CENTER *for*
BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Traumatic Brain Injury (TBI) Across the Lifespan: What Advocates Should Know

Lori G. Cook, Ph.D., CCC-SLP
Director of Pediatric Brain Injury Programs
Senior Clinician, Brain Performance Institute
Adjunct Asst. Professor, School of Behavioral & Brain Sciences
The University of Texas at Dallas

CENTER *for*
BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

THE VISION

Empower people of all ages to unlock their brain potential.

Center for BrainHealth® MISSION

Lead scientific research to enhance, protect and restore brain health across the lifespan.

Brain Performance Institute™ MISSION

Deliver brain science innovations to enhance how people think, work and live.

Traumatic Brain Injury (TBI) Focus Areas

ID & MONITORING

REGENERATION

RESILIENCE

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Why study brain injury?

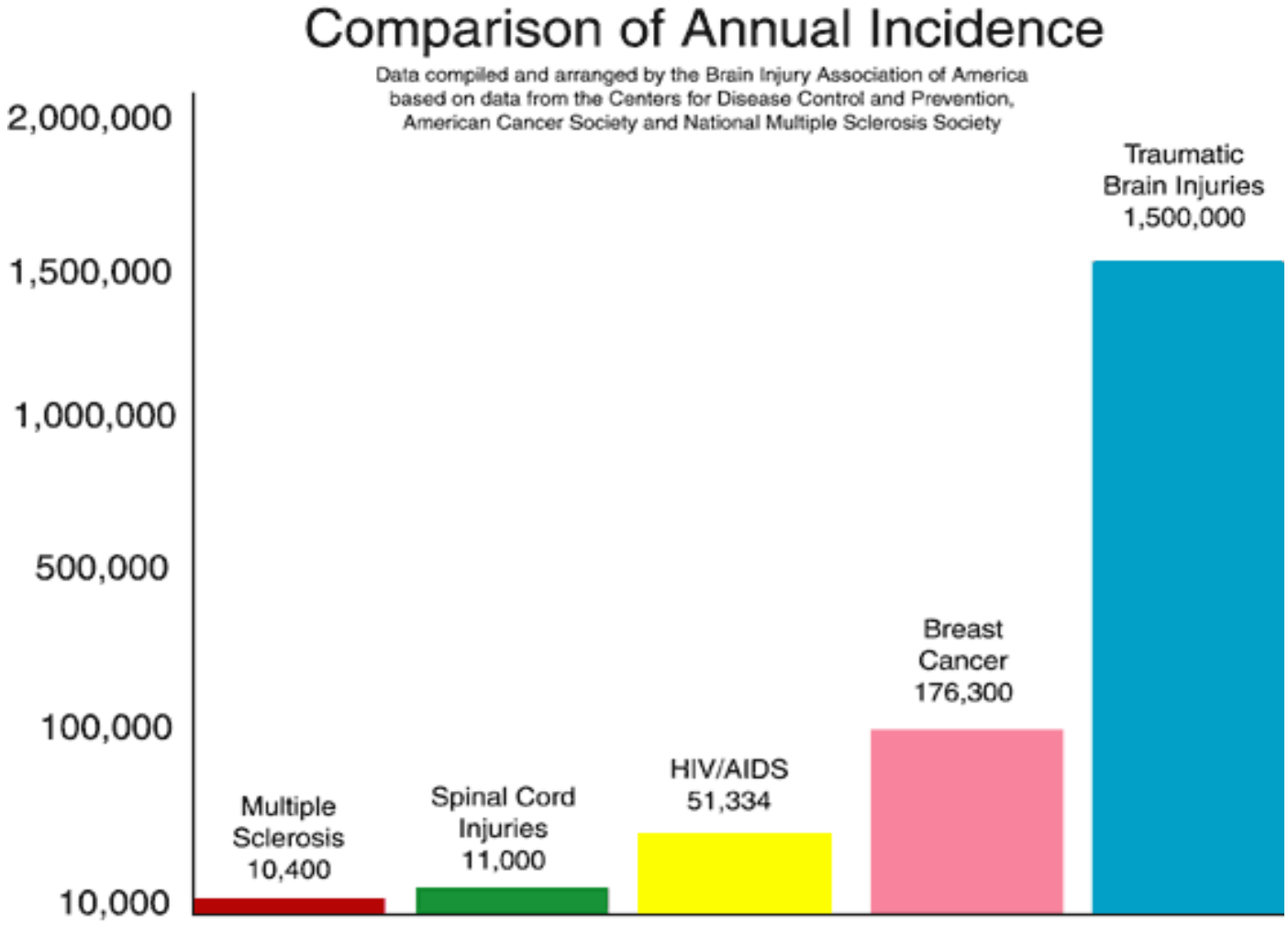
- Every 15 seconds, a U.S. citizen sustains a brain injury (approx. 1.5 million people each year)

- 1 in 30 children will sustain a brain injury before age 21 (some prevalence data has yielded figures 10x that when following people from birth and including non-hospitalization injuries)

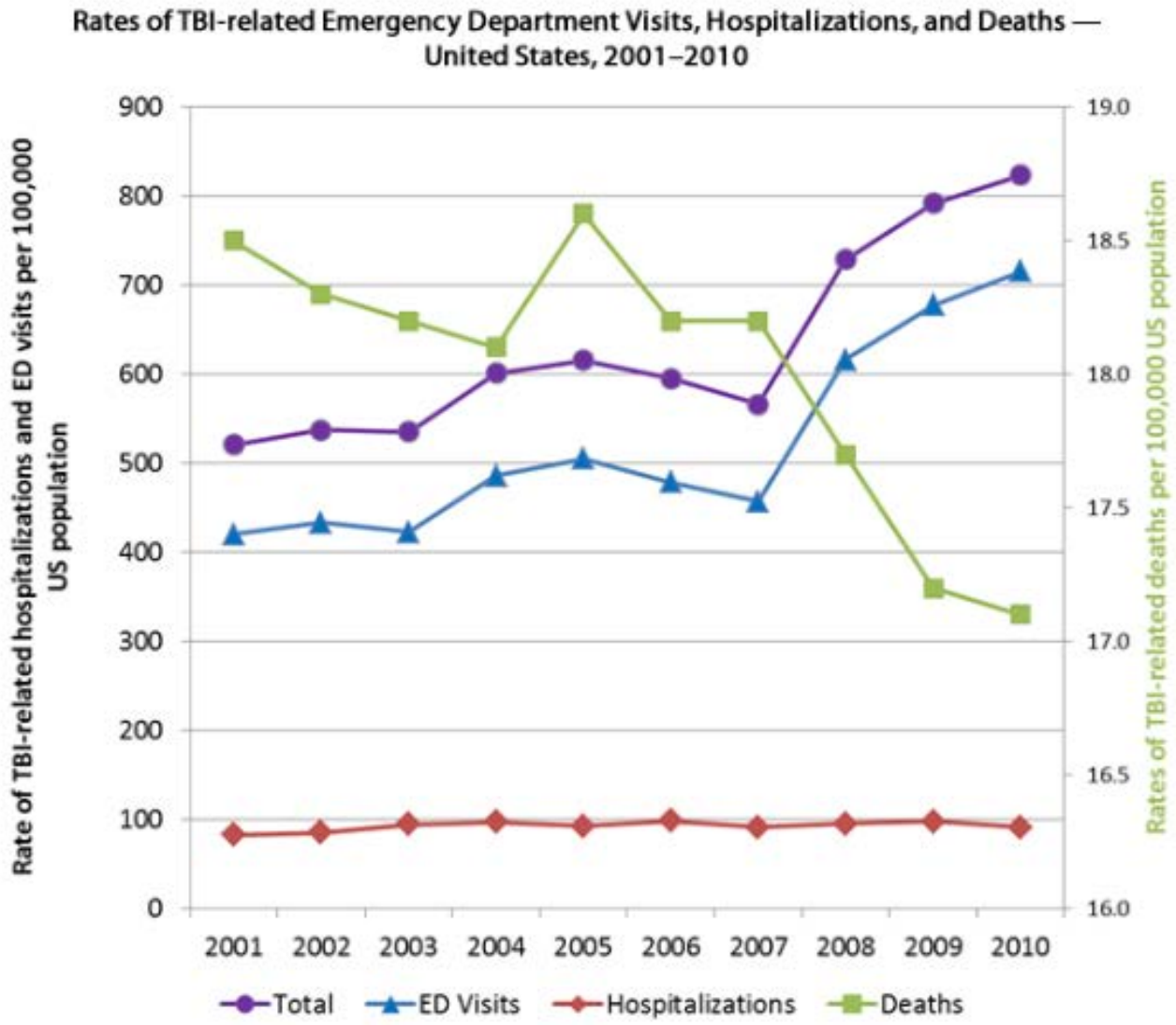
- **TBI is the most common cause of death & disability among children in the U.S.**

CENTER for BRAINHEALTH
THE UNIVERSITY OF TEXAS AT DALLAS

The Problem.



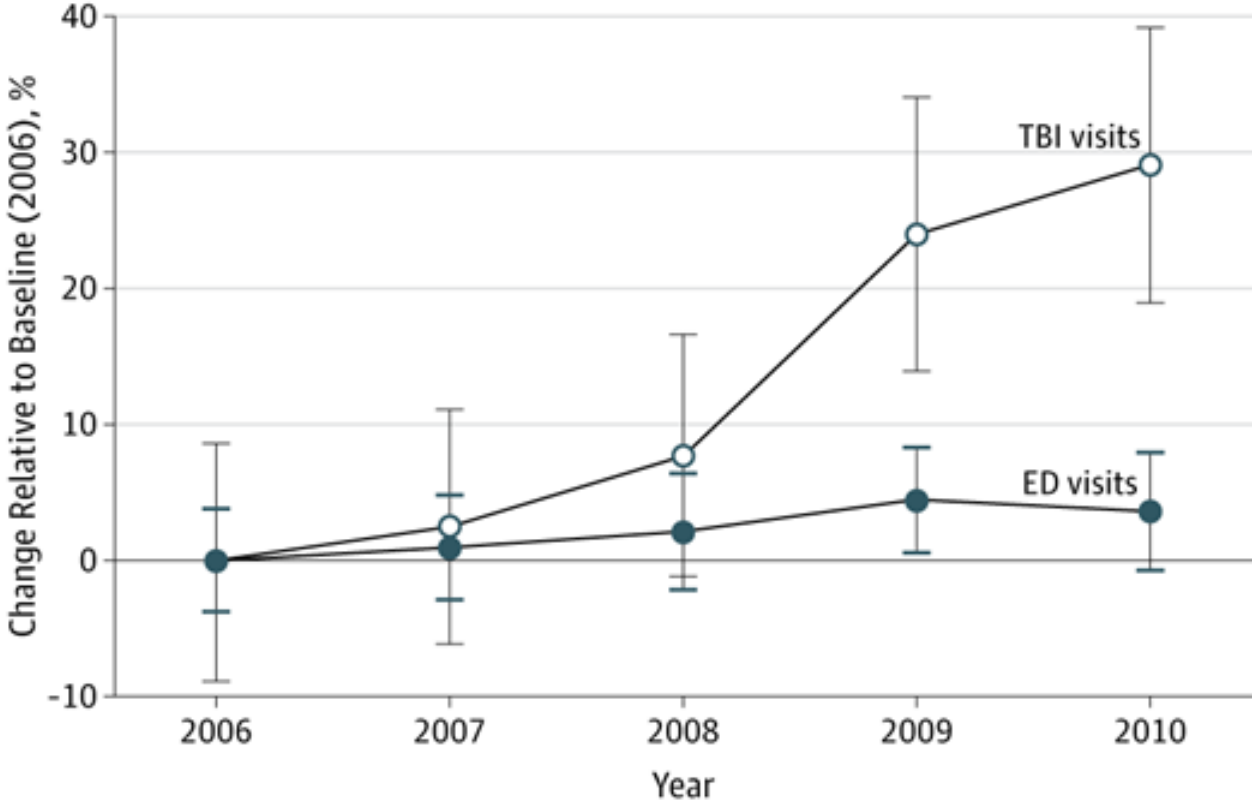
CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS



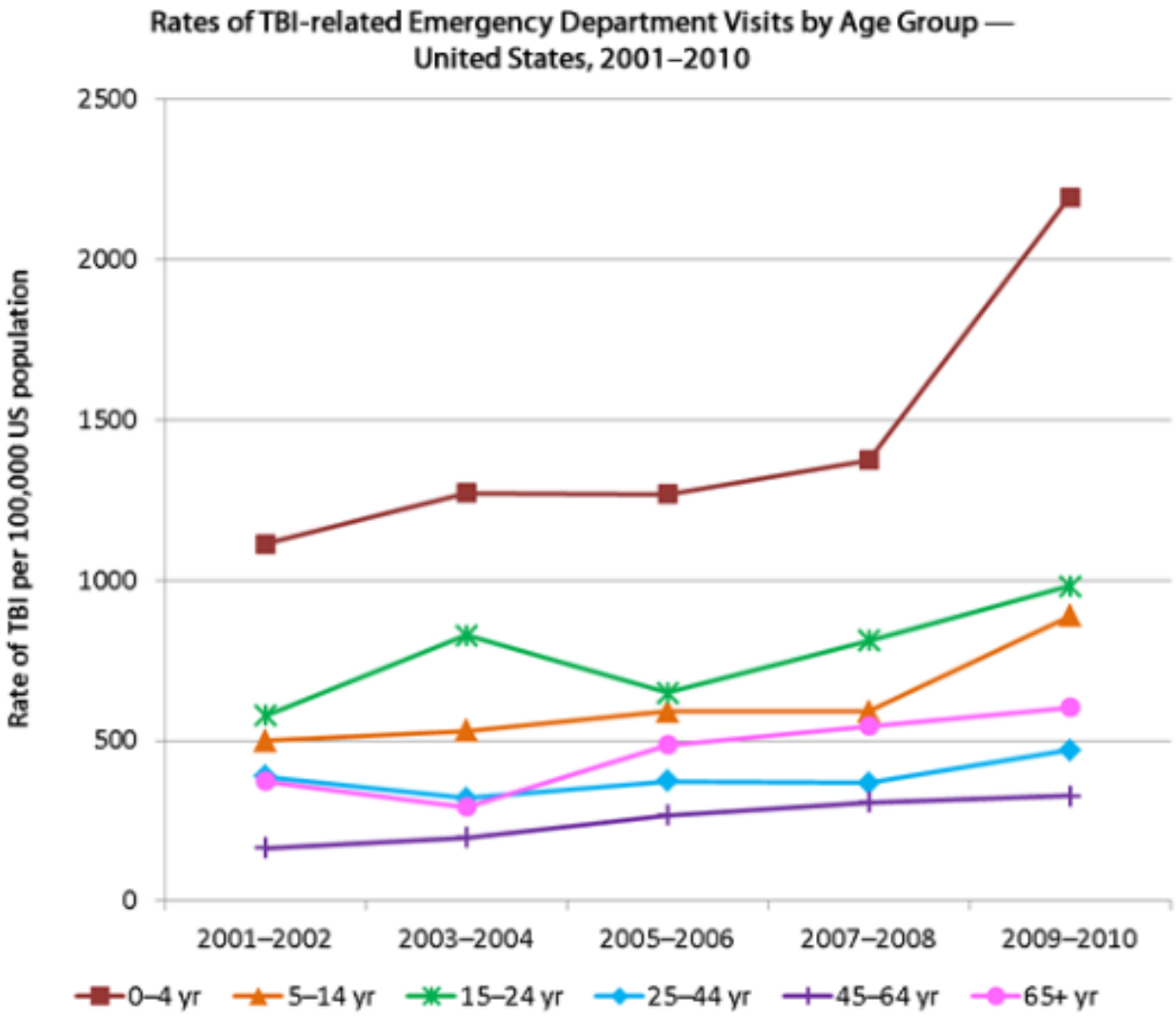
https://www.cdc.gov/traumaticbraininjury/data/rates.html

CENTER for BRAINHEALTH
THE UNIVERSITY OF TEXAS AT DALLAS

ER Visits for TBI Spiking (*JAMA*, 2014)



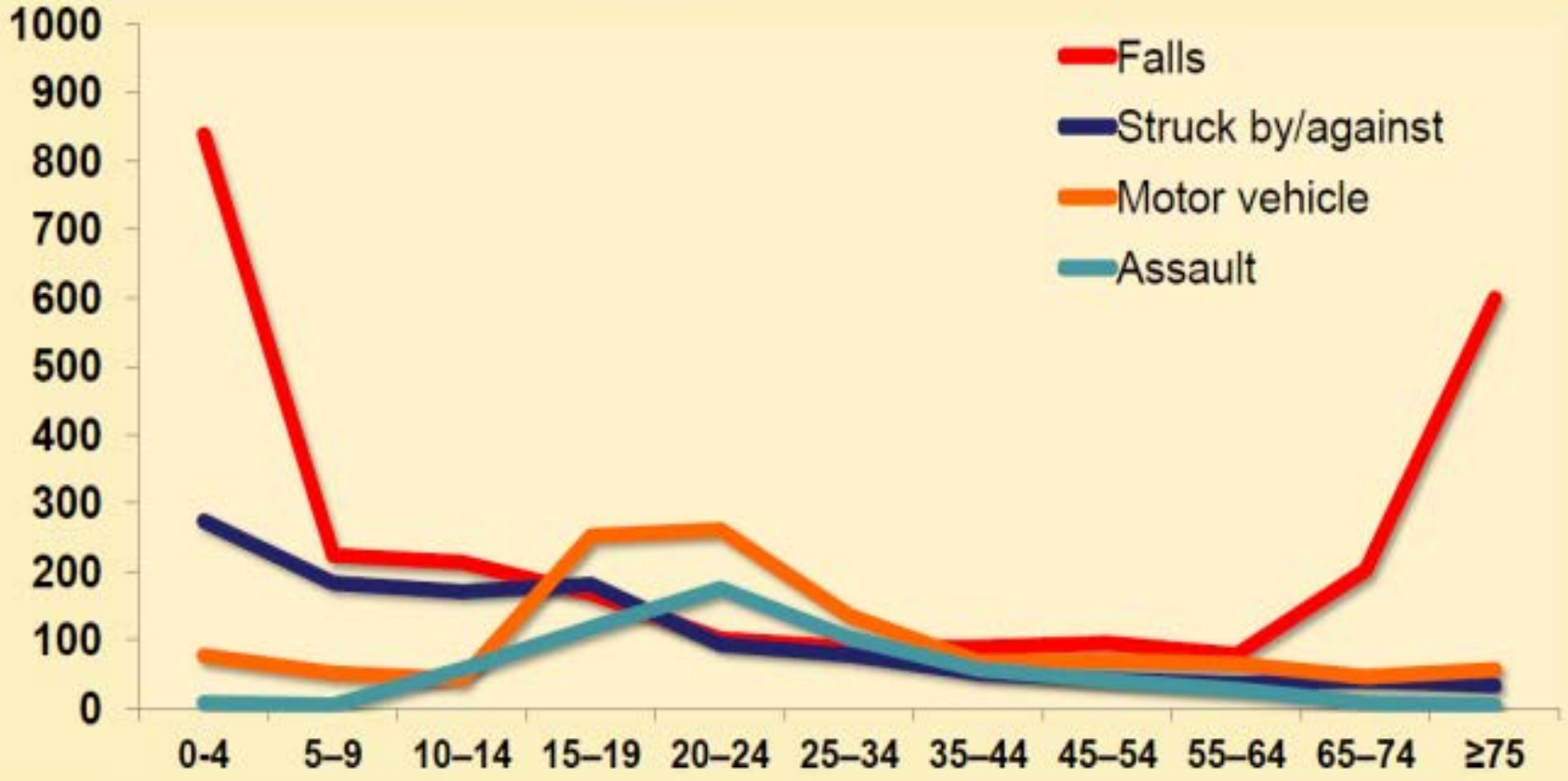
- Rate of emergency room visits for traumatic brain injury increased by 30 percent between 2006 and 2010
- Rose at a rate 8 times higher than that of ED visits overall
- Biggest increase seen in children under 3 and adults over 60



https://www.cdc.gov/traumaticbraininjury/data/rates_ed_byage.html

CENTER for BRAINHEALTH
THE UNIVERSITY OF TEXAS AT DALLAS

Causes of TBIs



Age group (years)

Faul, M et al. Centers for Disease Control and Prevention, National Center for Injury Prevention and Control, 2010

Brain Injury

Congenital Brain Injury

Pre-birth → During birth

Acquired Brain Injury

→ After birth /during childhood

Traumatic Brain Injury

- Closed Head Injury
- Open Head Injury

Non-traumatic Brain Injury

Savage, 1991

Brain Injury & Other Disabilities: Differentiating Characteristics

- A pre-injury self-concept as normal
- Inconsistent patterns of performance
- Variability and fluctuation in recovery process
- Problems generalizing & integrating information
- Inappropriate behaviors that may be more exaggerated
- A previously learned base of information which assists in relearning
- Uneven areas of deficits

Impact of Injury on the Developing Brain

“TBI needs to be treated as a chronic condition. While acute recovery care is essential, long-term monitoring and effective interventions are necessary to mitigate persistent or later emerging deficits and ensure maximum brain regeneration and cognitive performance.”

- Dr. Sandra Chapman, Founder and Chief Director at the Center for BrainHealth
  Dee Wyly Distinguished Professor in the School of Behavioral and Brain Sciences

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Center for BrainHealth
Pediatric TBI Research

NIH-funded study: *Neurobehavioral and Social Outcome of Head Injury in Children*

- Collaboration with Baylor College of Medicine in Houston (Drs. Harvey Levin & Gerri Hanten—Principal Investigators)
- Recruit kids/teens at time of injury (mild to severe)
- Evaluate at time of injury and at various time points longitudinally
  - *Cognitive assessment*
  - *Psychiatric assessment*
  - *Brain Imaging (MRI, DTI, fMRI, ASL/resting fMRI)*
- Most recent focus on executive functions serving social cognition
- Also investigate social function & psychosocial outcomes

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Neurobehavioral & Social Outcome of Head Injury in Children

- Executive Functioning
- Discourse and Strategic learning
- Social Cognition
- Motivation
- Academic Achievement
- Psychiatric & Behavioral Issues

CENTER for BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

What can affect performance on the road to recovery?

- Long-Term Effects
- Delayed Onset of Deficits
- Age Variability

Regions affected by Traumatic Brain Injury

Frontal Lobe:
-Planning
-Problem solving
-Social
-Emotional
-Impaired walking

Temporal Lobe:
-Learning
-Memory
-Language

Diffuse Injury:
-Disorders in Attention
-Impaired concentration
-Information processing
-Seizures

CENTER for BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Consequences of Pediatric Brain Injury

- Inefficient discourse processing—gist vs. details
- Decreased problem solving skills
- Impaired Motivation and response to rewards
- Impulsive behavior
- Prospective and working memory deficits
- Emergence of maladaptive behavior

Typical follow-up for pediatric brain injuries

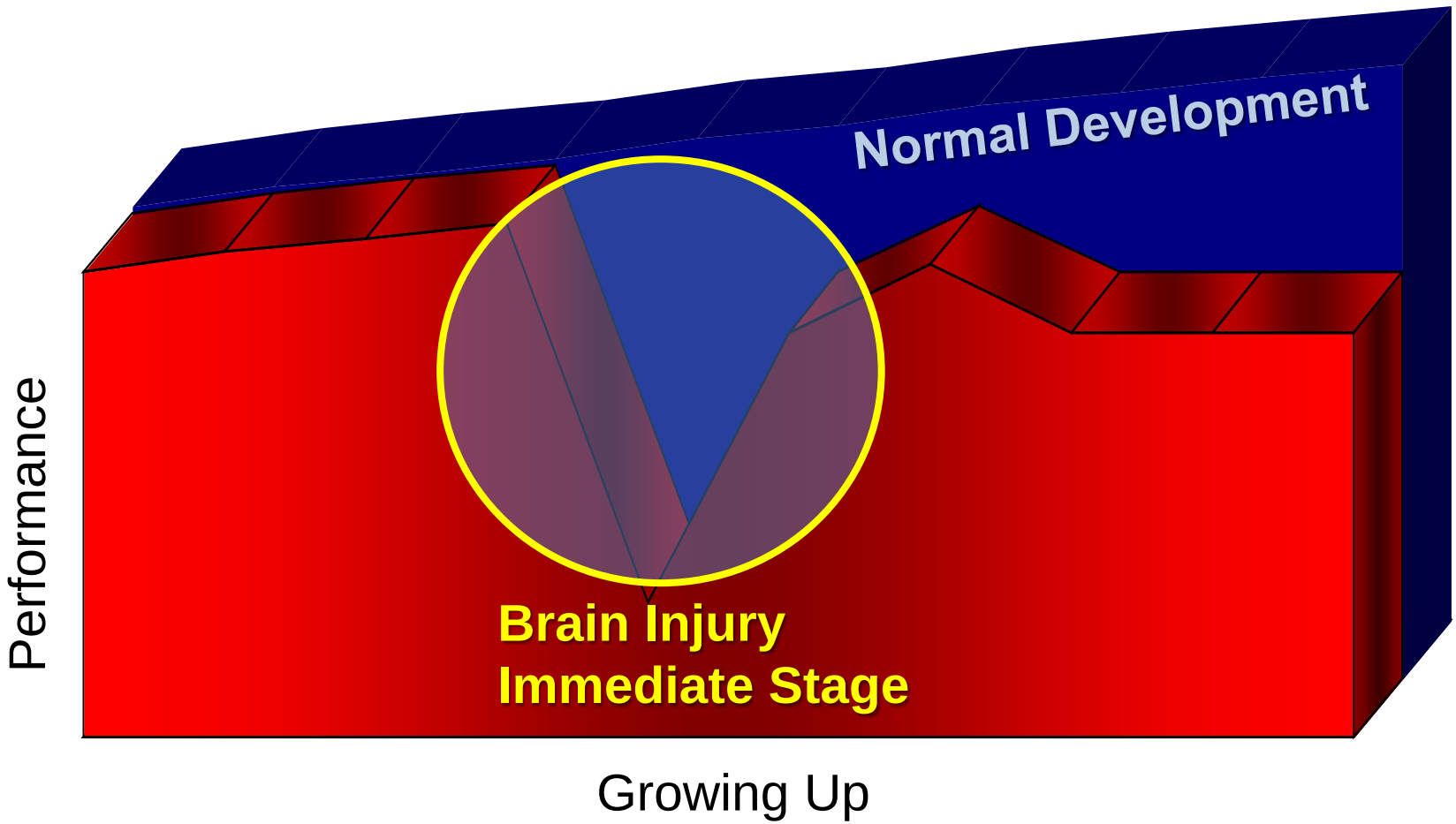
- Days to weeks in hospital ward
- Several weeks in rehabilitation
- Recommendations to schools
- Additional follow-up care may be limited

Younger is not better

1. Prognosis for functional recovery of *old* skills is better in early brain injury

2. Prognosis for acquiring *new* skills after injury is worse after early brain injury

Pediatric TBI: Immediate Phase of Recovery



(Chapman, 2006, Brain Injury Professional)

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Stages of Recovery

Immediate phase

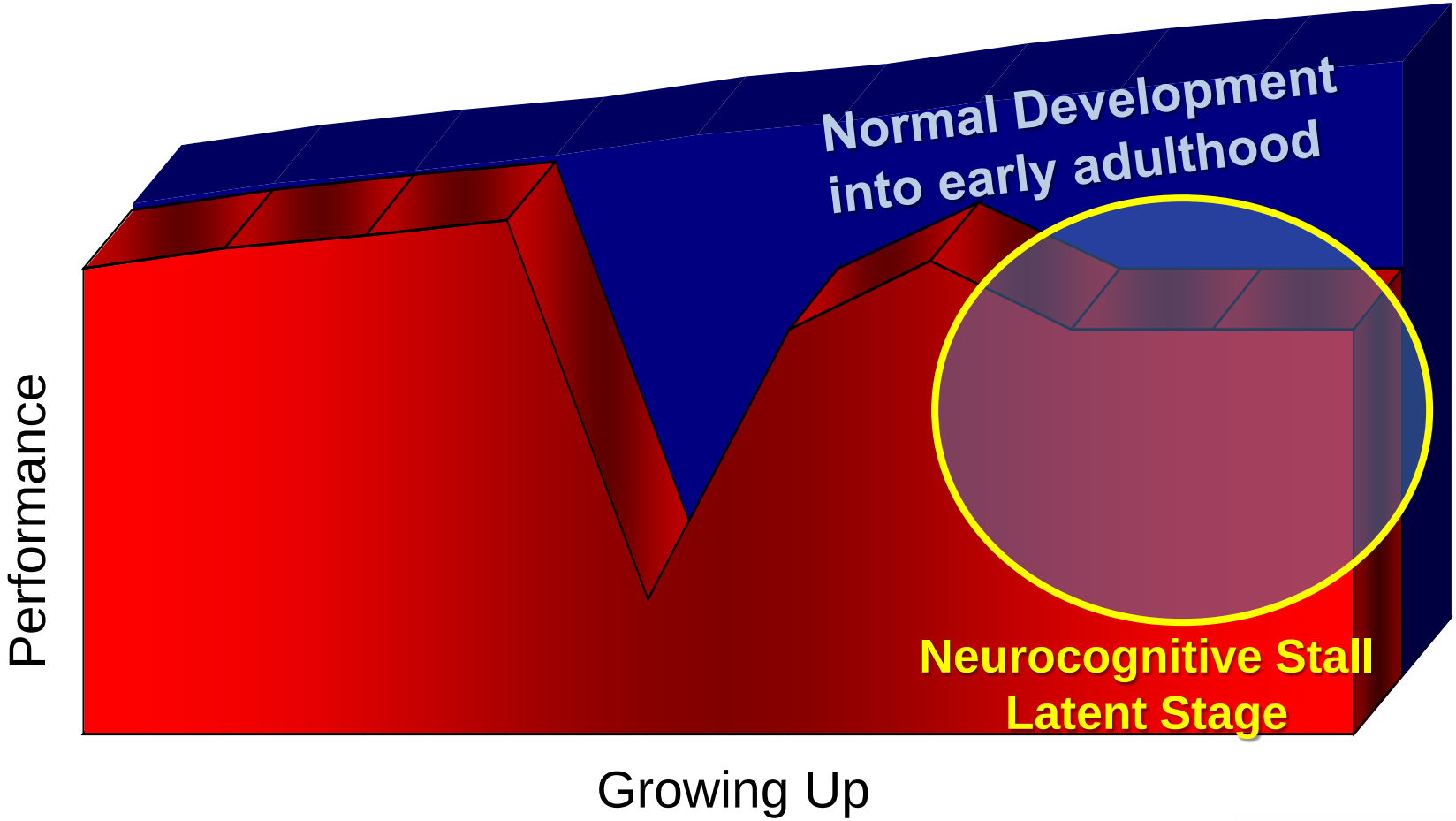
- From injury up to 1 year post injury
- Gains in emergency medical treatment have increased chances of survival
- Often intensive rehabilitation
- Younger = better immediate prognosis

Latent phase

- From 1 year after injury to years after injury (even up to young adulthood)

Neurocognitive Stall

Pediatric TBI: Latent Phase of Recovery



(Chapman, 2006, Brain Injury Professional)

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Neurocognitive Stall

- During latent phase
- Halting or slowing in later stages of cognitive, social, and/or motor development

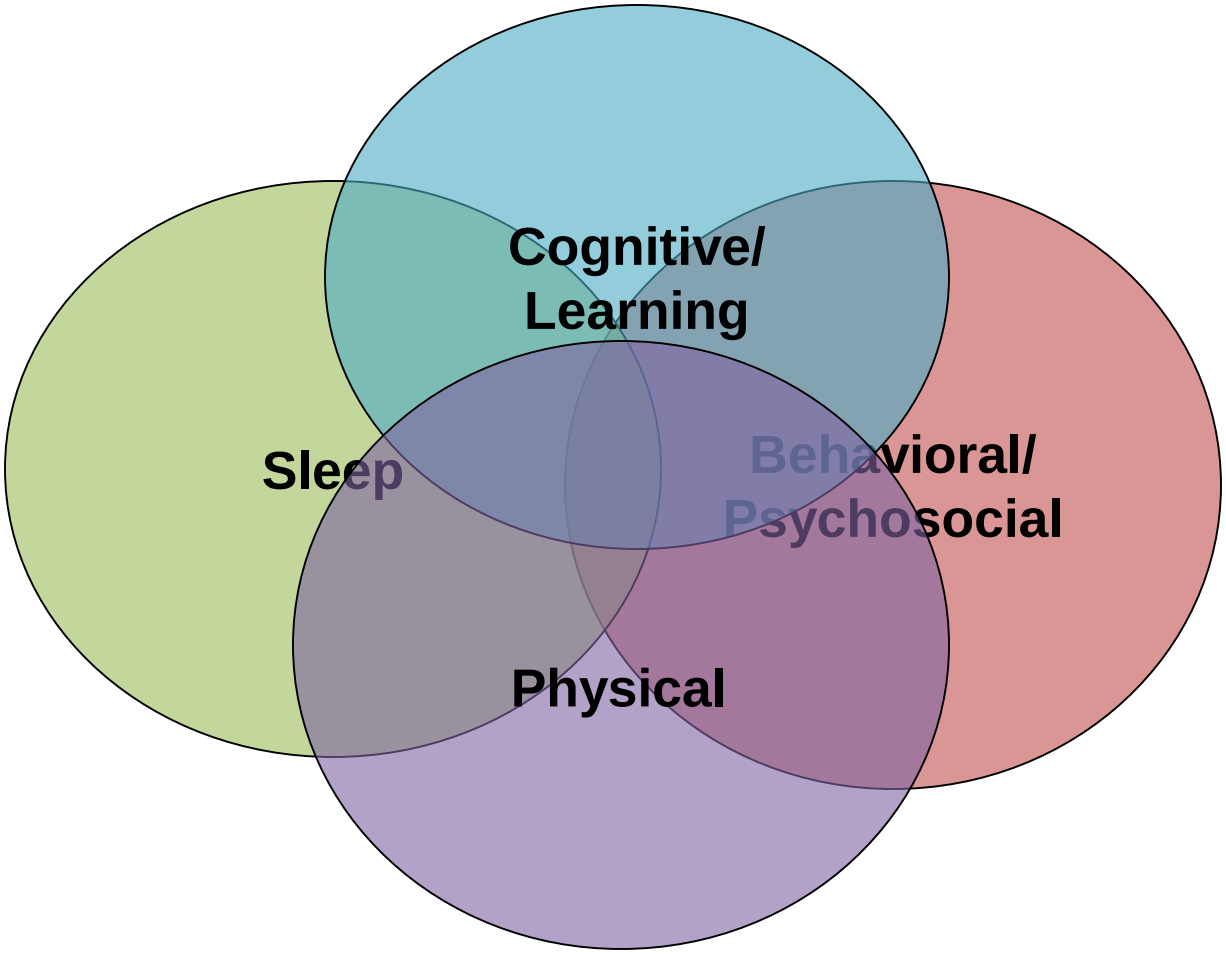
Not necessarily loss of already acquired skills but rather failure or lag in developing later emerging cognitive milestones

(Chapman, 2006, Brain Injury Professional)

Child TBI: Not Just “Little” Adults

- Some impairments may get worse over time
- New difficulties can emerge years later
- Children may have to recover at each new stage of development

Symptom Domains in TBI



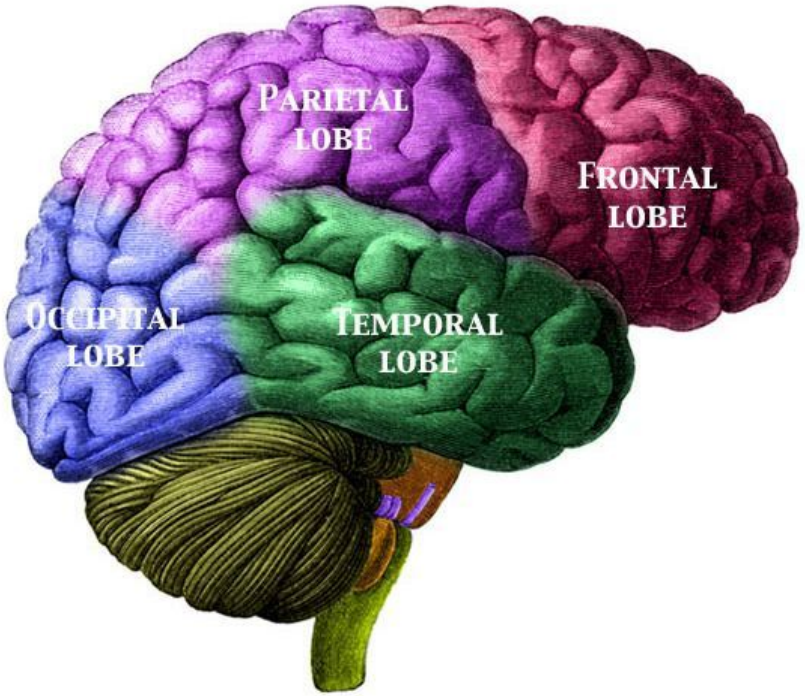
CENTER for BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Cognitive/Psychosocial Difficulties and the Effect on the Family

The Adolescent Brain

"High Horsepower, No Steering"

- Hormone Changes
- Emotional Brain
- Brain's reward system
- Frontal Lobe Development



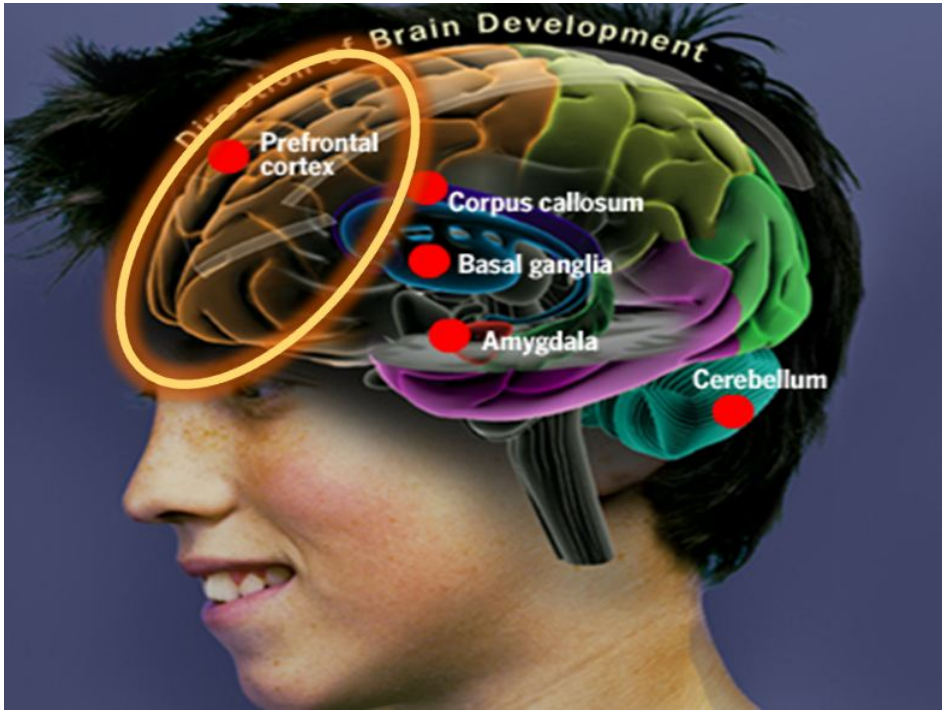
Frontal Lobe Functions

Key to dynamic thinking capacity for life

Undergoes dramatic ‘wiring’ from teens to young adulthood

Most optimal and vulnerable brain stage

The combination of heightened reward center, emotionality, and a still developing inhibitory and planning system results in an extremely vulnerable state for the teenage brain

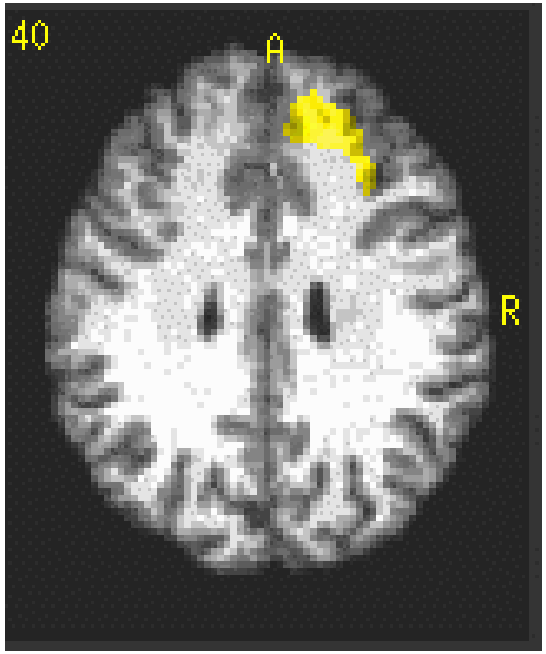


SOURCES: Dr. Jay Giedd, Chief of Brain Imaging, Child Psychiatric Branch—NIMH; Paul Thompson; Andrew Lee; Kiralee Hayashi; Arthur Toga—UCLA Lab of Neuro Imaging and Nitin Gogtay; Judy Rapoport—NIMH Child Psychiatry Branch. TIME Diagram by Joe Lertola. TIME.com graphic by Garrett Rosso. The Image Bank—Getty Images
FROM THE MAY 10, 2003 ISSUE OF TIME MAGAZINE; POSTED SUNDAY, MAY 2, 2003

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Importance of the Frontal Lobes

- The brain undergoes significant changes in adolescence
- The most significant brain changes occur in the frontal lobes
- The frontal lobes allow us to make sense of the massive amount of information flooding our brain constantly



A SMART BRAIN **IS FRONTAL LOBE INTEGRITY.**

Our frontal lobe separates us from all other forms of life.

Our frontal lobe is our brain's CEO (Cognitive Executive Officer.)

PLANNING

REASONING

NOVEL THINKING

DECISION-MAKING

JUDGMENT

MANAGING EMOTIONS

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Executive System

- Awareness of cognitive strengths/weaknesses
- Ability to set reasonable goals
- Plan & organize behavior to pursue goals
- Initiate behavior to achieve goals
- Inhibit behavior incompatible with achievement of goals
- Monitor & evaluate behavior in relation to goals
- Think strategically & solve problems flexibly

Psychiatric Disorders

- Preinjury psychiatric disorders are very common in children who sustain TBI, with occurrence ranging from 33 to 50%

- A study of children with severe TBI found that ongoing postinjury-onset depressive disorder occurred in 25% of children with severe TBI and that 1/3 of the children had a depressive disorder at some point after the injury

Personality Change

A persistent personality disturbance that represents a change from the individual's previous characteristic personality pattern.

The particular personality change can be specified by indicating the symptom presentation that predominates:

- Labile Type **
- Disinhibited Type *
- Aggressive Type *
- Apathetic Type
- Paranoid Type

Source: Diagnostic & Statistical Manual IV

Personality Change

Approx. 40% of children with severe TBI exhibit ongoing persistent personality change an average of 2 yrs. post injury. An additional 20% had more transient change. Change occurred in 5% of mild to moderate TBI, but was always transient. (Max et al., 2000)

Predictors:

Severity of injury

Superior frontal gyrus lesions (1st yr)

Frontal lobe white matter lesions (2nd yr)

Pre-injury adaptive functioning (2nd yr)

Source: Max, J et al. (2006)

ADHD & TBI

Almost one third of children with severe TBI develop ADHD secondary to brain injury.

Predictors:

- Severity of injury
- Pre-injury behavior problems

The combination of severe injury and secondary ADHD predicted poor inhibition.

Source: Schachar, R et al. (2004)

New-Onset Depression after TBI

- The psychiatric outcome of children 6-months post-injury (mild to severe) revealed that novel depressive disorders occurred in ~11%
- Novel depressive disorder was significantly associated with older age at the time of injury, family history of anxiety disorder, left inferior frontal gyrus (IFG) lesions, and right frontal white matter lesions
- Forty-percent of children with novel depressive disorder had a comorbid novel anxiety disorder

(Max et al., 2012, International Journal of Developmental Neuroscience)

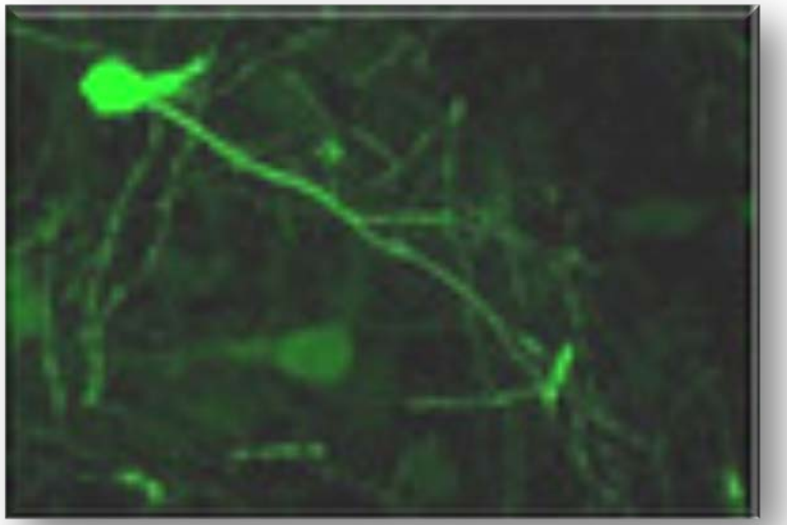
New Onset Anxiety after TBI

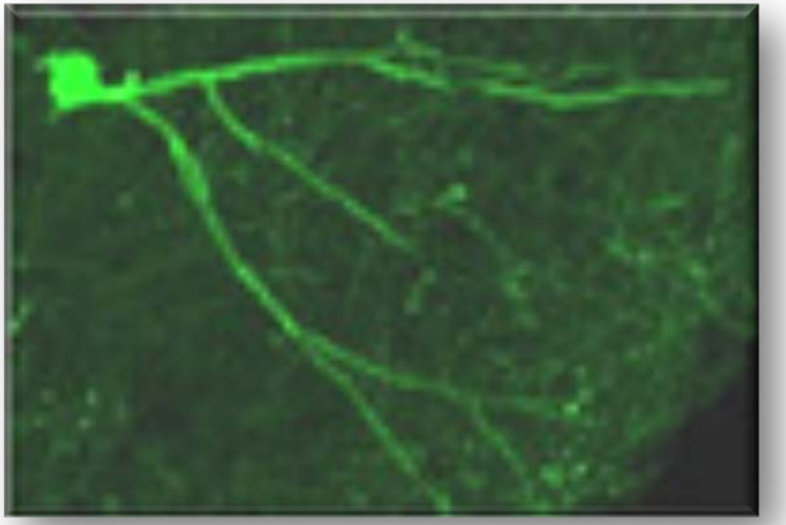
- The psychiatric outcome of children 12-months post-injury (mild to severe) revealed that novel anxiety disorders occurred in ~10%
- Novel anxiety disorder was significantly associated with concurrent novel depressive disorder and with novel personality change due to TBI
- Novel anxiety disorder was marginally associated with younger age at injury and with pre-injury anxiety disorder

- Findings suggest that, although relatively infrequent, when anxiety disorders did emerge, they were significantly associated with the emergence of other forms of affective dysregulation, such as novel depressive disorders and personality change due to TBI, especially in younger children and those with pre-injury vulnerability to anxiety.

(Max et al., 2015, Journal of Pediatric Rehabilitation)

A Brain Under Chronic Stress





- Chronic stress reduces neuronal activity
- When a brain is stressed, it does not operate efficiently
- Associated with high incidence of depression, anxiety, and rage in the general population
- A brain exposed to chronic environmental stress is not as effective at learning new information or storing new learning in memory networks

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Other Common Issues Post-injury

- Anger
- Social problems
- Perseveration
- Immaturity
- Legal trouble

TBI & Criminality in Juvenile Offenders

- Recent study in Texas (7 juvenile justice facilities)
- Administered Brain Injury Screening Questionnaire
- Linked results to offense history & psych. diagnoses
- Found that 1 in 4 met criteria for TBI *(21.9% of state sample & 41.3% of county sample)*
- Majority occurred prior to criminal offenses
- A history of TBI was related to more violent crimes as well as more mental health diagnoses and symptoms
- Need for preventative actions, interventions to compensate for challenges related to TBI, and programs to assist transition back into the community

Gordon et al., 2017, Journal of Head Trauma Rehabiltation

Comments from Parents

"Her friends are scared of her."

"He used to take care of his younger brother, now I'm afraid to leave them alone together."

"He has punched me a couple of times and punched several holes in the walls of our house."

"When his friends were over, he suddenly dropped his pants in front of them."

"Her physical recovery was a miracle but now she is a different person."

"Since her injury, my daughter has no manners."

"No words are adequate to express the comprehensive sorrow, pain, anger, disappointment, and hope shared by persons and families changed and challenged by the impact of a head injury." (Dell Orto & Power, 1994)

Impact on Families

- denial of deficits, just want him/her to be the same
- depression and/or anxiety as a result of dealing with the injury and post-injury personality changes
- uncertainty and frustration in handling new problem behaviors

****Importance of Counseling****

Transition to Adulthood

Transition to Adult Life: Current Problems

- Lack of and/or access to knowledgeable adult medical providers and specialists
- Lack of and/or access to knowledgeable psychologists, psychiatrists, and community mental health providers
- Lack of insurance coverage for ongoing, post-acute PT, OT, SLP, cognitive rehabilitation or other psychological treatments
- Lack of and/or access to opportunities for positive peer relationships, social interactions, community integration
- Lack of and/or access to these services negatively impacts all facets of one's Quality of Life

Transition in School to Work Process: Statistics

- High school dropout rates for students with disabilities are greater than 25%
- Unemployment or underemployment post-high school rates can exceed 75%

Successful Research Trends

- Transition appeared to be more successful for students who receive vocational education and early work experience

- A series of vocational-education classes was associated with significantly higher wages and rates of employment

- The presence of a transition goal (such as in an IEP) for either postsecondary academic or vocational training was related positively to achieving that goal

Two Different Approaches

https://www.youtube.com/watch?v=BMX7IqXEYw4

https://www.youtube.com/watch?v=C8t27dFau_Y

Neuroplasticity: The Hope of Restoration, Regeneration, & Resilience

Recent Discoveries in Brain Research

The Good News:

- The brain continues to make new cells (neurogenesis) throughout our life
- The brain has the capacity to reorganize, forming new connections and strengthening weakened neural pathways
- New, sophisticated brain imaging technology is making it possible to understand the brain's response to treatment

What can we do now?... A lot!

- Research regarding brain plasticity provides much hope
- Treatment can enhance functional and structural aspects in the brain
- Improvements can be made in meaningful real-life outcomes

Brain-based cognitive interventions

As we learn how the brain works, we can advance:

- Neurocognitive treatment development
- Educational teaching strategies and academic supports

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Restorative Approach

What works:

Active involvement/being engaged in something you like

Being challenged –"sweating it"

Being strategic

What doesn't:

Passive repetitive tasks – *automatic*

Mere involvement with sensory input

The Circle of Care

DePompei, 2003

Family-Centered Care Principles

- The family is the constant in the child's life
- Parent/professional collaboration is essential at all levels
- Complete & unbiased info should be provided to families in a supportive manner
- Appropriate policies & programs that provide emotional/financial support should be implemented
- Family strengths & individuality should be recognized & diverse methods of coping respected

Family-Centered Care Principles *(cont'd)*

- Developmental needs of infants, children, adolescents & families should be understood & incorporated in care
- Parent-to-parent support is encouraged
- Health care delivery systems should be designed to be accessible, flexible & responsive to family needs

Caregiving Notebook—Top 10 things caregivers don't want to hear

- Doesn't your insurance cover that?
- It must be hard to work and take care of your [child], so why don't you just quit your job?
- Your [child] belongs in a nursing home. OR: I could never put my [child] in a nursing home.
- You have to take care of yourself; your [child] needs you!
- Why don't you get your family to help out more?
- I don't see what you're complaining about. [Your child] seems fine to me.
- I don't know how you do it. You must be a saint.
- Just call me if you need some help.
- I know just how you feel.
- God doesn't give you more than you can handle.

http://www.texasbia.org/caregiving-notebook

CENTER for BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Caregiving Notebook—Top 3 things caregivers do want to hear

- I have a friend who is having a lot of difficulty getting started as a caregiver. Would you be willing to talk to her?
- I haven't seen you in awhile, and I miss our [lunches, shopping, volunteering, whatever].
- How are you doing?

http://www.texasbia.org/caregiving-notebook

Brain Injury Family Support Series

Communication Matters:

https://www.youtube.com/watch?v=exiB9TbJx2I

Brain Injury: What's in Your TBI Toolbox?

https://www.youtube.com/watch?v=fBpLIENu5FY

Creativity in Caregiving

http://www.brainline.org/content/2013/05/creativity-in-caregiving.html?utm_source=Twitter&utm_medium=Hootsuite&utm_campaign=BrainLineSM

1. Utilize Your Resources
2. Maximize Your Time
3. Become an Expert
4. Set Goals Together
5. Involve the Family

Professional Pointers for working with TBI survivors

- Provide ample time for individuals to:
  - *Process information*
  - *Respond*
  - *Complete tasks*
  - *Accomplish goals*

- Offer many reminders

- Always have a pen/paper, calendar, or other organizational tool handy for them to use

Professional Pointers for working with TBI survivors *(cont'd)*

- Avoid too much complexity or "information overload" (Less is more!)
  - *Keep instructions and explanations simple (not too many details)*
  - *Discourage overuse of too many calendars/e-mail addresses/credit cards (consolidate and streamline)*
  - *Avoid overstimulation (light/sound, activity, information)*

- Encourage them to:
  - *Prioritize daily tasks first thing in the morning*
  - *Complete difficult tasks first (e.g., schedule depositions in the AM)*
  - *Refrain from mentally taxing tasks after 4 PM*
  - *Avoid multitasking*
  - *Take "mental breaks" (at least 5-min. breaks 5 x a day)*

S.C.O.R.E. for Brain Health

S = SELECT

Reduce # of activities, goals or domains to focus on most important and salient—reduce multitasking!

C = COMPENSATE

When experiencing mental loss or difficulties, use alternative means (calendars, cue cards, etc.)

O = OPTIMIZE

Use your talents and passions to maximize your abilities

S.C.O.R.E. for Brain Health

R = REGENERATE

Build new brain pathways with meaningful mental and physical activities

Repetition builds stronger connections--whatever you practice gets better

Be sure to get plenty of rest

E = EMPOWER

Believe in yourself—You remember and un-forget a great deal more than you credit yourself

Acknowledgments

Center for BrainHealth—The University of Texas at Dallas

Dr. Sandi Chapman
Dr. Asha Vas
Dr. Jeff Spence
Nellie Caulkins
Molly Keebler

Children's Medical Center (Dallas, TX)

Dr. Wendy Goodwin
Dr. Dale Swift
Dr. Bradley Weprin
Dr. Lakshmi Raman

Baylor Our Children's House (Dallas, TX)

Dr. Frank MacDonald
Dr Raji Srinivasan

Baylor College of Medicine (Houston, TX)

Dr. Harvey Levin
Dr. Gerri Hanten
Carmen Vasquez
Xiaoqi Li

National Institute of Neurological Disorders and Stroke (2R01 NS21889-16 / 2R01 NS021889-26)

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS

Want more information now?

General Information resources:

http://www.brainline.org/ -- General brain injury issues

http://www.brainlinekids.org/ -- Specific to pediatric issues

http://www.brainlinemilitary.org/ --Specific to military issues

For more information:

www.centerforbrainhealth.org

www.brainhealthdaily.com

Lori G. Cook, Ph.D., CCC-SLP

Director of Pediatric Brain Injury Programs

Senior Clinician, Brain Performance Institute

Adjunct Assistant Professor, School of Behavioral and Brain Sciences

Lori.Cook@utdallas.edu / 972.883.3409

CENTER *for* BRAINHEALTH®
THE UNIVERSITY OF TEXAS AT DALLAS