

**“UNDERSTANDING TBI – A WALK  
THROUGH A YOUNG WOMAN’S  
LIFE AFTER INJURY”**

**“KNOWLEDGE IS POWER.  
INFORMATION IS LIBERATING.  
EDUCATION IS THE PREMISE OF PROGRESS.”**

**- KOFI ANNAN**

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# Today we will be covering....

- What is ABI/TBI?
- What are common side effects caused by ABI/TBI?
- What are the best compensatory strategies to use when assisting someone with ABI/TBI?
- What is the most effective continuum of care for ABI/TBI?
- How can we best assist person's with ABI/TBI when transitioning back into the community?
- How does MFP apply to ABI/TBI?
- How can the Brain injury Association of NC assist a person living with an ABI/TBI?



# Acquired Brain Injury (ABI)

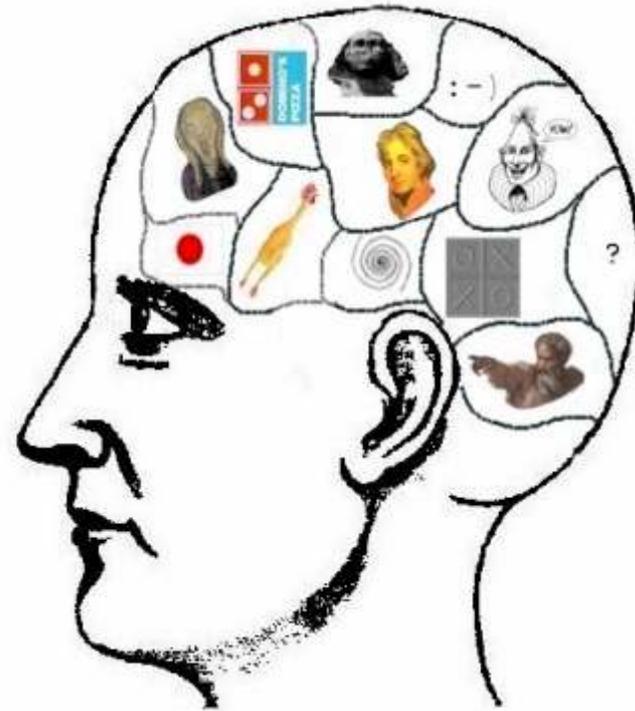
What is an Acquired Brain Injury (ABI)?

- An Acquired Brain Injury is brain damage caused by events after birth, rather than as part of a genetic or congenital disorder such as fetal alcohol syndrome, perinatal illness or perinatal hypoxia. ABI is often sudden and without warning.

Examples:

- Stroke, Aneurysm, Infection to the brain, Anoxia (a lack of oxygen to the brain), Tumor, Traumatic Brain Injury

# What is TBI?



# Traumatic Brain Injury (TBI)

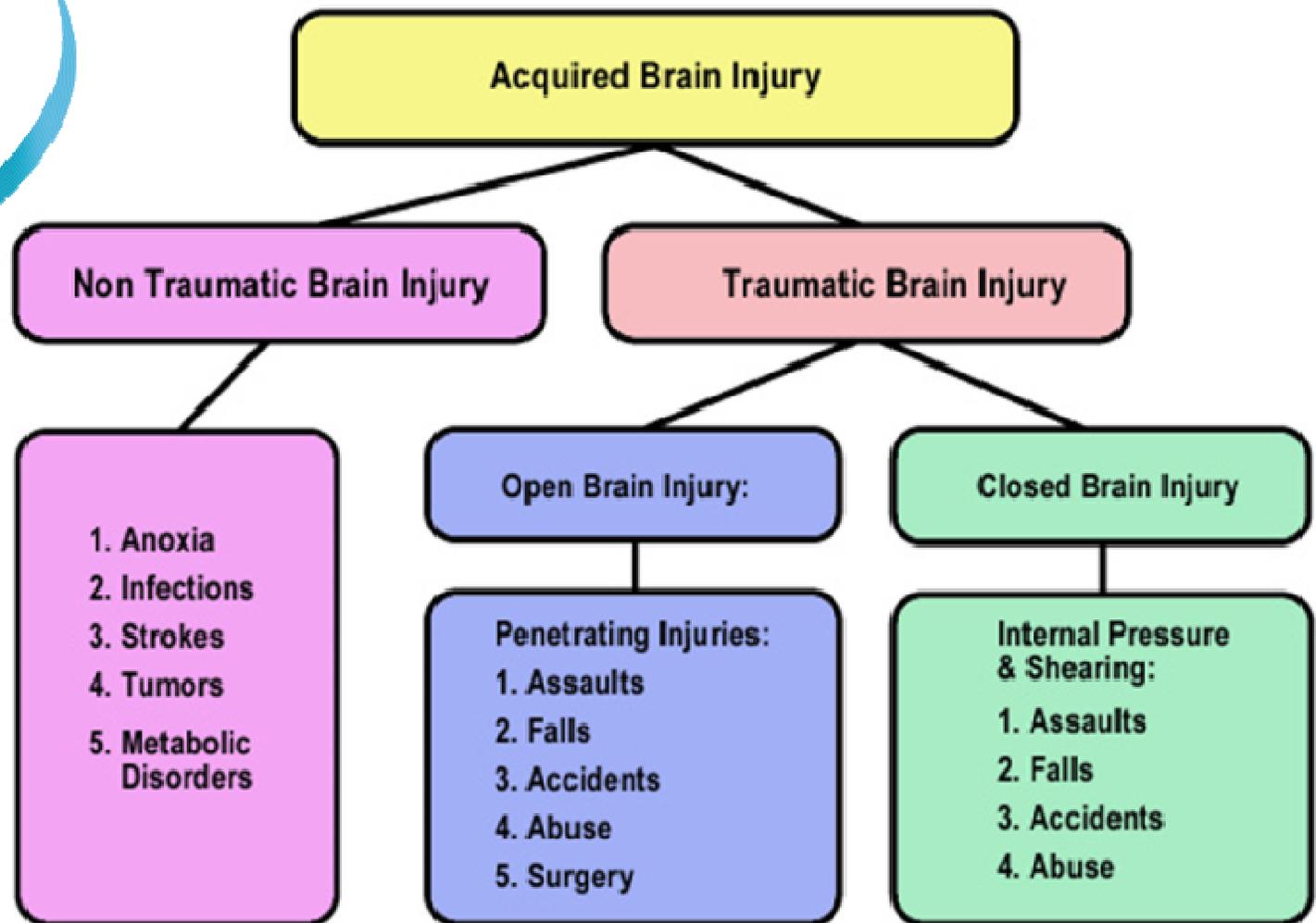
What is a Traumatic Brain Injury (TBI)?

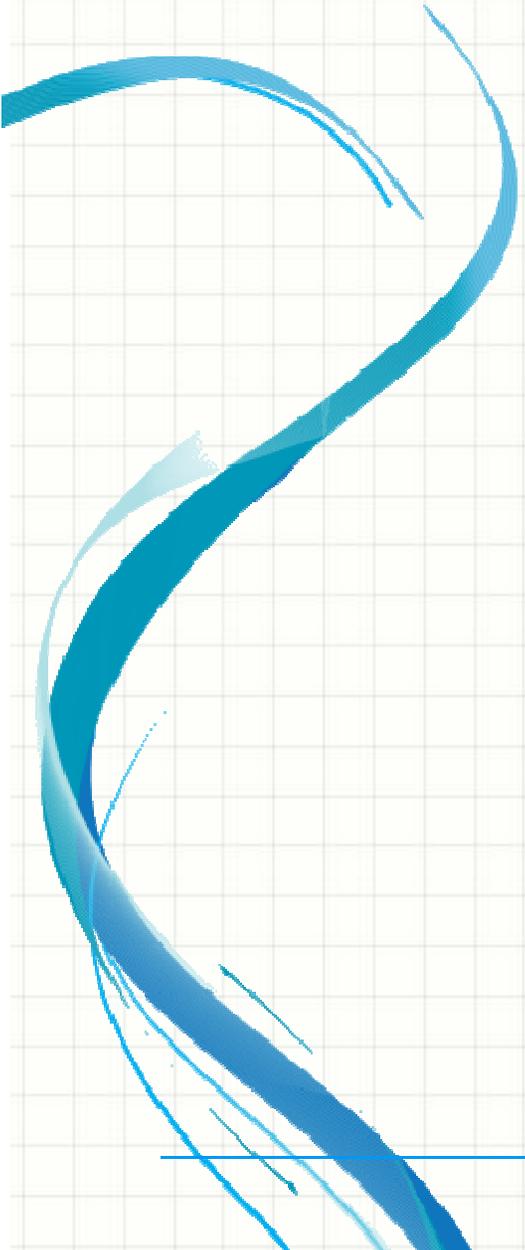
- A Traumatic Brain Injury (TBI) is an injury to the brain caused by an external, mechanical force.
- A TBI is often caused by a violent blow or jolt to the head or body.
- TBI is not caused by a degenerative or congenital nature
- TBI may produce a diminished or altered state of consciousness
- TBI may result in impairments of cognitive abilities or physical functioning
- TBI can also result in disturbance of behavioral or emotional functioning

## Examples:

- Falls
- Motor Vehicle-Traffic Crashes
- Bicycle/Motorcycle/ATV/Scooters/Etc. Collisions
- Gunshot Wounds
- Assaults
- Shaken Baby Syndrome





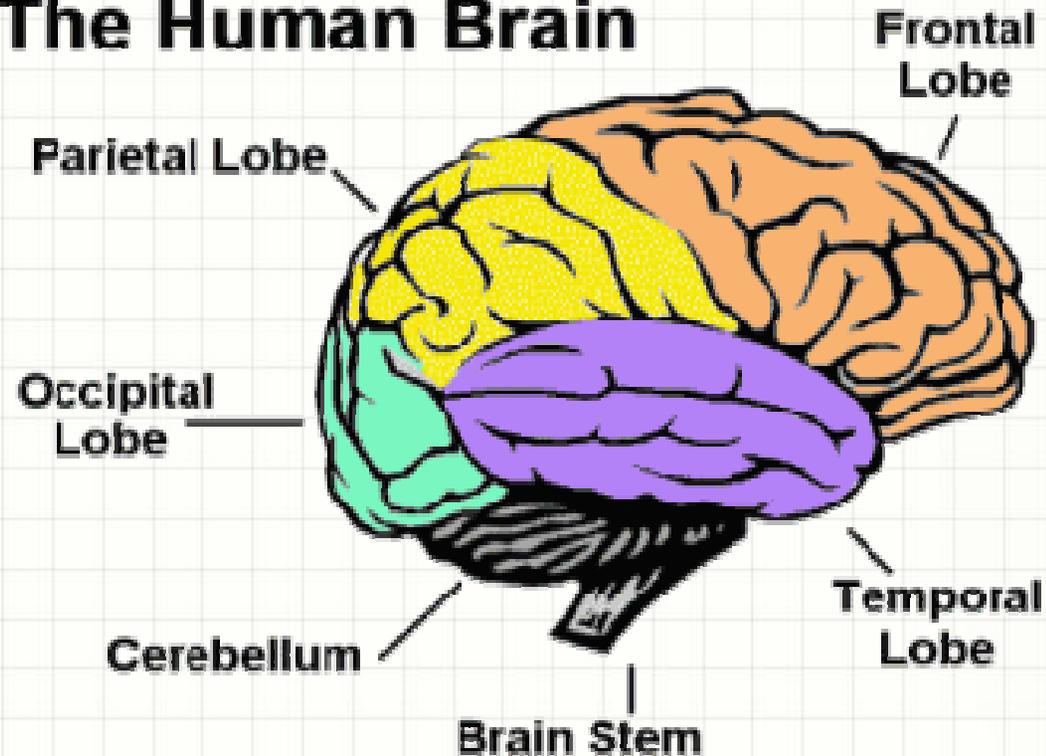


Have you ever stopped to think about how your mind and body works and what controls the intricate thoughts and movements that create YOU as an individual?

What would happen if one “connection” came loose or became blocked?

# What's Where?

## The Human Brain



# SIMPLIFIED BRAIN-BEHAVIOR RELATIONSHIPS

## PARIETAL LOBE

- Sense of Touch
- Differentiation: Size, Shape, Color
- Spatial Perception
- Visual Perception

## OCCIPITAL LOBE

- Vision

## CEREBELLUM

- Balance
- Coordination
- Skilled Motor Activity

## BRAIN STEM

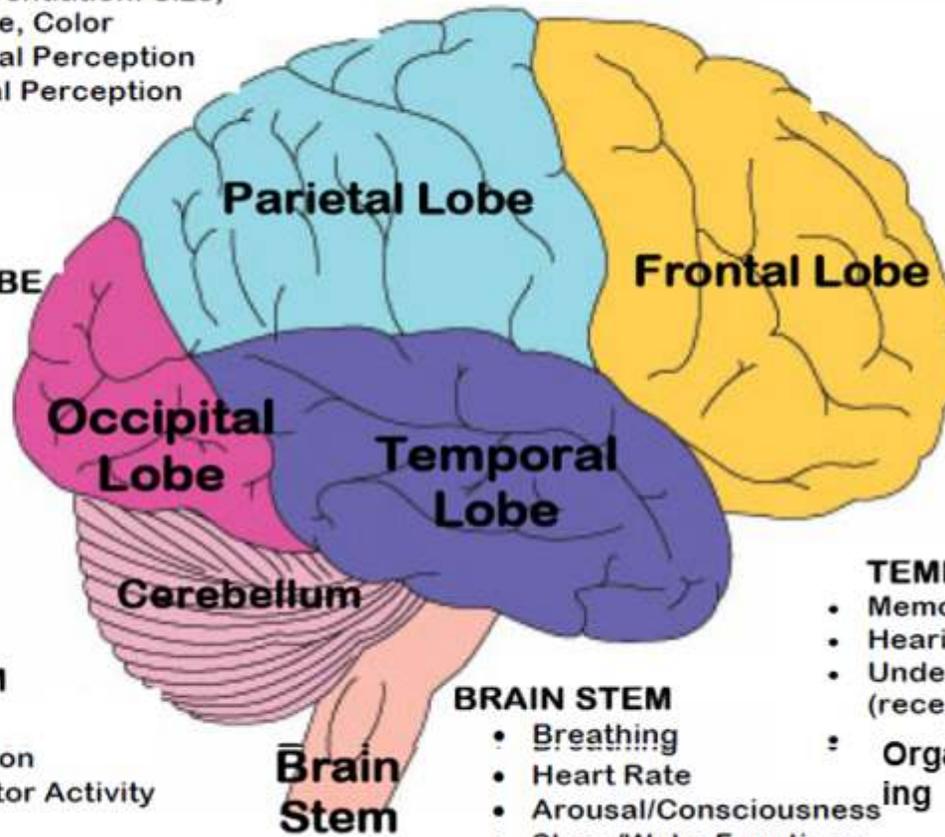
- Breathing
- Heart Rate
- Arousal/Consciousness
- Sleep/Wake Functions
- Attention/Concentration

## FRONTAL LOBE

- Initiation
- Problem-Solving
- Judgment
- Inhibition of Behavior
- Planning/Anticipation
- Self Monitoring
- Motor Planning
- Personality/Emotions
- Awareness of Abilities/Limitations
- Organization
- Attention/Concentration
- Mental Flexibility
- Speaking (Expressive Language)

## TEMPORAL LOBE

- Memory
- Hearing
- Understanding Language (receptive language)
- Organization/Sequencing



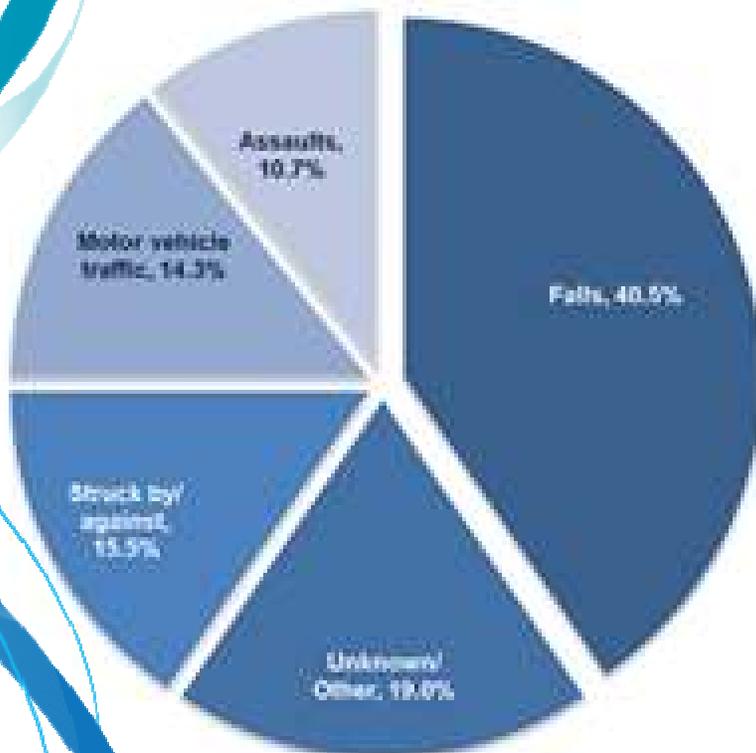
Project STAR at Carolinas Rehabilitation



**BRAIN INJURY  
ASSOCIATION**  
OF NORTH CAROLINA

# Major Causes of TBI

Leading Causes of TBI



Falls are the leading cause of TBI's due to our aging population, however vehicle crashes most often result in hospitalization and moderate to severe TBI's.

(CDC, 2015)

# 2015 Breaking News.....

- Traumatic Brain Injury costs our state over **\$2,500,000,000** a year!
- Insurance does not adequately cover the costs of care for TBI victims because many services such as cognitive retraining are not considered “medically necessary”.
- According to the CDC, roughly 2% of the population is currently living with TBI-related long term disabilities!
- In NC, this translates into approximately **198,000** of our fellow citizens

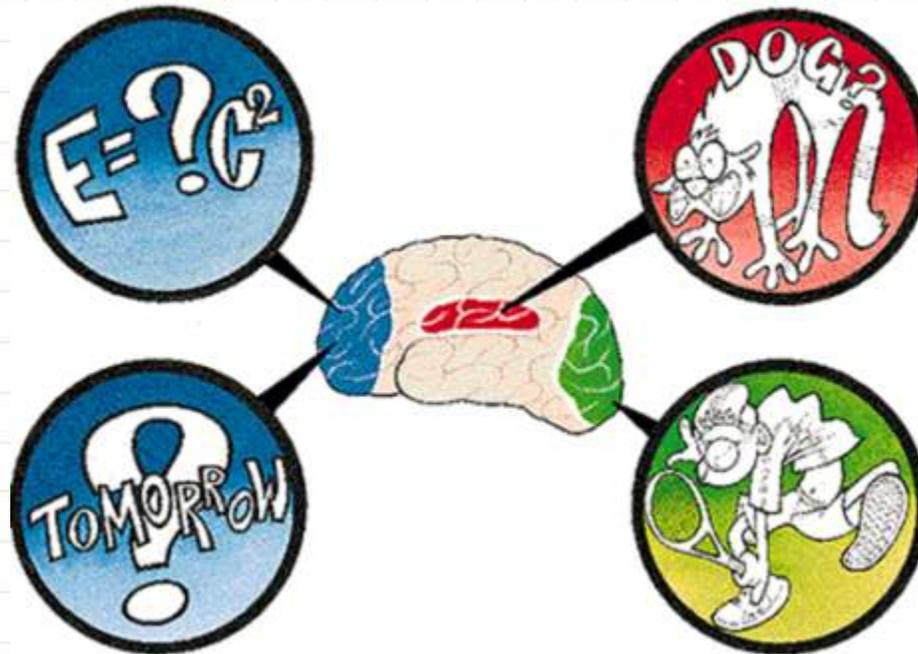
# If that number isn't high enough, add our injured military to the total count...



- NC has the third highest military population in the U.S.
- 33% of returning service members report symptoms of a mental health or cognitive condition. (Rand 2008)
- 19.5% of returning service members reported experiencing a probable TBI. (Rand 2008)

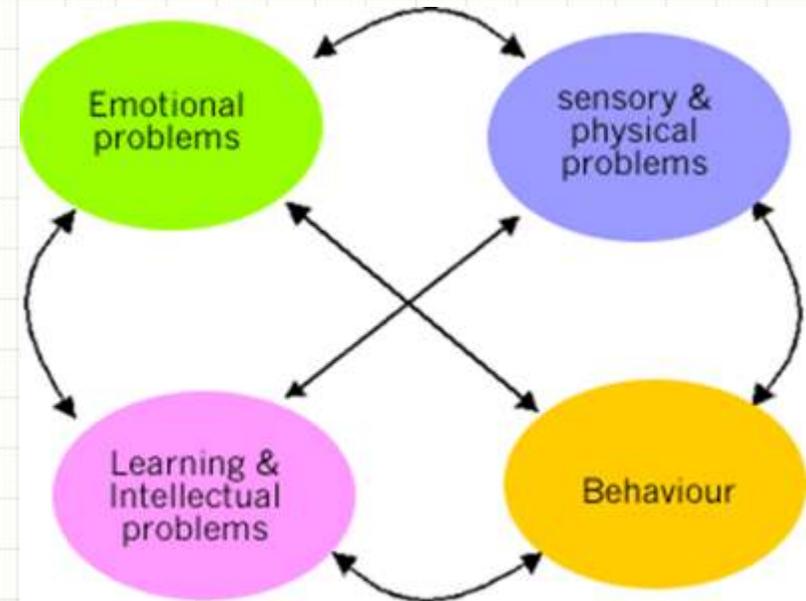
# Consequences of Brain Injury

What are common side effects caused by ABI/TBI?



# What might change....

- Physical Functioning
- Intellectual Ability
- Cognition
- Communication Skills
- Behaviors and Emotions



# Physical Consequences



- Seizures
- Muscle spasticity
- Changes in vision or hearing
- Loss of smell or taste
- Headaches
- Weakness or paralysis

# Physical Consequences

- Fatigue
- Balance and coordination difficulties
- Difficulty swallowing
- Changes in sensation
- Changes in sleep patterns



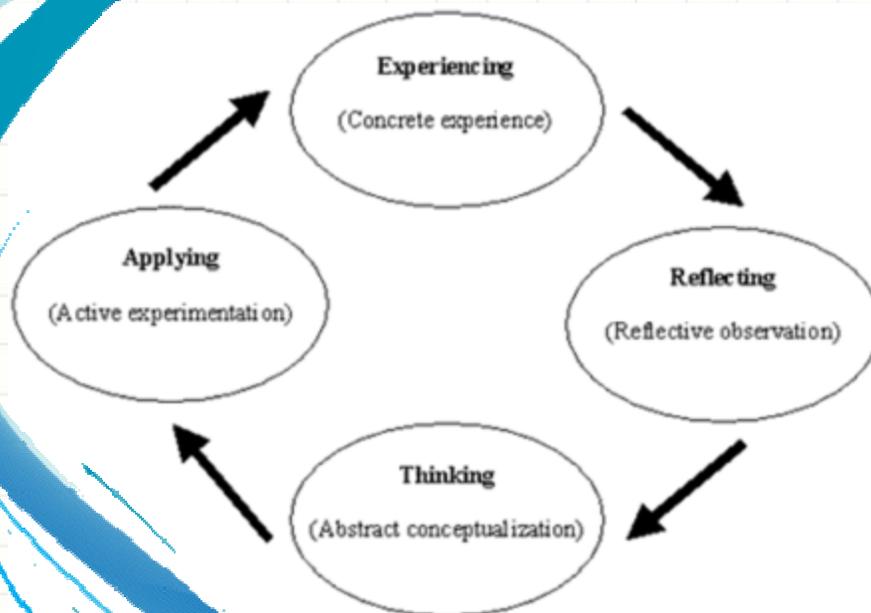
# Cognitive Consequences

## May Include:

- Short and long-term memory loss
- Planning and Organizational difficulties
- Difficulty with reasoning, problem solving, and decision making
- Difficulty initiating activities

# Cognitive Consequences

- Attention/concentration difficulties
- Difficulty with new learning
- Slowed responses
- Impaired judgment
- Disorientation
- Perseveration
- Mental Fatigue



# Communication Consequences



- Difficulty initiating conversation
- Difficulty finding words
- Difficulty taking part in a conversation
- Unaware of other's or own body language
- Perseveration
- Inappropriate wording or connection to topic

# Behavioral and Emotional Consequences



- Anxiety or irritability
- Depression
- Egocentricity
- Difficulty controlling emotions
- Disinhibition or impulsiveness
- Impaired self awareness

# Impulsiveness



*impulsive (adj.)*

motivated by emotion rather than thought; spontaneous actions based on desires, whims or inclinations

# Brain Teaser...

Read This....

Accdrnig to a rseearch sduty at Cmabrigde Uinervtisy, it deosn't mttar in waht oredr the ltteers in a wrod are, the olny iprmoetnt tihng is taht the frist and lsat ltteer be in the rghit pdae. The rset can be a toatl mses and you can sitll raed it wouthit porbelm. Tihis is bcuseae the huamn mnid deos not raed ervey lteter by istlef, but the wrod as a wlohe.



# **WHAT CAN WE DO?**

What are the best compensatory strategies to use when assisting someone with ABI/TBI?

# Strategies for Cognitive Difficulties:

- Use of planner, tape recorder, check lists, palm pilot—Visual Cues
- Use step by step written and verbal instructions
- Develop routines
- Structure environment



# Strategies for Cognitive Difficulties:



- Reduce distractions
- Build on “old learning”
- Encourage repetition of instructions
- Consistent review

# Communication Strategies



- Ask open-ended questions
- Do not ask yes-no questions
- Rephrase the question
- Give extra time to respond
- Cue by using the first sound of the word
- Pre-arrange a signal/ cue to indicate when conversation is being dominated
- Ask the person how their comments relate to the topic

# Communication Strategies

- Let the individual know of your difficulty following their conversation
- Model clear topic changes for the individual to observe
- Respectfully inform individual when he/she has made the same comments or shared the same story several times
- Make the person aware of how his/her actions differ from what he/she is saying.
- Provide on-the-spot feedback
- Redirection

# What can we do?



- Do not ignore the behavior
- Provide on-the-spot feedback
- Benefits of group intervention
- Never reinforce the behavior
- Be specific about why change is needed
- Provide a positive model for behavior
- Teach social interaction skills
- Provide positive feedback

# Direct Skills Training

- Role playing
- Modeling
- Skills Generalization
- Specific Skills Instruction

... AND  
**ACTION!**

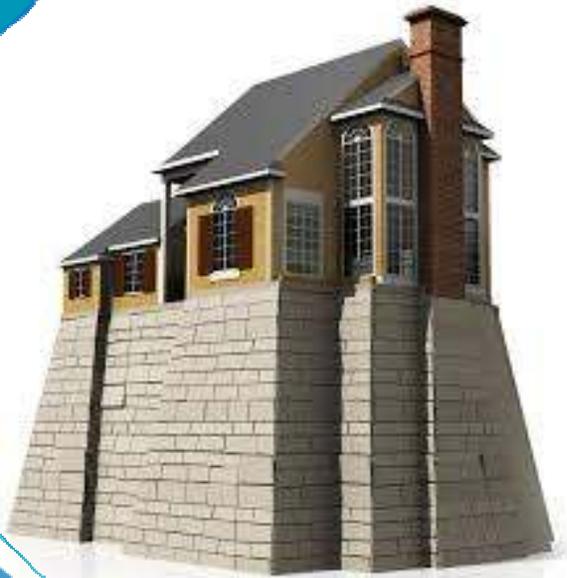


# Developing Community Opportunities and Supports for Individual with Brain Injury

- Individuals need opportunities to develop compensatory strategies.
- Individuals must have opportunities to understand what and where strategies are needed—increase awareness.
- Opportunities to develop daily and weekly routines and structure.
- Support and guidance may assist with developing realistic short term and long term goals.
- May be a long process!!!!!!!!!!!!

# Key Elements of Successful Intervention

- Structure
- Consistency
- Repetition
- Assure you have attention before proceeding
- Using clear and simple language
- With immediate reinforcement
- Identify key person/s
- Overlearn and habituate learned skills
- Pair old learning with new learning
- By all team members



# Key Elements of Successful Intervention Continued..

- Build on strengths and successes
- Systematic gradation of intervention activities
- Habituate and then generalize
- Provide choices and encourage initiation when ever possible



# Get To Know The Person

## **Person Centered Thinking**

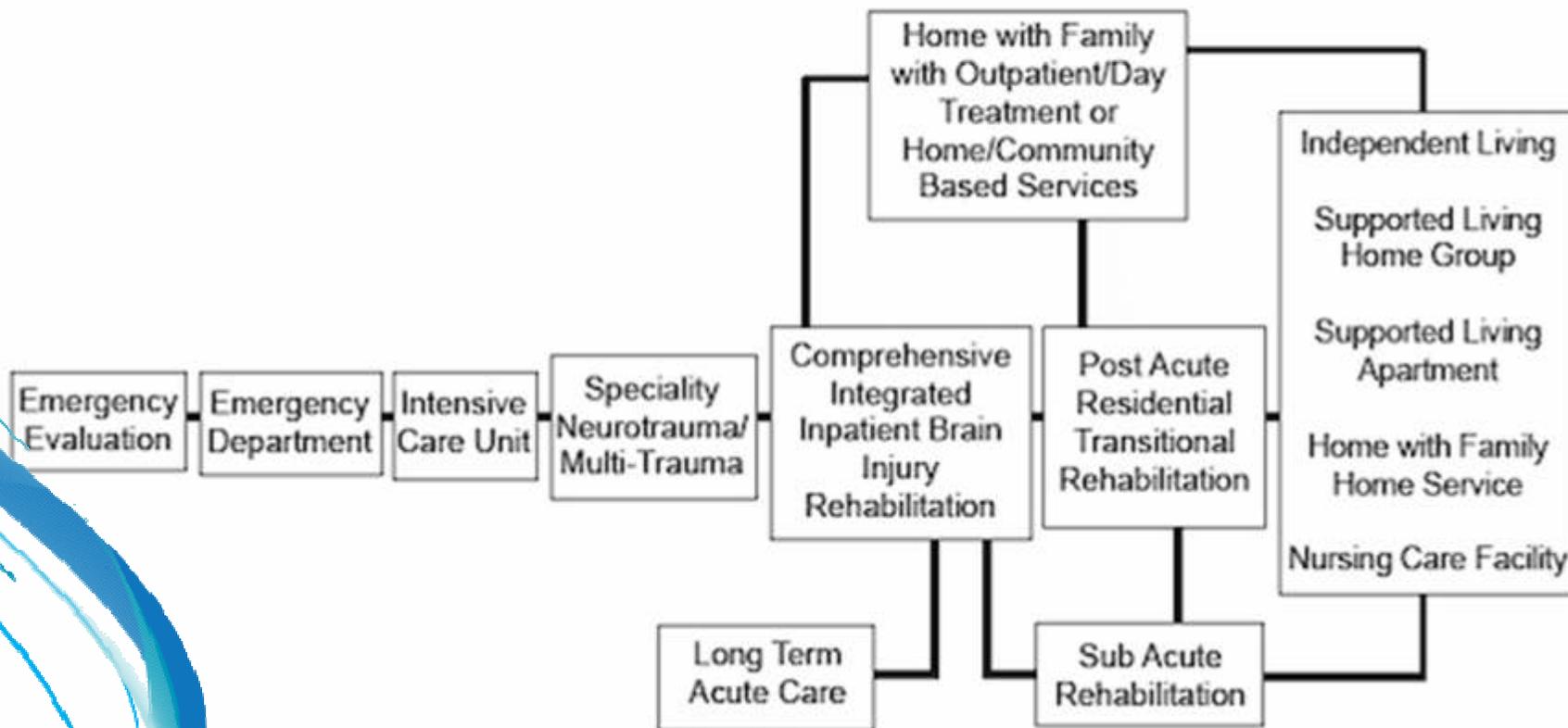
In a system-centered approach you see someone as a client and focus on their deficits and their needs, which lead you to certain conclusions as to what kind of treatment the client needs or what kind of support the client needs. In a person-centered approach, we see someone as a person first, not someone who is defined by their disability. By understanding who this person is, we see the person in terms of the person's capacities; we appreciate the person for what the person can do, for the gifts the person has, and how the person can contribute to others. This shifts thinking to how can we help the person have as normal a life as possible. This does not mean ignoring the disability but rather supporting it in as normal a way as possible. The focus is on supporting the personhood as much as possible.



What is the most effective  
continuum of care for  
ABI/TBI?

# Traumatic Brain Injury Continuum of Care

Adapted from the Rocky Mountain Regional Brain Injury System to depict the continuum of care for individuals with moderate and severe TBI



# Meet Kate....



- Kate is a 35 year old female who sustained a TBI after an automobile accident.
  - Kate has difficulty with Short Term Memory, Anxiety, Executive Functioning Skills, and is no longer able to walk independently.
  - Kate has her MBA and wants to continue with her job at a local marketing firm.
  - Kate wants to keep her apartment near her friends in the city.
- 
- Kate is a very social person, who enjoys hanging out with her friends on the weekends, yoga, camping, kayaking, reading, and traveling.
  - Kate has dreams she has not given up on and is determined to not allow her injuries hold her back.

# Who is there to assist Kate?



- Kate's family lives out of town. Though they are extremely supportive and stay in touch with her regularly, it is difficult for them to assist Kate due to the distance. Without someone giving up their current life, job, residents, etc., they can only assist over the phone or during visits. This leaves Kate responsible for finding additional support.



Where does Kate turn?

# Kate's Social Outlet....



- Kate has always been active in her community, but is now limited by income and mobility challenges. Her once busy social schedule has now become limited due to the amount of time it takes for her to get from point A to point B. The positive reinforcement she once received from these interactions is now decreased and this is emotionally taxing to Kate in an already challenging time.

What does Kate do?



## Kate attempts to juggle her healthcare needs...

Kate's executive functioning deficits are causing her difficulties with the organization of information and the ability to follow through with processes. She has a lack of understanding of her own deficits and though she tries to explain her needs this is a challenge. Over time, Kate's frustration triggers an increase in her anxiety, anger, and depression. Due to Kate's difficulty with Executive Functioning, Kate has trouble keeping up with all of her appointments and daily schedule. Kate could benefit from an advocate or Care Manager, that knows her story and the challenges she has but this is no longer an option.

She has tried reaching out and calling for help but she finds herself talking to someone new each time and has to try to explain her situation again. Due to her difficulty with memory and communication, this is not always an easy task and she runs into issues getting the assistance that she needs.





# Kate gets a Direct Support Professional

- Kate's family has hired a Direct Support Professional who provides personal care assistance once daily. Because Kate is no longer able to walk, it is challenging for her to handle all of the daily household responsibilities she has and it is also difficult for her to maintain some of her personal healthcare needs.
- Due to the frequent turn over, she is constantly having to re-train her staff. She gets along with some of the DSP's but not all of them. This adds additional emotional stress to Kate's plate. Not only is she having to get used to being dependent on others for help, she is also having to get used to total strangers regularly.
- With depression and anxiety being the two top side effects of TBI, Kate is already struggling with her emotional stability. Having all of these additional challenges is causing this to become even worse.

# Getting Kate a Primary Care Doctor



Kate finds a primary care doctor to help her with her needs. Once again, Kate finds the frequent turn over to be an issue. In addition, her primary care doctor has very little knowledge about TBI or community resources. Because of the lack of knowledge, the primary care doctor does not realize he has to communicate with Kate differently, use compensatory strategies like written notes describing her medications, an extra call before scheduled appointments, etc. When Kate misses an appointment, it takes 2 weeks to get another. Kate is out of her medication and she can't get more until she has her appointment.

# Kate's Employment is at Risk....

Kate has had some physical difficulty due to pressure soars. Kate is extremely fatigued by the long week she has experienced while attempting to get medical care and this is causing her anxiety and confusion to become worse. She is trying to remember all of the directions she was given by her doctor but is feeling overwhelmed and lost. Her DSP does not come again until morning. Kate is alone.

Kate has missed more than her allotted days of work due to the trouble she's been having and her boss is beginning to question her ability to do her job. Kate has tried working from home, but the fatigue is causing her cognition to worsen and the skills she needs for her job to decrease. What will she do without the money and insurance she gets from her job? Kate is terrified at the risk of losing this and her anxiety worsens.

Her friends are enjoying their Friday nights events and Kate is feeling very down because she can't transport herself, she is physically and mentally drained, she's feeling extremely depressed about the changes that have occurred in her life and she is having trouble creating a plan to improve her current situation.



# Cost of Medication and Side Effects...



Kate's medication to assist with her attention, anxiety, and depression and the therapist she is seeing are costing her over \$300 a month.

Some of the supplies she is needing for wounds and wheelchair are considered OTC, so it is out of pocket. Kate has been asked to work part time and her budget is not able to cover all that she needs. Kate is beginning to realize her independence is at risk and she may not be able to live alone.



In addition, Kate was given medication to assist with her anxiety and depression. The side effects of the medication are causing Kate to become extremely tired. Kate is becoming more forgetful with her fatigue and misses a day of her medication. The inconsistency is causing additional mood swings. Kate is feeling more and more agitated and distraught. She has become closed off and the friends who are closest to her don't understand why Kate's personality has changed so much, so they are coming around less frequently.



## Kate realizes she has to look for alternative living options...

Kate finally realizes her inability to find the appropriate help and her lack of funding has gotten to be too large of a burden. Kate ends up at the emergency room for a second visit. From the hospital she is discharged to a skilled nursing facility because it is evident her safety is at risk. Kate's feelings about her situation have exacerbated her current deficits related to her TBI and caused additional challenges.

In order to move, Kate has to give up her job. Her circle of friends no longer come to visit. She feels cut off from her world at 35.

Had Kate had further assistance from those who understood the needs of TBI survivors from the start, some of these challenges could have been prevented.



How can we best assist person's  
with ABI/TBI when transitioning  
back into the community?

# What could have been done differently for Kate so that she could remain living independently in her community?



- Discharge Planning: Kate could have benefitted from a more individualized transition plan.
- Advocate: Kate could have used help communicating during important service settings.
- Support Groups: Kate could have benefitted from the opportunity to meet others who could relate to her challenges. Building supportive relationships and finding a commonality with a new social group could have minimized the depression.
- Vocational Rehabilitation: Kate could have used Vocational Rehabilitation to educate her employer on appropriate modifications to assist her in keeping up with her work. Assistive Technology could have benefitted Kate with tools to strengthen her memory, organization and communication.
- TBI Informed Providers: Without knowledge the correct approach to care can be missed.

# Know Your Resources -



- Awareness of community services available
- Include family and friends in screening/assessment
- Home Visits
- Awareness that needs may not be apparent
- Give the consumer written information
- Reminder calls



## Where does TBI fit in the North Carolina MH/IDD/SA System?

### How does MFP apply to ABI/TBI?

- Traumatic Brain Injury (TBI) is generally treated under Intellectual & Developmental Disabilities (IDD) in the state of NC for service provision and funding purposes (by statute) when a person qualifies for IDD services.

# Definition of Developmental Disability

- (12a) "Developmental disability" means a severe, chronic disability of a person which:
  - a. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
  - b. Is manifested before the person attains age 22, **unless the disability is caused by a traumatic head injury and is manifested after age 22;**
  - c. Is likely to continue indefinitely;



# Definition of Developmental Disability

- d. Results in **substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, capacity for independent living, learning, mobility, self-direction and economic self-sufficiency; and**
- e. Reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated;



# Funding Options in NC Managed by each LME/MCO

Medicaid

State Funded (non Medicaid)

- Single Stream State Service Definitions
- TBI Specific non UCR state dollars



# Federal Definition of DD

- Only includes TBI that occurs before the age of 22
- Consumers with a TBI which occurred after the age of 22 are not able to participate in Innovations Waiver services



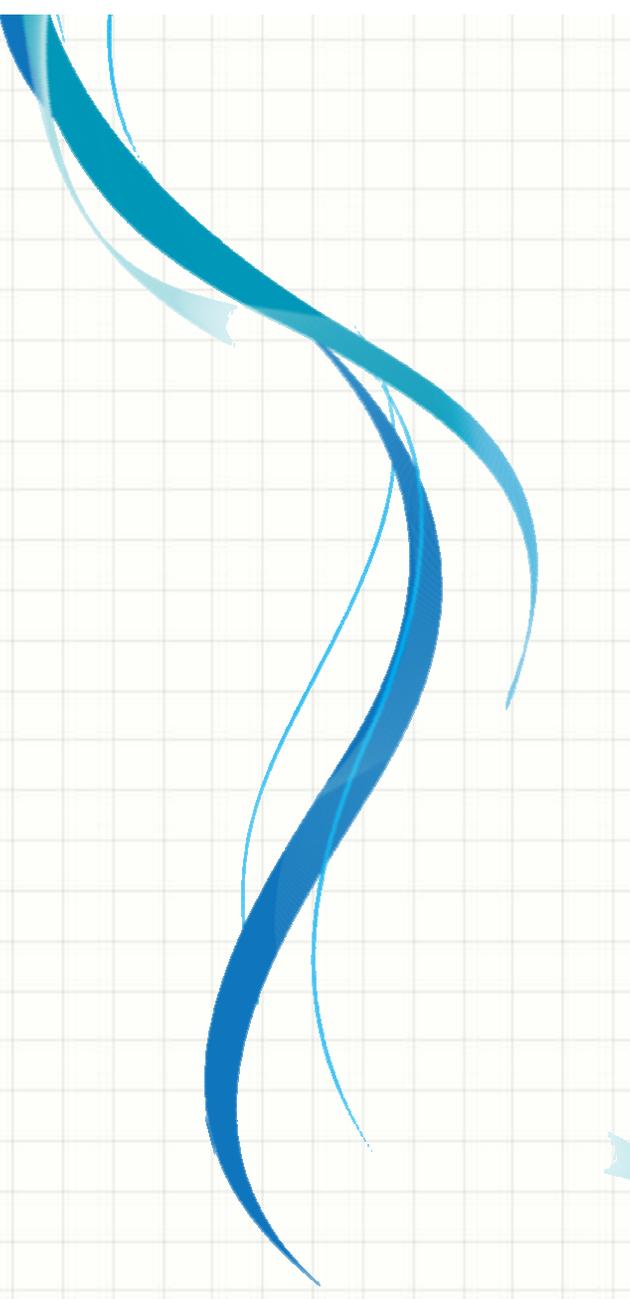
# Medicaid waiver programs:

- Innovations 1915(c) IDD and TBI (injured prior to age 22)
- 1915 (b) MH and/or SA
- CAP DA (Disabled Adult)



How can the Brain injury  
Association of NC assist a  
person living with an  
ABI/TBI?

quiet  
goals breathe help  
encourage patience learn  
heart love Caregiver  
assist  
understanding  
family



“We offer help,  
hope, and a voice  
for people with  
brain injury and  
their families.”

- We answer support and resource calls, from survivors, family members, and professionals In need.
- We are active in our communities, getting to know our local and statewide partners. This is extremely important in making the right referrals for our clients.
- We provide an updated **Online Resource Book**.
- We plan educational and training programs, fundraising events, and support events.
- We facilitate local and regional support groups, assisting in the initial training of their leaders, and assuring their ongoing success.
- We work closely with case managers, and discharge planners throughout our states medical facilities as a part of the Brain Injury Continuum of Care, assisting in community reintegration.
- We work on legislative and advocacy initiatives to improve the rights of those living with brain injury.



# Discharge Planning Assistance

The Brain Injury Association of NC has:

- A list of community practitioners trained in TBI
- A list of TBI programs in NC
- Brain Injury Resource Centers to help find community resources
- Trained ombudsmen
- Over 30 local brain injury support groups

Assistance from the DMH/DD/SAS state TBI Program,  
accessed through LMEs



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**Toll Free: 800-377-1464**



# North Carolina Resources

- **Free Online Training with Certificate**  
[www.nctbitraining.org/](http://www.nctbitraining.org/)
- **Information about the DMH/DD/SAS TBI Program:**  
[www.ncdhhs.gov/mhddsas/services/tbi/index.htm](http://www.ncdhhs.gov/mhddsas/services/tbi/index.htm)
- **TBI & Service Members, Veterans, Families**  
[www.veteransfocus.org/](http://www.veteransfocus.org/)
- **Brain Injury Association of NC**  
[www.bianc.net/](http://www.bianc.net/)
- **Neuro-Restorative Knowledge Center**  
[www.neurorestorative.com](http://www.neurorestorative.com)