NEW YORK ASSOCIATION ON INDEPENDENT LIVING

Meeting the Needs of People Living with Brain Injury

Karen Thomas, CBIST BIANYS

Director of Family Services

Brain Injury Association of New York State

10 Colvin Avenue
Albany, NY 12206
518-459-7911
800-444-6443

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Brain Injury: A Silent Epidemic

Epidemiology

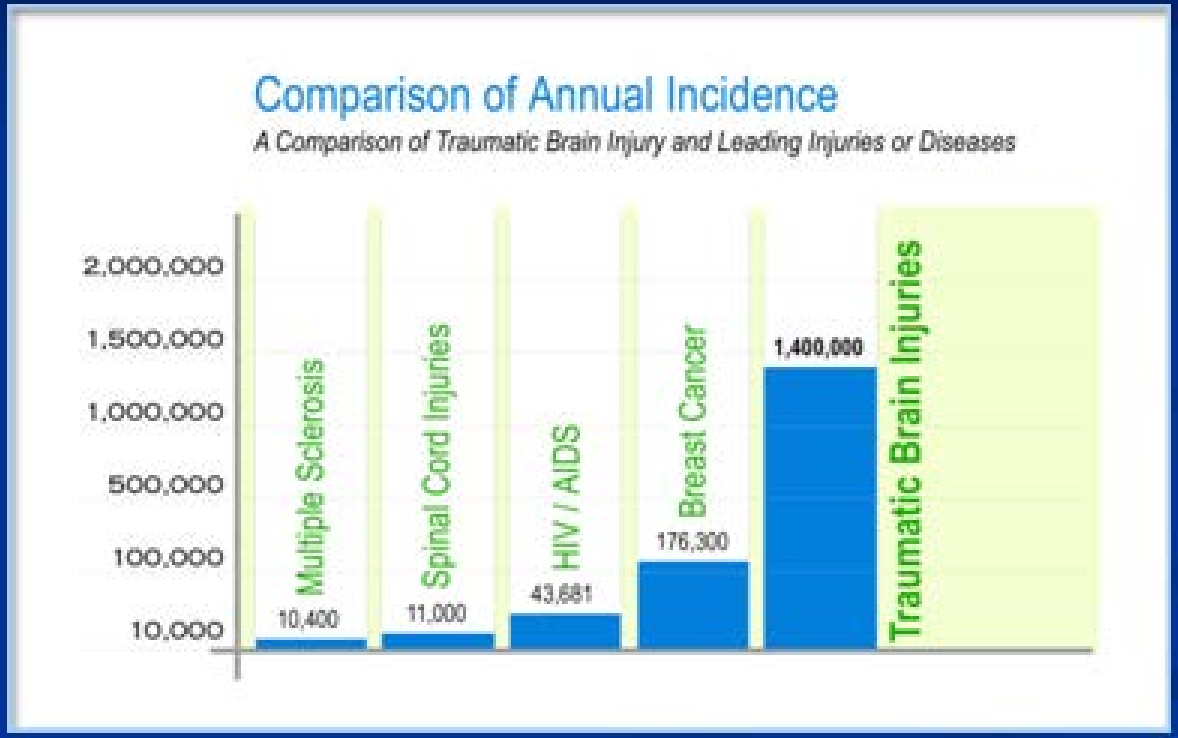
- Every 13.1 seconds, one person in the United States sustains a traumatic brain injury.

- According to the Centers for Disease Control, there were 2.5 million TBI's in 2010. This only includes the reported ED Visits, Hospitalizations, and deaths. This number does not include ABI or those who sought help at a primary care doctor or pediatrician.

- More than 50,000 people die every year as a result of traumatic brain injury. (138 per day)

- 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.

Comparative Incidence



Brain Injury Association of America, 2005

The Brain

Controls everything we do

…breathing

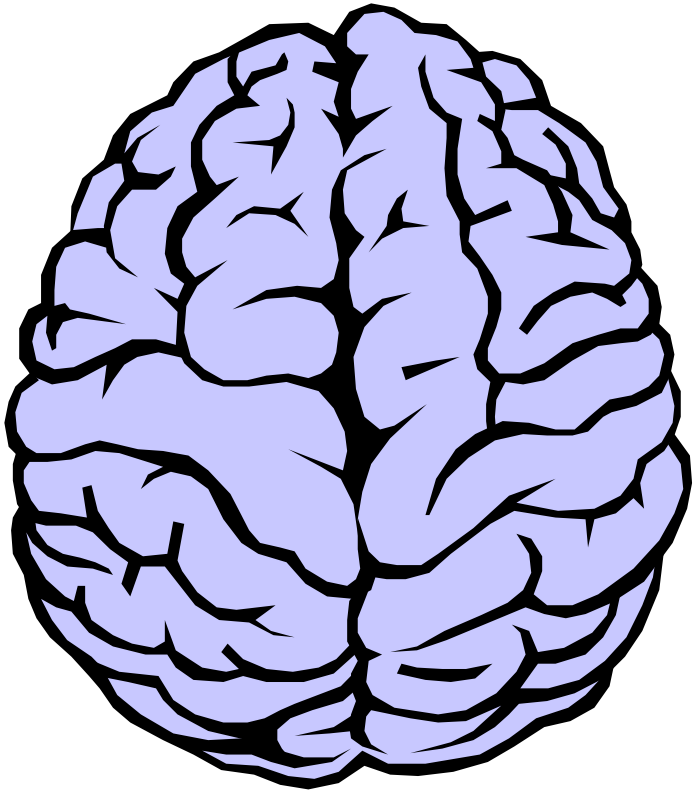
…walking

…talking

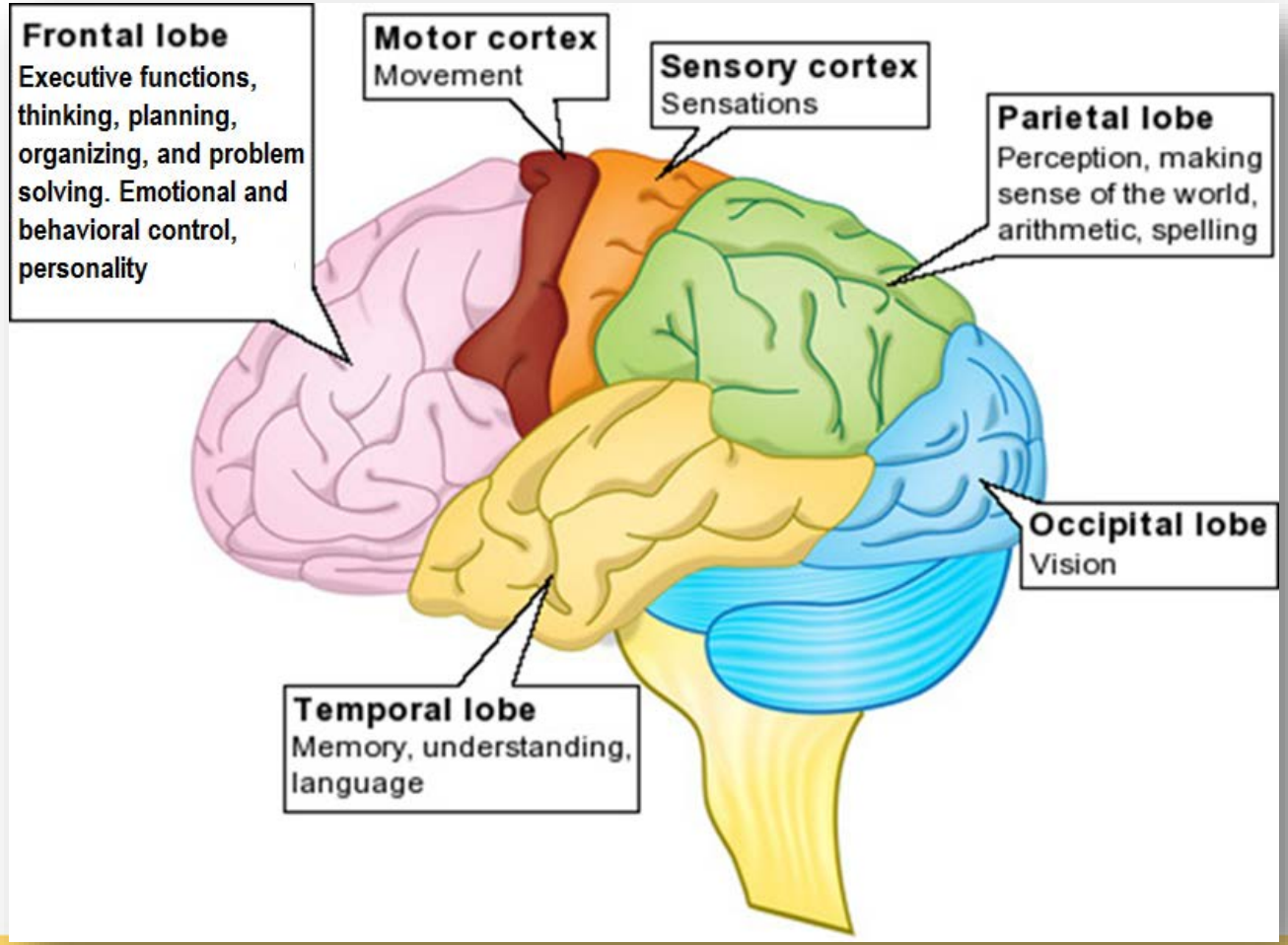
…thinking

…behaving

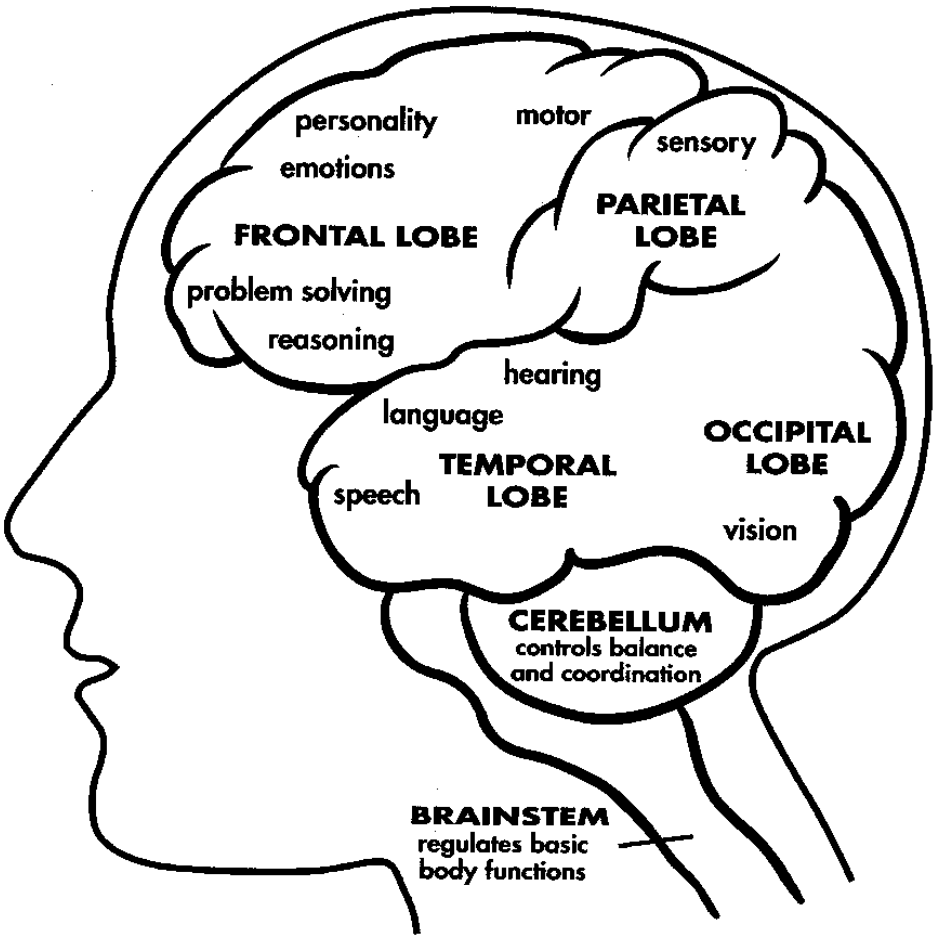
…feeling



The Brain


Frontal lobe
Executive functions, thinking, planning, organizing, and problem solving. Emotional and behavioral control, personality
Motor cortex
Movement
Sensory cortex
Sensations
Parietal lobe
Perception, making sense of the world, arithmetic, spelling
Occipital lobe
Vision
Temporal lobe
Memory, understanding, language

The Brain


personality
emotions
motor
sensory
FRONTAL LOBE
problem solving
reasoning
PARIETAL LOBE
hearing
language
speech
TEMPORAL LOBE
OCCIPITAL LOBE
vision
CEREBELLUM
controls balance and coordination
BRAINSTEM
regulates basic body functions

Definition – 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.

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)

Acquired Brain Injury Excludes:

- Progressive Disorders
  - Alzheimer's Disease
- Psychiatric Disorders
- Congenital Disorders
  - Intellectual Disability
  - Cerebral Palsy
  - Birth Injuries*

Definition – 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

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 in a TBI

- 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 in a TBI

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 TBI/ABI

- 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

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 mislead 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
- 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
- This is hard!!!
- 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

The Brain Injury Association of New York State

- Project LEARNet
- BITS Program
- Support Groups
- Family Advocacy, Counseling & Training Services Program (FACTS)
- Statewide resources
- CBIS Review and Exam
- Annual Conference & Professional Symposium

Resources

- New York Independent Living Center
- NYS Office for the Aging
- NYS Department of Health
- Consumer Directed Program
- NY Connects

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

Thank You for your time & attention!