Pediatric Brain Injury
What is Happening at the State & National Levels?

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TYPES OF BRAIN INJURY

- Perinatal (e.g., birth stroke)
- Congenital (e.g., PKU)
- Congenital and Perinatal (no period of normal development)
- Non-traumatic (internal occurrence e.g., tumor)
- Traumatic (external physical force)
- Acquired (following a period of normal development)
- Open (e.g., gunshot)
- Closed (e.g., fall)
Causes of BI-TRAUMATIC

Open Head Injury (penetrating)

The skull is broken or penetrated, resulting in bleeding & bruising inside the brain - focal injury

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Causes of BI-TRAUMATIC

Closed Head Injury

Impact, acceleration injury causing non-specific diffuse damage from brain moving inside the skull causing bruising, bleeding and....

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Causes of BI-Traumatic, cont’d.

• Shearing & tearing of neurons known as **DAI-Diffuse Axonal Injury**
Secondary Effects of TBI

- Edema due to increase in CSF
- Hypoxia
- Hemorrhage or Hematoma
- Seizures

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A BRAIN INJURY CAN CAUSE...
SIGNIFICANT IMPACT ON STUDENTS’...

PHYSICAL
COGNITIVE
COMMUNICATIVE
SENSORIMOTOR
PSYCHOSOCIAL
BEHAVIORAL
ACADEMIC
ABILITIES

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Long-term Consequences of TBI

• The Centers for Disease Control & Prevention estimates that at least 5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI.

• Estimated lifetime costs of BI (including direct medical costs & indirect costs such as lost productivity) = $60 billion in 2000.

• About 40% of those hospitalized with a TBI had at least 1 unmet need for services one year after TBI. The most frequent unmet needs were:
  – Improving memory & problem solving
  – Managing stress & emotional upsets
  – Controlling one's temper
  – Improving one's job skills
Brain injury is the leading cause of death & disability worldwide.
### TBI Statistics...

**Incidence of TBI per Age Group per 100,000 in the US Each Year**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>1,121</td>
</tr>
<tr>
<td>5-9</td>
<td>659</td>
</tr>
<tr>
<td>10-14</td>
<td>629</td>
</tr>
<tr>
<td>15-19</td>
<td>814</td>
</tr>
</tbody>
</table>

**TOTAL:** 3,223 per 100,000

**Percent:** 3.223%

*CDC, 2006*
CA CDE #’s

• According to the 2008-2009 California Department of Education (CDE) Dataquest statistics, only 1,851 out of over 6,200,000 students who were enrolled in public schools in the state were identified as eligible for special education as a student with a TBI under the IDEA
CA: LET’S DO THE MATH......

• 6,200,000 X 3.22% = 199,640* students who statistically sustain a TBI each year
• 75% mild= there should be 149,730 mTBI
• 25% Moderate-severe=There should be 49,910 Mod/severe TBI

*Some of these children did not survive

...and CA has 1851?
These #’S **Do Not** Include Brain Injury From Non Traumatic Causes Such As…..

- Strokes/Vascular Accidents
- Ingestion of Toxic Substances/Med errors
- Metabolic Disorders
- Brain Tumors
- Anoxic/Hypoxic Incidents
- Infections
- Seizures

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SO....
WHERE ARE THEY???

The problem lies in appropriate identification, assessment & eligibility following ATBI in children & adolescents

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WHY? Students w/ ATBI are Often Misidentified…

Many students with ATBI from both traumatic & non-traumatic events may look like & be made eligible as students with:

- VI
- MR/DD
- OI
- MD
- ED
- SLD
The Individuals with Disabilities Act Defines TBI as:

“...an acquired injury to the brain caused by an **external physical force**, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child’s educational performance. The term applies to open or closed head injuries resulting in impairments in one or more areas such as cognition; language; memory; attention; reasoning, abstract thinking; judgment; problem solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or to brain injuries induced by birth trauma.”

34 Code of Federal Regulations 300.7 (c)(12)

Discussion section of the Federal Register (Vol. 57, No. 189, p. 44842, Tuesday, September 29, 1992) it is stated that "The definition of traumatic brain injury does include an acquired injury to the brain caused by the external physical force of near-drowning."
CA Definition of OHI ...

“having limited strength, vitality, or alertness due to **chronic or acute health problems**, including but not limited to: a heart condition, cancer, leukemia, rheumatic fever, chronic kidney disease, cystic fibrosis, severe asthma, epilepsy, lead poisoning, diabetes, tuberculosis and other communicable infectious diseases, and hematological disorders such as sickle cell anemia and hemophilia which **adversely affect a pupil’s educational performance.**”

The health impairment will not qualify the pupil for special education if it is temporary in nature.  [5 C.C.R. Sec. 3030(f).]

Under state law, “temporary” means a disability which will terminate at some point and which, when it terminates, will not prevent the student from returning to a general education class without the need for any special interventions.

[5 C.C.R. Sec. 3001(aj).]
ATBI: Issues with Assessment & Eligibility…

- Standardized, norm-referenced measures…
  - May not assess the full range of skills
  - Assessment in 1-1 setting may not measure abilities in active classroom settings
  - May have limited predictive validity

- Timed tasks may reflect motor slowing, not ability
Assessment Issues

- Measures of prior knowledge may not reveal difficulty with ability to acquire & retain new information
- Students may have high level ability areas w/gaps in knowledge
- Neurologic recovery & reorganization can continue for months/years, requiring need for more frequent assessment
- Need for environmental analysis/observations of child in real world settings
- Effects of injury on the developing brain: age injury occurred…
So, Maybe Eligibility Depends on the Levels of Severity of The ATBI??

- **Severe**
  - In coma >24 hours

- **Moderate**
  - In coma <24 hours/or shows neurological signs of brain trauma (Skull fracture w/contusion, hemorrhage, or focal findings on EEG or CT scan)

- **Mild (mTBI)**
  - Brief or no loss of consciousness at time of injury
  - Signs of concussion (vomiting, lethargy, dizziness, lack of recall of injury)

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CADE

- Age 13, car T-boned family van 2/05
- Depressed skull fracture, 14 day coma, 11 month hospitalization, 5 months inpatient rehabilitation
- Nonverbal, communicates with blinking for yes-no, high tone, non-ambulatory, significantly limited motor skills
- Current services: CCS PT/OT; home nursing, mix of home inst. & school attendance; speech therapy
ELIGIBILITY??
Sarah
Age 6 Hypothalamic Astrocytoma
Left Temporal Lobe

• Surgery, chemotherapy, more surgery. **At age 14**...

• Legally blind, severe articulation deficits, shunt, right hemiparesis, great auditory learner, poor reading/learning challenges; endocrine issues

• Severe behavior, depression, suicidal ideation

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ELIGIBILITY???
Claudia C. Age 17-mTBI

- Was in a car crash age 16; knees & back were treated. No one paid attention to the fact she hit her head. She looks normal.

- A CT scan did not show any damage or lesions to the brain—there are no scars.

- No one recognized that she had a TBI. She’d had been a good student before & was seen as not putting forth her best effort, was called “lazy”, a “screw up” & failed classes.

- People talk to fast, conversations often don't make sense; cannot take notes.

- Has trouble organizing thoughts to write an essay.
Claudia C. mTBI

- Has headaches, & sleeps a great deal—does not want to get up for school.
- Sometimes can't recall what she ate for breakfast; where she put things. Her mother found the toaster in the refrigerator.
- She has to write down everything she is asked to do.
- She needs help with organization.
- She is frustrated & depressed... knows she is smart, has always been a hard worker, but simply cannot, despite the willingness, do it.
- Keeps trying to do things the way she did before, & that does not work any more & it depresses her.

Eligibility???
mTBI/Concussion

- Known as the... *silent epidemic*...
- Approximately 800,000 people in US sustain a mTBI each year
- Involves:
  - Any period of LOC (loss of consciousness), or no LOC
  - Any loss of memory for events immediately before or after an accident
  - Any alteration in mental state at time of accident
  - Focal neurological deficits that may or may not be transient

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mTBI-Definition by CDC

- A disturbance of brain function is related to neurometabolic dysfunction, rather than structural injury, & is typically associated with normal neuroimaging findings (CT, MRI).
- May or may not result in LOC.
- Duration of symptoms are variable & may last for as short as several minutes, or as long as several days, weeks, months or even longer, in some cases.
B: DTI brain scan of child with TBI indicating absent fiber tracts.
C: DTI brain scan of uninjured, demographically matched child.
Federal and State Approaches to Brain Injury
Founded in 1980, the Brain Injury Association of America (BIAA) is the leading national organization serving & representing individuals, families & professionals who are affected by TBI. Together with its network of more than 40 chartered state affiliates, as well as hundreds of local chapters and support groups across the country, the BIAA provides information, education and support to assist the 5.3 million Americans currently living with TBI and their families.
BIAA’s ACBIS

• Academy for the Certification of Brain Injury Specialists
  – National certification program for professionals working in brain injury services
  – Provides staff & professionals the opportunity to:
    • Learn important information about brain injury
    • Demonstrate learning in a written examination
    • Earn a nationally recognized credentials-CBIS and CBIST.

• www.acbis.pro

www.helpingkidsbrains.com
California Brain Injury Association-CAL BIA

• In December of 2007, CAL BIA became a chartered state affiliate of the Brain Injury Association of America (BIAA)

• Goal of CAL BIA:
  – Create a better future through brain injury...
    • Prevention
    • Research
    • Education
    • Advocacy
    • [www.calbia.org](http://www.calbia.org)
Sara Jane Brain Project

• **Phase 1** October 2007
  – Patrick Donahue of NYC, whose daughter Sara Jane sustained a TBI due to Shaken Baby launched the Open Source Initiative which was the first time in medical history someone's (Sarah Jane's) medical records & therapy videos were made publicly available using open source principles

• **Phase 2** began immediately when he started:
  – recruiting other families to participate in the Open Source Initiative
  – Attracting the best in the field of PABI to join his National Advisory Board.
Sarah Jane Brain Project

• **Phase 3** January 2010 NYC
  – National Advisory Board developed the first-ever National PABI Plan (a comprehensive continuum of care model system).
  – PABI Plan is posted on the website

• **Phase 4** GOAL:
  – Congress passing the PABI Act which will fund and fulfill the PABI Plan

[www.TheBrainProject.org](http://www.TheBrainProject.org)
Sports Injury Stats

• It has been estimated that more than 6 million high school students participate in sports nationwide.

• Over 715,000 sports related injuries occur annually & in last 2 years, over 125 middle & high school athletes died as a result of an injury.

• California suffered 18 fatalities.
The San Jose Mercury News reported on a 2009 study that showed that 41 percent of high school athletes who suffered a concussion return to play prematurely.
The American Academy of Neurology defines a concussion simply as "a change in mental status from a blow" that may involve loss of consciousness.

According to Brian Chavarin, Program Director for the USC Center for Athletic Medicine, brain swelling is what causes that change -- but concussions are actually diagnosed by the signs and symptoms.
Age 16-TBI from 2nd Impact Concussion During Football, w/subsequent Stroke

- 3 week coma
- 5 months acute & rehabilitation hospital
- Left hemiparesis; very high tone
- Moderate cognitive issues
  - Executive functioning deficits
- Moderate learning challenges
- Perseverative behaviors
- Visual field cut deficit & poor eye convergence
Josh’s School Re-integration

- Public school reintegration with support of ABI education specialist
- Made eligible with medical disability
- Started on home teaching, LAS
- Diagnostic prescriptive teaching
- Partial day attendance mixed with home teaching until able to attend full day
- Assessment 6 months after TBI
- Multiple trainings provided to school staff; frequent IEP meetings held as his needs changed
- School program tailored to his needs:
  - Accommodations
  - Modifications
  - Assistive technology
  - RSP, VI, PT, SLP, OT, Counseling, CCS
Josh Graduated on time with his class!!
CIF CONCUSSION PROTOCOL

• Recognition of and procedural practices in response to suspected head injuries to athletes at every level has become a “hot button” issue throughout the nation.

• The CA CIF Sports Medicine Committee has developed and introduced a proposed new bylaw covering the “return to play” decision process for any student who may have received a concussion or head injury. The protocol, which will be up for adoption at the Spring 2010 CIF Meeting, reads as follows:
A student-athlete who is suspected of sustaining a concussion or head injury in a practice or game shall be removed from competition at that time for the remainder of the day. A student-athlete who has been removed from play may not return to play until the athlete is evaluated by a licensed health care provider trained in the evaluation and management of concussion and receives written clearance to return to play from that health care provider.
Dr. Cindy Chang, a member of the CIF Sports Medicine Committee, presented a full briefing to the CIF Council on head injury, including:

- Some alarming data about undiagnosed cases
- Longer recovery periods for adolescents
- The dangers of secondary impact
- The need for more focused in-service training for coaches
Laws for Prevention of TBI
Student Athletes: Laws

A number of states are considering legislation to better protect their high school students. Three states have already done so:


– Texas enacted "Will's Bill" in 2007, which requires every high school coach to be trained in basic safety and emergency procedures, with special emphasis on concussions and second-impact syndrome.
Student Athletes

– Washington State's "Zackery Lystedt Law“ requires all athletes under the age of 18 who are suspected of having a concussion to get written consent from a licensed medical provider trained in evaluating concussions before returning to play.
CA: AB 1646

Incorporates the following into high school coaches' existing training requirements:

1) Recognizing the signs and symptoms of potentially catastrophic injuries, including, but not limited to, head & neck injuries, concussions, second impact syndrome, asthma attacks, heatstroke, & cardiac arrest

2) Learning appropriate emergency action planning

3) Effective communication with emergency services.

This training requirement would be phased in as coaches renew their CPR & first aid
CA: AB 1647 (Introduced)

Catastrophic Injury Prevention

• Will protect high school athletes from sports related injuries by:
  – requiring medical clearance before a student athlete can return to play
  – Making available an automatic external defibrillator at sports practices and contests after July 2014,
  – requiring persons holding themselves out as an "athletic trainer" to have specified medical training,
  – requiring the Department of Education to adopt a heat acclimatization program for use by school districts.
SNOWBOARDING...

SMART

NOT SO SMART

www.helpingkidsbrains.com
SB 880
Helmets for Children Skiers/Snowboarders

- Half of all skiing deaths are caused by a head injury.
- Recent studies show that when helmets are used, the incidence of traumatic brain injury has been reduced 29% -56%
- The Federal Consumer Products Safety Commission (CPSC) has found that more than 7,000 head injuries per year on the slopes in the U.S. could be prevented or reduced in severity by the use of a helmet.
SB 880

- The CPSC study also showed that for children under 15 years of age, 53% of head injuries (approximately 2,600 of the 4,950 head injuries annually) are addressable by use of a helmet.
Injuries that are sustained without a helmet are not only dangerous, but also pose significant financial hardship.

According to the AMA, 1st year acute care costs for all skiers under age 17 who sustain a head injury range from $1.5 million for patients with mTBI to $82 million for those with severe TBI.

Annual lifetime care costs per an individual, excluding first year costs, range from $329,000 for mild TBI to $8.96 million for severe TBI.

An estimated cost for life care for an 11 year-old with a mild TBI is about $6.5 million.
SKIING

SMART

NOT SO SMART

www.helpingkidsbrains.com
CALIFORNIA HELMET LAW

• Went into effect JANUARY 1, 2003
  – HELMETS REQUIRED FOR ANYONE UNDER AGE OF 18 WHILE RIDING A
    • BIKE
    • SKATEBOARD
    • ROLLER SKATES
    • MOTORIZED SCOOTER

www.helpingkidsbrains.com
BICYCLE HELMETS...

• Decrease the risk of head injury by 69%.
• Decrease the risk of severe brain injury by 74%.
• Are equally effective in protecting cyclists in crashes involving motor vehicles & those not involving motor vehicles.
• Provide substantial protection against lacerations and fractures to the upper- and mid-face, but appear to offer little protection to the lower face.
CTC
Traumatic Brain Injury (TBI)
Authorization Standards
Proposed & Submitted
TBI Standard 1: Characteristics of Students with Traumatic Brain Injury

The program provides opportunities for the candidate to identify the unique characteristics of students within Traumatic Brain Injury. The candidate demonstrates unique knowledge of the core challenges associated with the neurology of open or closed head injuries resulting in impairments in one or more areas such as:
cognition; language; memory; attention; reasoning, abstract thinking; judgment; problem solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. Transition from hospital/home instruction for appropriate school reintegration and knowledge that the child is recovering and will make changes in these areas is vital for appropriate service delivery.
TBI Standard 2:
Teaching and Learning for Students with TBI
The program ensures that each candidate is able to demonstrate knowledge, skills and abilities to become proficient in implementing evidence based and multi-faceted methodologies and strategies necessary in teaching and engaging students with TBI. The candidate is able to use/interpret appropriate assessments from school as well as medical and neuropsychological assessments to drive program decisions, particularly for those students regaining skills that were lost due to the injury.
TBI: Standard 2, cont’d.

Candidates are able to adjust teaching strategies based upon the unique profile of students who present with physical access/medical issues, splinter skills, or who retain a general fund of knowledge, but demonstrate difficulty acquiring and retaining new information due to poor memory and processing. The candidate understands and appropriately utilizes research based teaching strategies, structured teaching, as well as the use of adaptations, compensatory strategies, assistive technology and visual supports.
TBI Standard 3: Behavior and Emotional Strategies for Students with TBI

The program will focus on developing the candidate’s knowledge regarding the underlying cause of a student’s behavioral and emotional issues following a traumatic brain injury. The candidate will demonstrate the appropriate and consistent application of positive behavior supports, as this practice is essential to the success of these students.
Candidates will possess the knowledge that the diminishment or loss of previous abilities (learning, social, physical) may have a significant effect on the self-concept and emotional well-being of a traumatic brain injury survivor, and provide the students with appropriate supports and services to address these issues.
TBI Standard 4: Collaborating with Other Service Providers

The program provides proactive monitoring opportunities for candidates working with students with TBI to demonstrate skills as a member of a collaborative team, including systems for interfacing with other service providers (both school and agency based) including: Hospital/rehabilitation based personnel, Occupational Therapist, Speech and Language Pathologist, Physical Therapist, Psychologist, Paraprofessional, School Nurse, Behavior Analyst, California Children’s Services, Regional Center, and other appropriate providers.