section at a time
- Pay attention to lights and sounds that may act as CNS irritants → increase fatigue → increase behaviors → decrease learning capacity
- Preferential seating, visually clean, low stimulus environment (tables clean, chairs pushed in, easily scanned)
- Create brain injury friendly environment

Memory

- Frequently repeat and summarize information
- Teach person to use devices such as sticky notes, calendars, and assignment books as self-reminders to compensate for memory problems

Additional Considerations

- Be encouraging
- Focus on strengths (yours & theirs)
- Acknowledge their struggle
- Use humor
- Use non confrontational approach
- When agitated, allow for time to decompress
- Offer choices, empower the person
- Use Person Centered approach

Additional Considerations

- You work for the individual
- Be honest but gentle and tactful
- Don't take things personally
- Treat everyone with DIGNITY & RESPECT
- Don't talk down to the person
- Allow for grief
- Avoid arguments or blame game
- Respect your differences
- Understand cultural & personal values
- This is hard!!!
- Progress may be slow, but keep at it

Additional Considerations

- Privacy, home environment
- Delicate balance between assisting and increasing independence
- Dignity of Risk
- Can VS Can't
- Right to Fail
- Take care of yourself by seeking supervision and support from your supervisors & peers
- Give yourself a pat on the back for a job well done!!!

Additional Considerations

- Structure the person's day, use a schedule to help orient them
- Allow for pre-sets in the schedule, "in 5 minutes we will have to go to lunch"
- Offer choices "would you like to go in 3 minutes or 5 minutes"?
- Pay attention to what happens before, during, and after the behavior (A, B, C's)
- What purpose does the behavior serve? (reward, escape, attention)
- Praise the positive, ignore the negative (when able)

Additional Considerations

- Gain attention first before making a demand
- Use a positive, upbeat tone
- Limit sarcasm
- Multisensory approach
- Remember that what works one day, might not work the next
- This is an invisible injury and it is unpredictable due to fatigue, and a variety of variables



BIANYS is:

- Membership organization of individuals with brain injury, family members, professionals, clinicians, providers and advocates
- The NYS affiliate of the Brain Injury Association of America (BIAA)
- A Statewide organization with a volunteer Board of Directors

The mission of BIANYS is to improve the quality of life for the individuals with brain injury and their families and friends, and to prevent injury. BIANYS provides extensive information about all aspects of brain injury, rehabilitation services, living in the community, and prevention.

The Brain Injury Association of New York State

- FAMILY HOT LINE -- Statewide Resource & Referral
- Family Advocacy, Counseling & Training Services Program (FACTS)
- Support Groups
- Training
- Annual Conference & Professional Symposium
- School Resources
- Public Awareness & Advocacy
- Prevention
- Website www.bianys.org and Facebook page

GET The FACTS!!

- **F**amily **A**dvocacy, **C**ounseling and **T**raining **S**ervices
- Funded by the NYS Office for People with Development Disabilities (OPWDD)
- A statewide support program for families and individuals who sustained a Brain Injury prior to age 22.
- FACTS Coordinators are employees of the Brain Injury Association of NYS
- Located in each region of the State.
- They are not clinicians or direct service providers

Thank you for listening!

The Brain Injury Association of New York State

10 Colvin Avenue

Albany, NY 12206

(518) 459-7911 (518) 482-5285 fax

(800) 444-6443 FAMILY HELP LINE

Email: info@bianys.org

Website: www.bianys.org