



Challenges of Addressing TBI in Children

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Main Points

- Defining TBI
- What happens after TBI?: Mechanisms and consequences of TBI
- Epidemiology of TBI and related disability
- TBI in children
- Unidentified TBI in children
- Serving children with TBI

Defining TBI

Multiple names

- Traumatic brain injury (TBI)
- Concussion
- Acquired brain injury (ABI)
- Closed head injury (CHI)
- Head injury

Definitions

- Mild TBI is “threshold” diagnosis
- No “gold standard” definition used across disciplines, however:
 - American Congress of Rehabilitation definition is widely used
 - World Health Organization
 - American Academy of Neurology (concussion)
 - ICD-10 Postconcussional disorder
 - DSM-IV Postconcussional disorder
 - IDEA

Mild TBI Definition (ACRM)

- A traumatically induced physiological disruption of brain function, as manifested by at least one of the following:
 - any loss of consciousness
 - any loss of memory for events immediately before or after the accident
 - any alteration in mental state at the time of the accident (e.g., feeling dazed, disoriented, or confused) and
 - focal neurologic deficit(s) that may or may not be transient

Mild TBI Definition (ACRM)

- But where the severity of the injury does not exceed the following:
 - loss of consciousness of approximately 30 min or less
 - after 30 min, an initial Glasgow Coma Scale score of 13–15 and
 - post-traumatic amnesia not greater than 24 hr

Of note

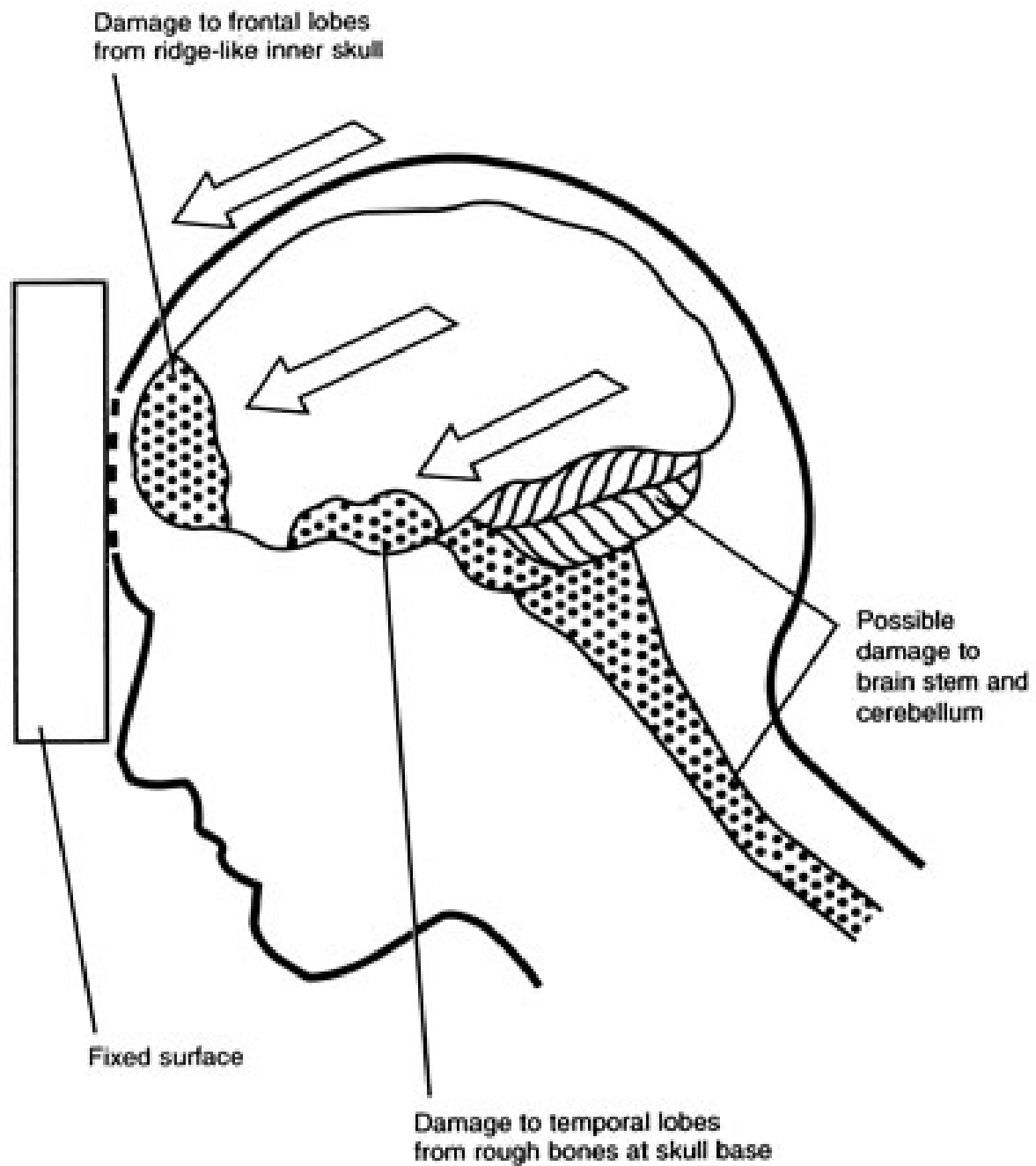
- The severity classification of TBI is based on injury characteristics, not subsequent severity of disability – even mild TBI may produce severe disability
- It is common for there to be no evidence of injury on neuroimaging

What happens after TBI?: Mechanisms and consequences of TBI

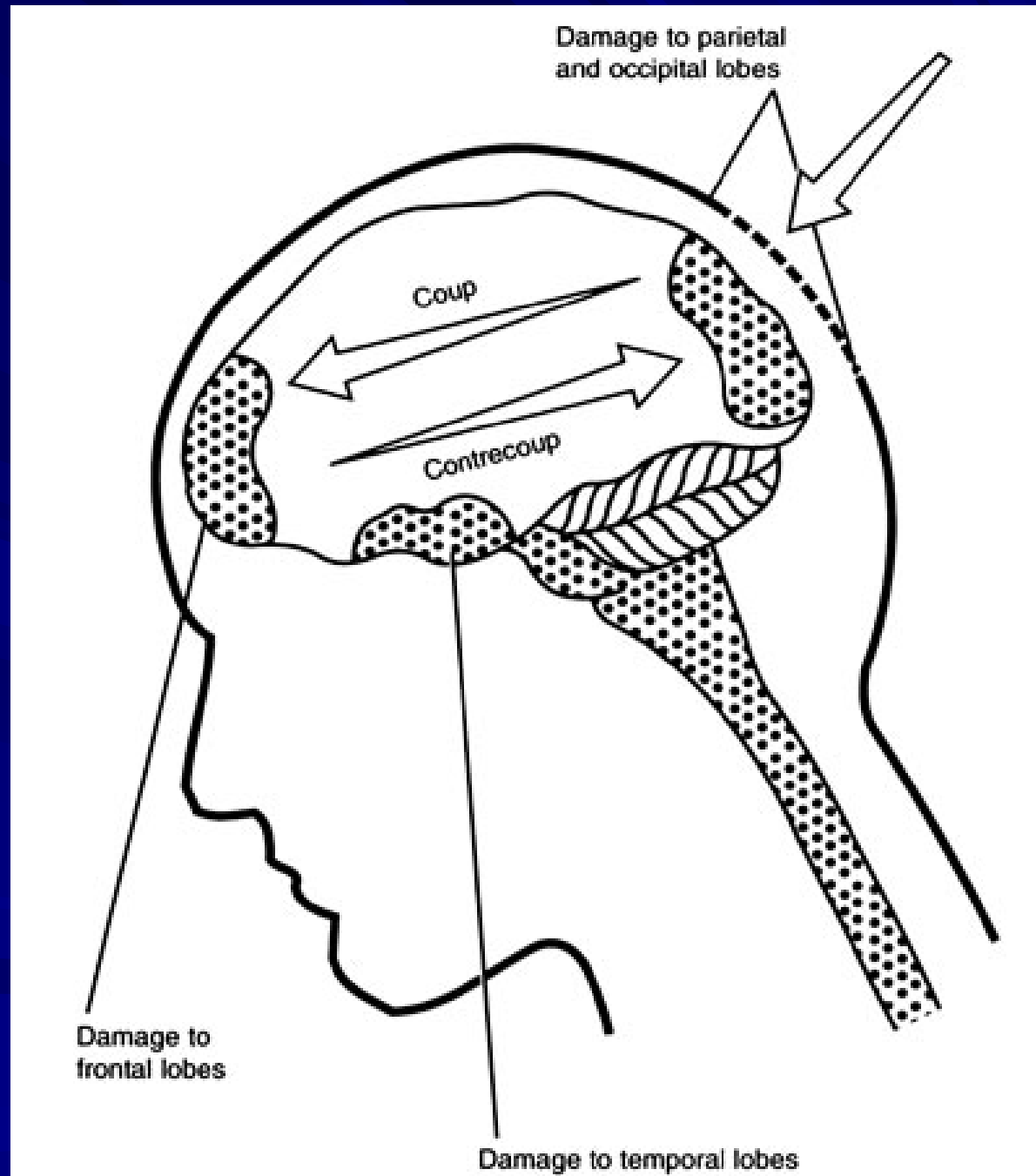
Type of injuries

- Impact
- Inertial

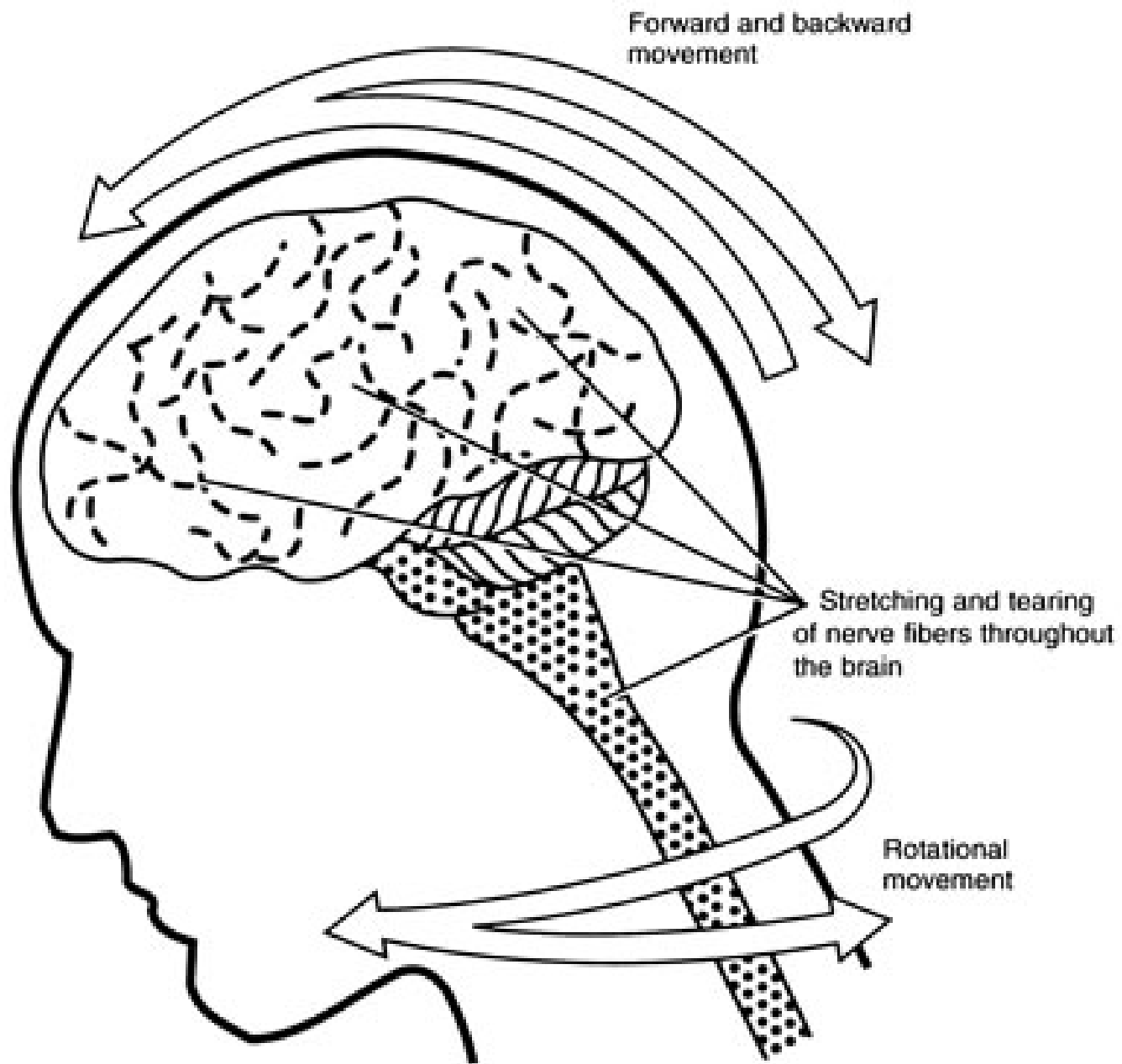
Stoller &
Hill (1998)



Stoller &
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TBI is a biological event within the brain

- Tissue damage
- Bleeding
- Swelling
- Diffuse axonal injury
- Cytotoxic cascade (toxicity to brain cells)
- Neurotransmitter disturbances

Levels of TBI Severity:



Levels of TBI

Severity:

- Most people with mild TBI make a complete recovery (80% to 90%)
- “Miserable minority” have chronic disability
- Recovery typically takes place in weeks or months (if at all)

Ruff et al. (1996)

- Moderate-severe TBI
 - Hospitalized
 - Rehabilitation

- Mild TBI
 - Emergency room
 - MD office
 - Often unreported, undiagnosed

Problems and Symptoms After TBI

- Problems with thinking affect
 - Awareness and insight into one's own behavior
 - Processing speed
 - Attention/Concentration
 - Memory
 - Executive functioning (execution of goal-directed activities, planning, organization, multi-tasking etc.)
 - Judgment
 - Cognitive fatigue

Problems and Symptoms After TBI

- Emotional and behavioral problems
 - Difficulty controlling emotions
 - Impulsivity and poor self-control
 - Disinhibition
 - Frustration
 - Agitation
 - Restlessness
 - Aggression
 - Apathy
 - Depression
 - Self-doubt and self-criticism
 - Anxiety
 - Isolation
 - Avoidance
 - Grief, disbelief and confusion over losses and changes

Problems and Symptoms After TBI

- Physical problems
 - Pain
 - Sensory disturbances
 - Sleep disorders
 - Fatigue
 - Dizziness and balance problems
 - Seizures
 - Endocrine problems
 - Sexual dysfunction

Problems and Symptoms After TBI

- Functional problems
 - Difficulty at school and work
 - Difficulty maintaining relationships
 - Difficulty communicating with others
 - Difficulty socializing
 - Difficulty taking care of ADLs and IADLs
 - Substance abuse
 - Criminal behavior

Recovery after TBI is:

- A multistage process
- Continues for years

Epidemiology of TBI and related disability

TBI & Disability

- 1.7 million TBI-related deaths, hospitalizations, and ED visits occur in the U.S. each year.
- An estimated 124,626 people with TBI experience long-term impairment or disability from their injury each year.
- So these figures suggest that over 7% of TBIs result in significant disability
- At least 2% of US population have TBI-related disability

(Centers for Disease Control and Prevention, 2010)

Cost

TBIs requiring hospitalization cost the nation over \$56 billion each year.

(Includes decreased tax revenues and increased welfare costs when injured persons or their caregivers are unable to return to work)

(CDC, 2001)

TBI in Children

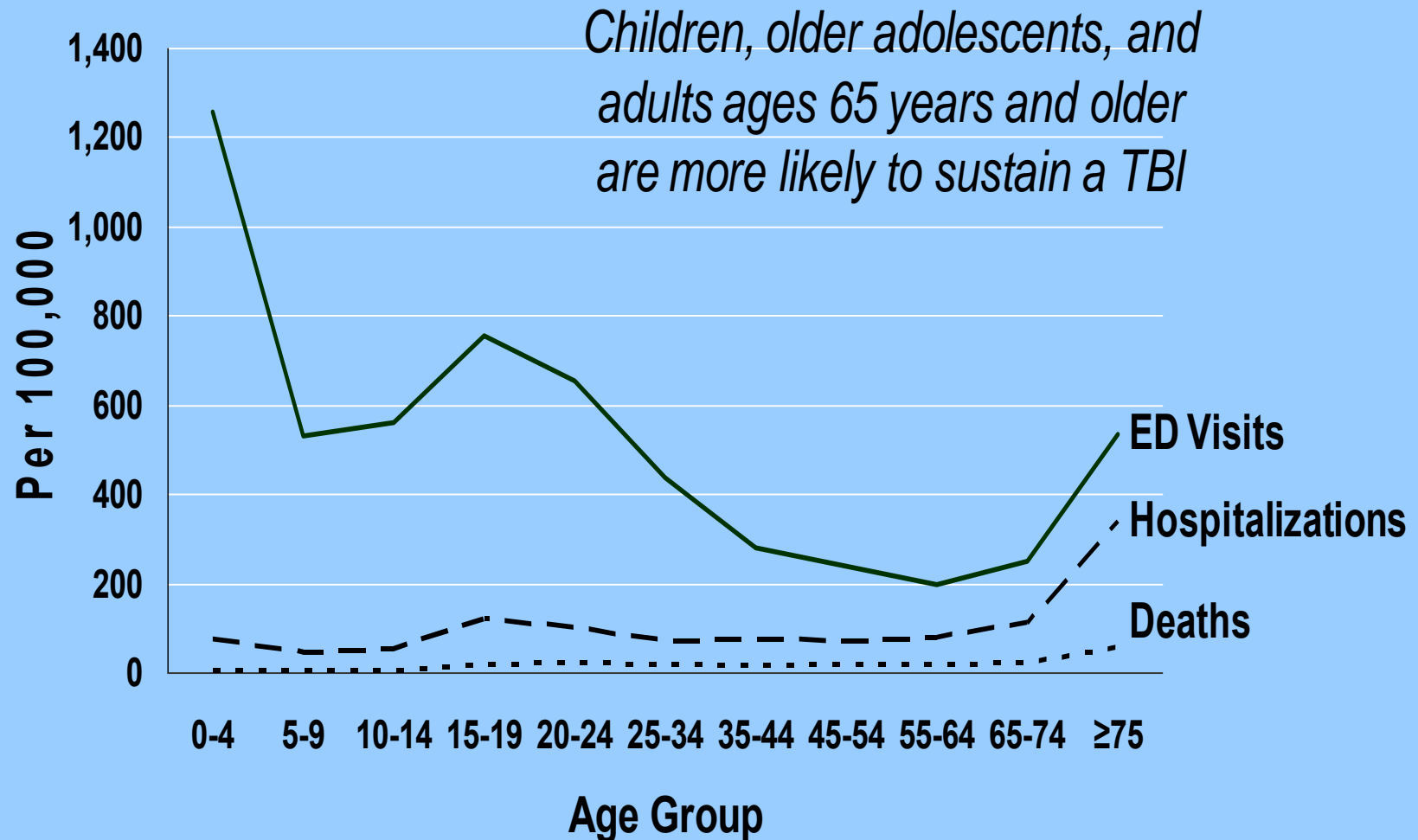
TBI in the United States

Children (0-19 years)

- Annually about 630,000 TBIs among children
- Leading cause of death in children
- Most children (over 90%) are treated and released from the emergency department (if seen by a health care provider at all)
- TBI is a high incidence event!

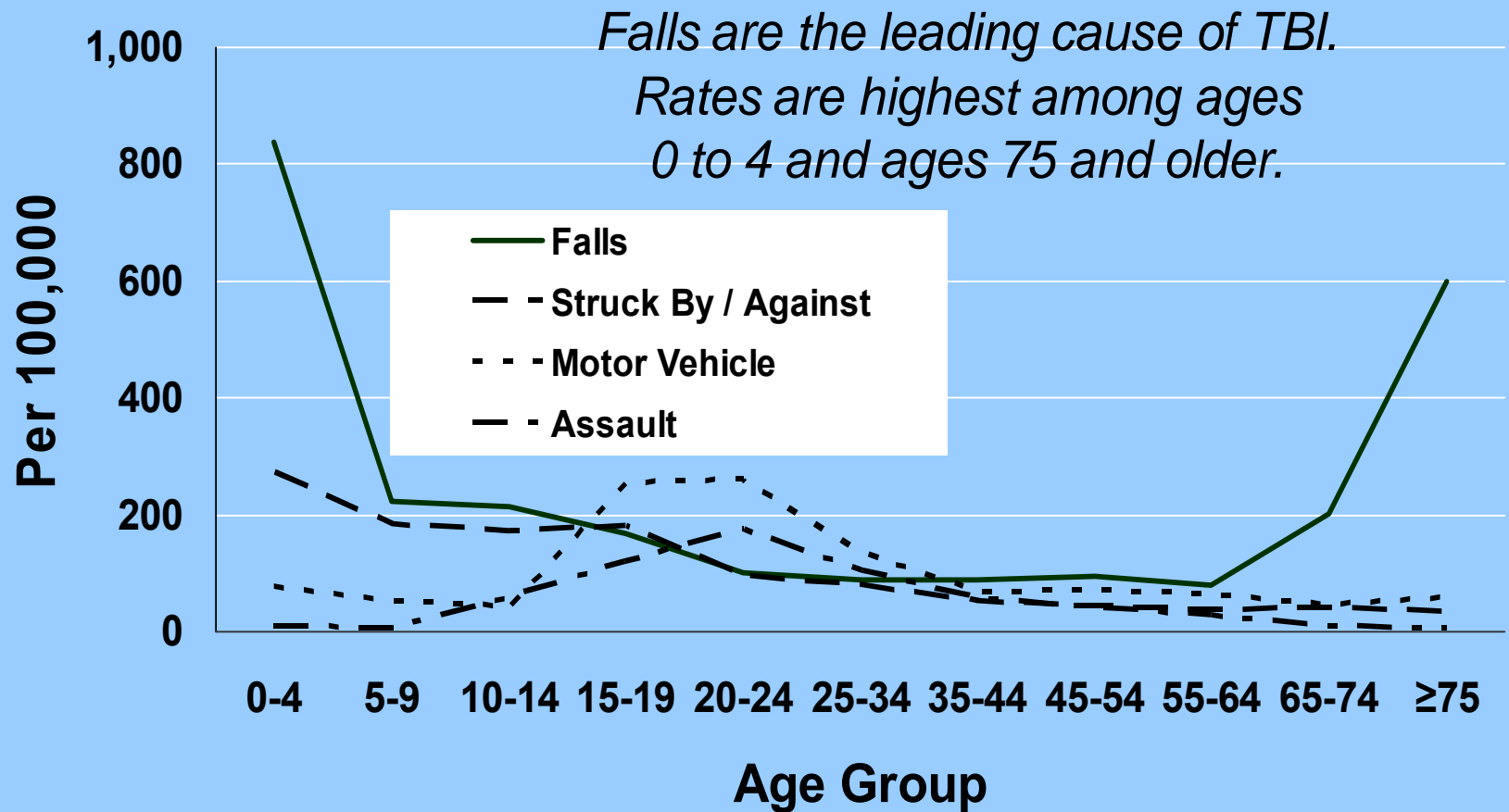
TBI in the United States

TBIs by Age Group



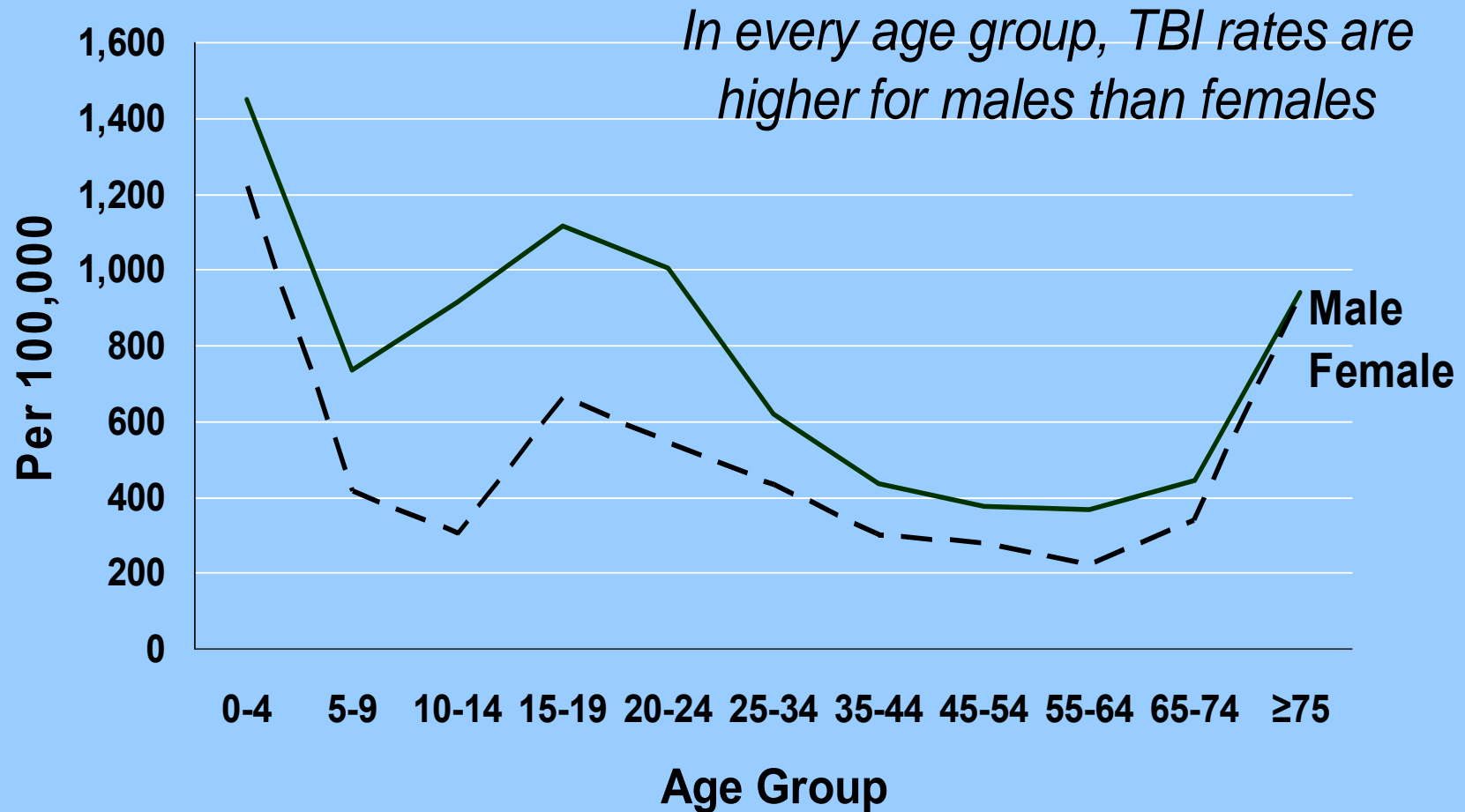
TBI in the United States

TBIs by Cause



TBI in the United States

TBIs by Sex



TBI in the United States

For More Information

- Visit the CDC website

http://www.cdc.gov/traumaticbraininjury/tbi_ed.html

TBI in Connecticut 2000-2004

- 14,534 TBI-related ED visits a year
- 56% percent of TBIs occurred in the 0 – 24 years old age group
- 36% of TBIs occurred in children <15
- 12.5% of TBIs occurred in age group 15 - 19
- 7.6% of TBIs occurred in age group 20 – 24
- Highest rates of TBI-related injuries were among:
 - Toddlers <1 year (1,331.6 per 100,000 population)
 - Children 1 – 4 years (1,087.7 per 100,000 population)

(Connecticut Department of Public Health Injury Prevention Program, 2008, http://www.ct.gov/dph/lib/dph/hems/injury/ed_databook/final_ed_databook_051508.pdf)

Impact of TBI on Development

- TBI-related problems may impact all subsequent developmental stages
- Lags (or non-development) of expected cognitive/emotional/work related abilities
- Lack of achievement of “expected” developmental milestones across the lifespan
- Challenges may take years to emerge and not be related back to early onset TBI

Impact of TBI on Development

- Childhood onset TBI threatens:
 - Academic performance
 - Social and emotional development
 - Identity formation
 - Chance of being a happy, productive member of society

Impact of TBI on Development

- Prognosis is worse and recovery slower with
 - Early injury
 - More severe injury
- Prognosis is better with
 - Higher SES
 - Learning support and stimulation in the home
 - Higher family function (more cohesion, flexibility, more positive relationships)

Anderson et al. (2005; 2009), Gerrard-Morris et al. (2010), Rivara et al. (1993; 1994), Taylor et al. (2008), Yeates et al. (1997)

Unidentified TBI in Children

Why is Identification an Issue?

- **Statistics underestimate the enormity of the problem** (National Center for Injury Prevention and Control, 2003)
- **Include only those children who die, are hospitalized, or who receive care in an emergency room** (Langlois, 2001).
- **An unknown number are not included in TBI statistics because they are not treated in hospitals, if they receive treatment at all** (Bryan, 1995; Carney & Schoebrodt, 1994).

Why is Identification an Issue?

- 630,000 brain injuries in children under 20 every year (CDC, 2010)
- If, for example, approximately 7% have long term disability (CDC, 2010)...then...
- About 44,000 kids likely become disabled by TBI every year (approx. 500 in CT)

Why is Identification an Issue?

BUT...

- 6,752,694 kids with disabilities served under IDEA (US Dep. of Ed., Fall, 2006)
- Only 24,446 kids classified with TBI under IDEA (US Dep. of Ed., Fall, 2006)

http://www.ideadata.org/arc_toc8.asp#partbCC

Some Screening Data

- In Denver schools among 101 children referred to special education, 36% of kids screened had moderate to high probability of TBI with sequelae
- In NYC public schools
 - among 174 kids screened, 9% found to be “at risk for having had a BI” and
 - 75% of At Risk group showed some impairment on neuropsychological and/or behavioral measures

(Cantor et al., 2006)

Why is Identification an Issue?

- Children may be:

- Unidentified (kids who function “OK” but fall well short of potential)

- Misidentified (“behavior problem”, ADHD, LD, developmentally disabled, “bad kid”, “slow”, etc.)

Lack of identification may lead to:

- Misdiagnosis
- Inappropriate treatment
- Mismatch between treatment and cognitive impairment
- Academic and vocational failure
- Increased psychopathology
- Reduced quality of life

Why is Identification an Issue?

- Children with TBI who remain unidentified or misidentified are likely to fail or fall behind in school (D'Amato & Rothlisberg, 1996)
- Children with TBI and their families benefit from interventions and instructional practices designed for them or adapted for them (Braga et al., 2005; Feeney & Ylvisaker, 2003; Glang et al., 2008; Mastropieri, 1988; Ylvisaker et al., 2005; Ylvisaker & Feeney, 2009)

Why is Identification Poor?

- Poor transition services between hospital/ED and school
- Ignorance amongst physicians/allied health providers/educators/social workers/school psychologists/etc. about potential consequences of TBI and how to manage them
- Lack of communication between service providers
- Reliance on the family to report brain injury to the school, physician and other relevant parties
- Delayed presentation of problems (can be years!)

Glang et al., 2008

Serving children with TBI

What Steps Are Needed?

- Screening
- Education (public-at-large, kids, families, teachers, health care professionals, social workers etc.)
- Integrated services provided in the context of schools and family life
- Communication between service providers and families

(Ylvisaker et al., 2005)

What Services are Needed?

- **Beneficial services and interventions include** (Ylvisaker et al., 2005 based on the New South Wales South West Brain Injury Rehabilitation Service Kids Team)
 - Screening
 - Assessment
 - Problem-solving consultation and case management for schools and families implemented in school and home settings
 - Occasional direct therapy services
 - Training/support for local service providers
 - Development of acquired brain injury competence in local schools
 - Development of referral networks
 - Sibling support
 - Development and distribution of resources, such as “Fact Packs” given to families, schools, and other stakeholders
 - Creation of local support networks

What Services are Needed?

- BrainSTARS: The Children's Hospital, Aurora, CO (Dise-Lewis et al., 2007)
- Effective support for students with brain injury requires a team effort.
- Program provides education for parents and school personnel so that they can create and support knowledgeable, maximally functional family-school teams.
- BrainSTARS Manual
 - Includes background information about brain injury, child and adolescent development, ways to create positive change, a comprehensive list of problems associated with brain injury, recommended interventions, and worksheets.
 - Reviewed by an advisory board of parents, school personnel, and students with brain injury, as well as by a group of national experts.
 - Extensively field-tested with parents and school teams and revised to represent current best-practices in the education and development of students who have acquired brain injuries.

What Services are Needed?

- Training events and workshops have been provided for school personnel, family members, therapists, medical professionals, and other members of the community.
- Consultation with school personnel by telephone helpline, classroom observation, telephone conferences, records review and interpretation, IEP consultation, and on-going in-school consultation.
- <http://www.thechildrenshospital.org/conditions/rehab/camps/brainstarrs.aspx>

Thank you

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and www.tbicentral.org

