

Identifying Students with TBI: Clear as Mud

PA Department of Education
Conference
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Director, TBI Program

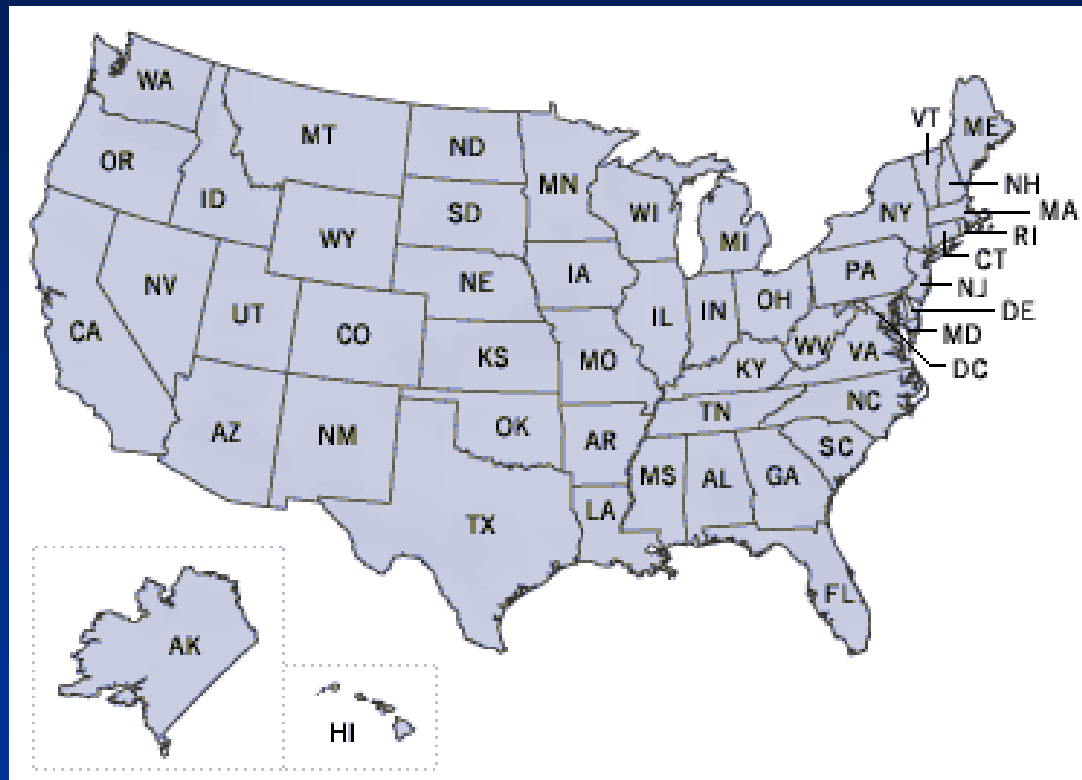
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National Picture



Incidence of Brain Injury: National Data

- Brain injury is the leading cause of death and disability of children in the U.S. (Pediatric Registry)
- CDC reports annual incidence of TBI for Children 0-14:
 - 2,685 deaths
 - 37,000 hospitalizations
 - 435,000 ED visits

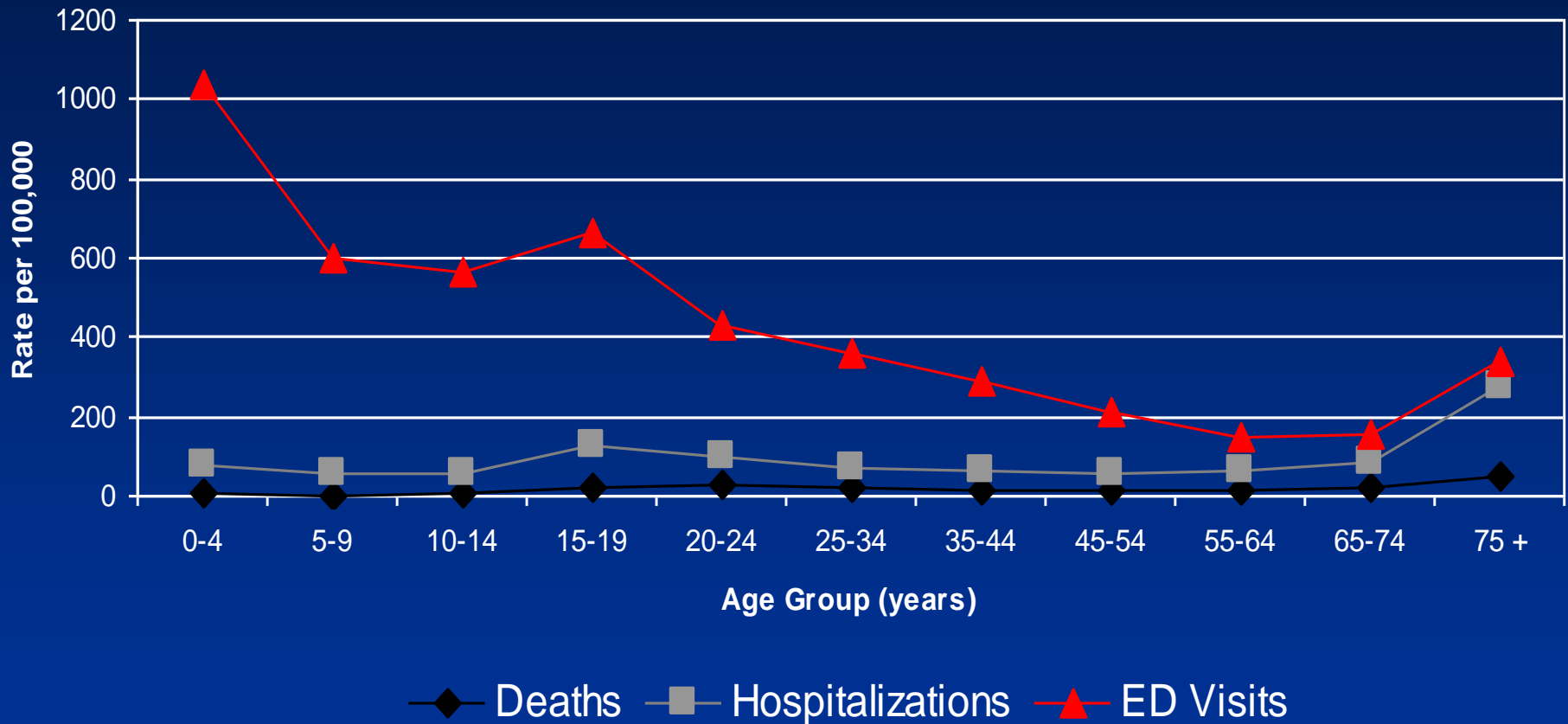
These numbers do not include children who sustained a TBI and did not seek medical care or were treated and released without mention of potential TBI

Incidence of Brain Injury: National Data

- Each year an average of 475,000 TBIs occurred among children.
- Most children who sustained a TBI (91.5%) were treated and released from the emergency department without further treatment.

TBI in the United States

TBIs by Age Group*



* Average annual rates, 1995-2001

U.S. Department of Education Data (Students ages 6-21)

- During the 1991-92 school year there were a total of 4,499,824 students receiving special education services of that total only 245 were served under the TBI disability category
- During the 1999-2000 school year there were a total of 5,683,707 students receiving special education services of that total there were 13,874 served under the TBI disability category

U.S. Department of Education, Office of Special Education Services: Annual Report to Congress, 2000

U.S. Department of Education Data (Students ages 6-21)

- 2005 data shows there were a total of 6,021,462 students receiving special education services of that total there were 23,449 served under the TBI disability category. 2007 there were 23,864 with TBI
- Interesting fact, Autism became a disability category in 1991 also; in 1992, 15,302 students were identified, in 2000, 79,085 were identified and in 2005 192,643 students were identified under the autism disability category. 2007 there were 258,305 with Autism.

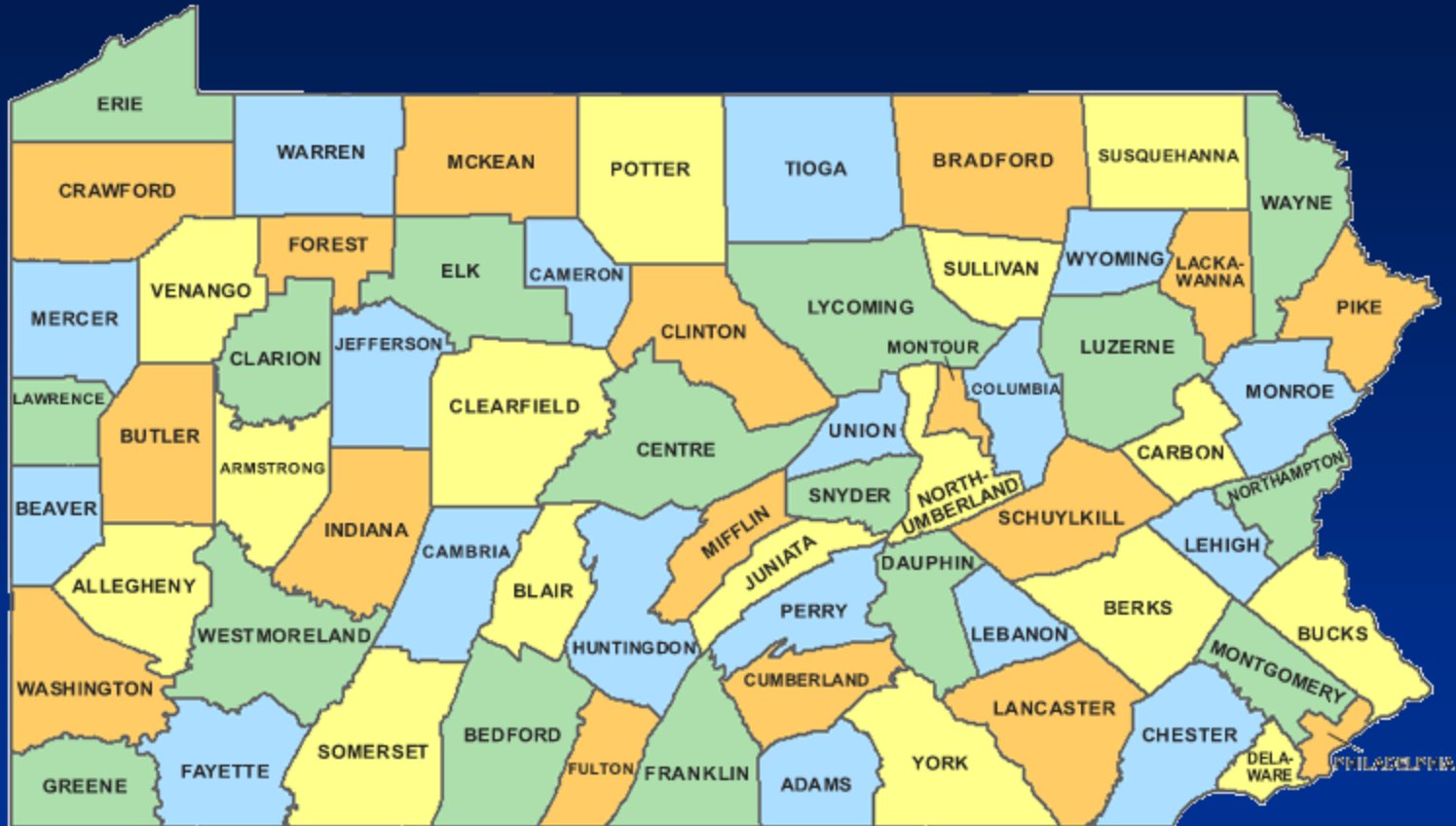
Let's Recap: You do the Math...

- Each year an average of 475,000 TBIs occurred among children (0-14)
- The National Pediatric Registry reports that it is estimated that 19% of youth who sustained a brain injury will have long term disabilities
- Reviewing data from USDOE in 2006 there were 23,777 students with TBI receiving special education services. In 2007 there were 23,864 served under the TBI disability category (0-21). Totaling an increase of 87 students.

Let's Recap: You do the Math...

- Conservatively, using the 19% guideline, we could estimate roughly 90,250 with long term disabilities resulting from brain injury annually.
- Get your calculators out.....
- $19\% \text{ of } 475,000 = 90,250$, USDOE increased by 87 in one year.....
- Are we missing 90,163 students annually with brain injury?

Pennsylvania



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Where Does PA Stand?

- CDC indicates that between 1 and 2% of population has TBI
- Pediatric Registry estimates 19% of children with TBI will have long-term consequences associated with that TBI

Where Does PA Stand?

- 2008 Census data indicates the population of PA is 12,448,279 with 22.2% under 18 (2,763,518)
- 1% of 2,763,518 = 27,635
- 19% of 27,635 = 5,250



More Specific PA data

Each year, approximately

25,975

children in Pennsylvania sustain a
traumatic brain injury

(mild, moderate, or severe)

Source: The Brain Injury Association of Pennsylvania, 2008

Children Hospitalized with TBI in PA

In 2006

3,938

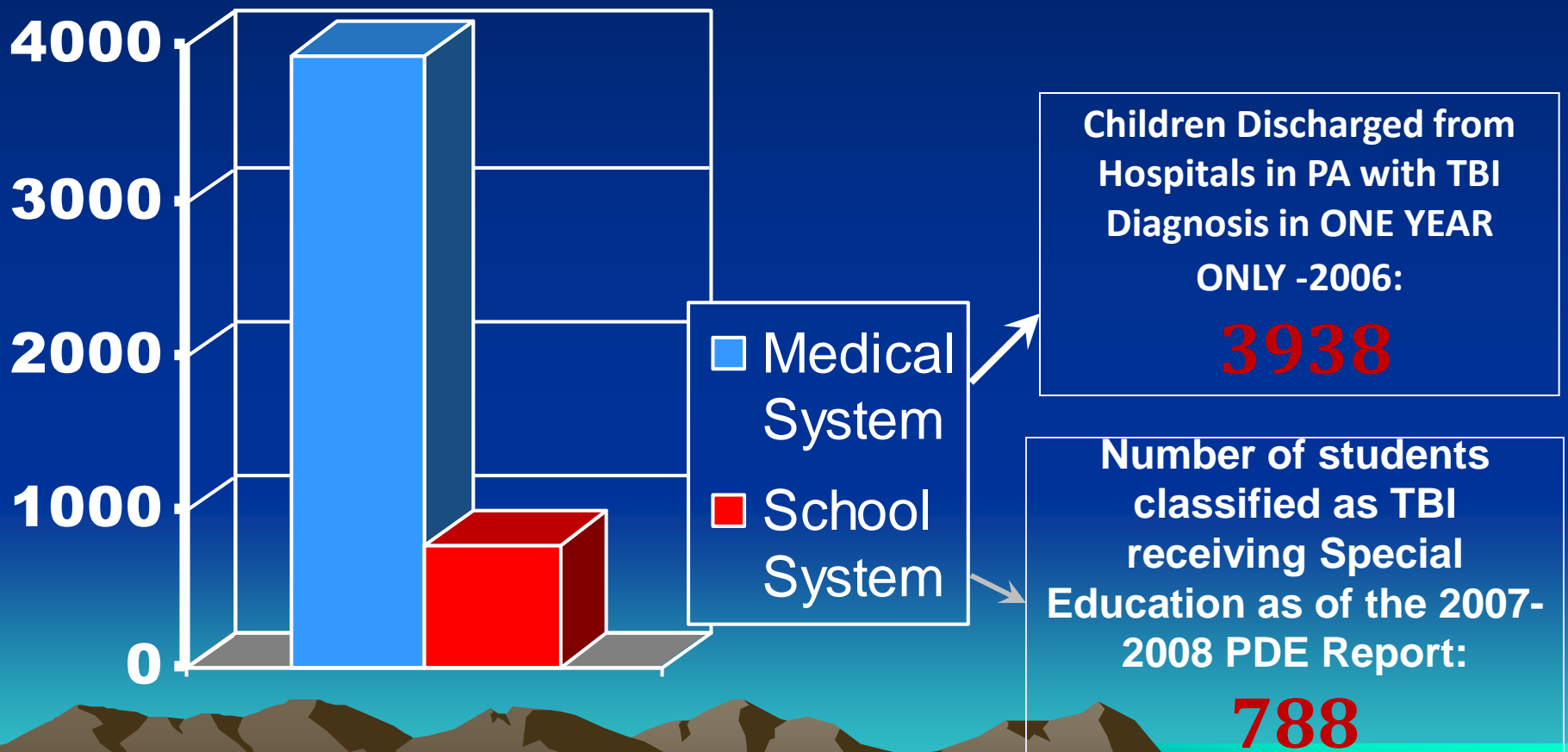
Children & Adolescents in
Pennsylvania were
HOSPITALIZED with TBI

Source: The Pennsylvania Department of Health, 2009



Statistics in Pennsylvania

In one year (2006) the PA Department of Health recorded **3938** children ages 0-21, who were hospitalized with TBI.



GET THE PICTURE?



Why Are We Missing These Kids?

- Transition support from medical setting is rare or poorly coordinated
- From hospital fewer than 2% are recommended for special education (though 19% have cognitive limitations)
(National Pediatric Registry)
- Treat and Release from the EDs

Why Are We Missing These Kids?

- Brain injury often goes undiagnosed
- The effects of brain injury can be very subtle
- Families and school personnel have limited knowledge about brain injury

How IDEA Plays into the Problem

- USDOE has given discretion to the states to interpret their definition of TBI
- USDOE does not indicate what documentation is required for determining a student eligible for special education under the TBI category
- Medical documentation of mild to moderate TBI may not be available

What Colorado is Doing



Colorado Department of Education

August 2008

Medical Documentation of TBI

or

Credible History of TBI

and

Educational Impact

DEFINITION OF ELIGIBILITY: TRAUMATIC BRAIN INJURY

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

Team has determined: 300.306(b) If the answer is "no," to any of these questions the student cannot be considered eligible for special education at this time.

- No 1. the evaluation is sufficiently comprehensive to appropriately identify all of the child's special education and related services needs, whether or not commonly linked to the disability category
- No 2. the student **cannot** receive reasonable educational benefit from general education alone
- 3. the student's performance:
 - is** **is not** due to a lack of appropriate instruction in reading, including the essential components of reading instruction
 - is** **is not** due to a lack of appropriate instruction in math; and
 - is** **is not** due to limited English proficiency.

...or a Physical Disability in the area of TBI preventing the student from receiving reasonable education benefit from general education should be dependent upon whether the student meets the educational criteria for Traumatic Brain Injury and interferes with the following:

Student's Physical Disability in the area of TBI is characterized by:

- No Medical documentation of a Traumatic Brain Injury **or** History of a Traumatic Brain Injury **and**
- No Educational evidence of an deficits relating to the Traumatic Brain Injury

Student's Physical Disability in the area of TBI interferes with: (check those that apply)

- No Walking, writing, and self-help skills; **and/or**
- No Ability to recall information and learn new material; **and/or**
- No Language skills; **and/or**
- No Attention/Memory; **and/or**
- No Visual-spatial and motor deficits; **and/or**
- No Planning and organization; **and/or**

No **The team agrees that this student has a disability as defined in the State Rules for the Administration of the Exceptional Children's Act and is eligible for special education.**

Colorado's Challenge

To put into place an effective and efficient identification protocol

Medical documentation:

- ❖ Sometimes difficult to get
- ❖ Does not guarantee educational impact
- ❖ Does not direct intervention

CDE recommends “Gold Standard”

It is still best practice is to establish traumatic brain injury through medical documentation via hospital records and/or from a doctor or clinician who has knowledge of the Center for Disease Control (CDC) requirements for TBI.

Severe and moderate TBI– usually (not always) lend themselves to medical documentation.

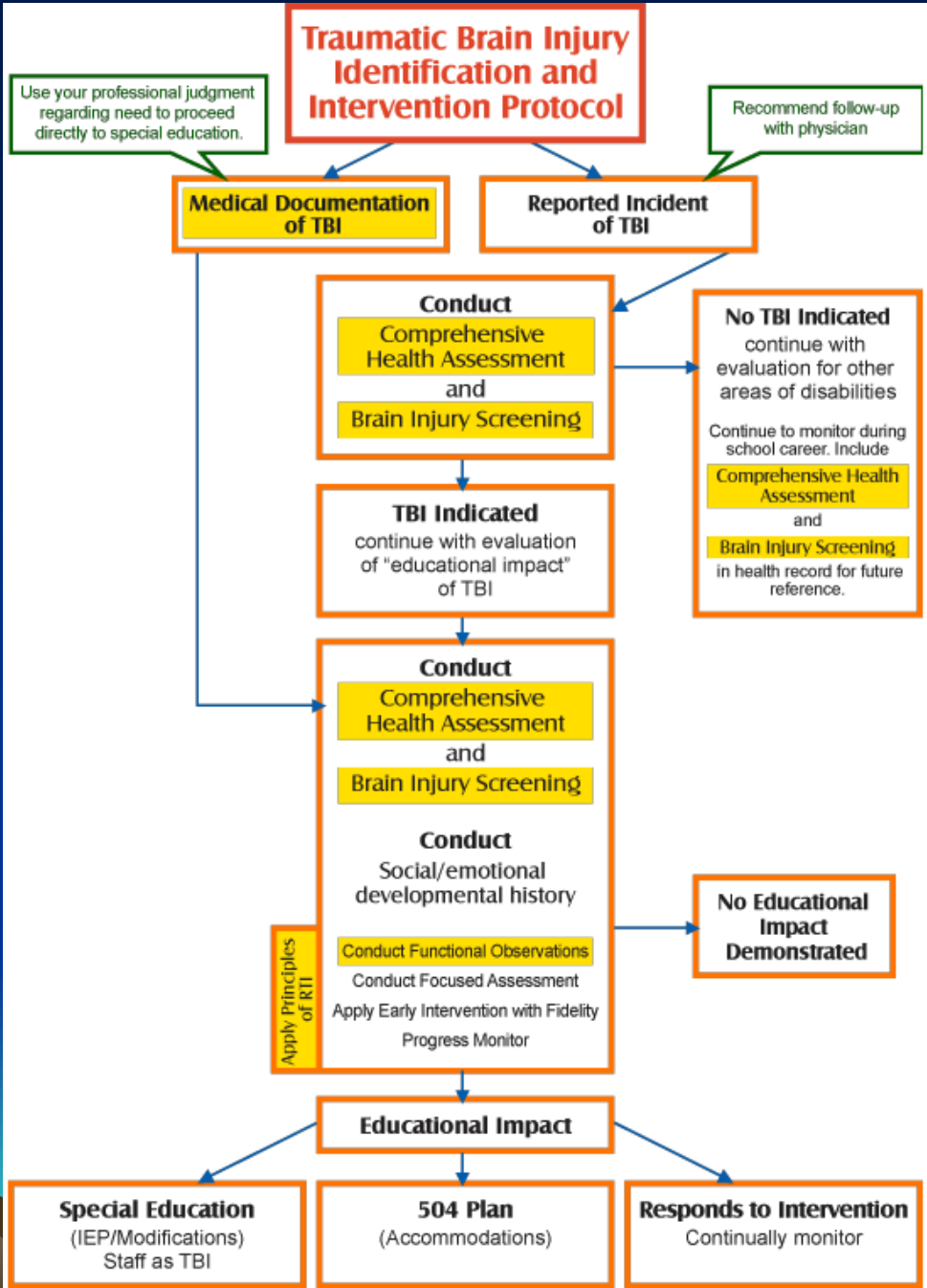
Mild TBI (mTBI) aka Concussion

- 1.6 to 3.8 mTBI per year in the United States.
- How many mTBI are not seen by a medical professional?
- Estimated 42% are not seen by medical professional.

Very difficult to establish medical documentation on mTBI cases

Identification Protocol

1. Medical Documentation
2. Reported Incident
3. Credible History
4. TBI Screen
5. Establish Educational Impact



Credible History

“The gold standard for determining prior TBI is self/parent-report as determined by a structured or in-depth interview” (Corrigan & Bogner, 2007)

Comprehensive Health History Interview

(Health history must be an interview; it cannot be a form mailed to the parent/caregiver)

Credible history of TBI requires a skilled interviewer to know how to ask certain questions, to ask pointed questions multiple times and in a variety of ways, to establish the details of the TBI(s).

Questions should include:

- Where
- When
- How
- Medical intervention(s) sought at the time, later, through the recovery
- Are answers medically plausible?
- Be aware of assumptions – for example, the report of a “scalp laceration” or “head injury” does not automatically define a “brain injury”

Credible History continued...

2. There needs to be a reported incident(s) as well as on-going symptoms/behaviors that persist beyond the incident (Corrigan & Bogner, 2007).
 - During the health interview, details of the incident should be clear and consistent. The description of the injury should not vary widely from report to report, from reporter to reporter (if there are multiple reporters of the same incident).
 - If there are multiple injuries, specifics about each injury should be well-detailed and consistent.

Interviewer must know acute and latent symptoms of TBI

Acute symptoms:

Physical Headache Blurred vision Poor balance Seeing “stars” Dizziness Nausea/vomit Sensitivity to light/sound Vacant/glassy look	Cognitive Feeling in a “fog” Slowed speech Difficulty remembering/concentrating Distracted Feeling “slowed down” Easily confused
Emotional Personality change Irritable Anxious Emotionally labile Sad Apathetic	Maintenance Fatigue Excess sleep Unable to initiate or maintain sleep Drowsiness Sleeping less than usual

Latent symptoms that emerge or develop later, symptoms that “morph”.
Assess pre versus post-injury learning, behaviors, social skills, personality.

Credible History continued...

3. Finally, a screen or in-depth interview is not enough to “diagnose” TBI. These tools are simply to “screen” for potential TBI. If a screen or in-depth interview suggest there has been a credible history of TBI, a thorough assessment/evaluation is suggested (Corrigan & Bogner, 2007).

Confirm credible history with:
CSU Brain Checklist Screen

CSU Brain Checklist Screen

3 Primary Sections

1. Injury or Illness
2. Behaviors that Affect Learning
3. Symptoms

Code: _____ Date Received: _____



Colorado State University

Department of Occupational Therapy
College of Applied Human Sciences
Fort Collins, Colorado 80523-1373
(970) 491-4253
FAX: (970) 491-6290

Brain Check: Screening Tool Project
Parent/Guardian Survey

Student Information

Today's Date: ____/____/____ Child's Age: _____
Child's Date of Birth: ____/____/____ Child's Gender: Male Female

Child's race: (circle one or more)	1: American Indian/Alaska Native 2: Asian 3: Native Hawaiian or Other Pacific Islander	4: Black or African American 5: White 6: More than one race Please describe: _____
Child's ethnicity: (circle one)	1: Hispanic or Latino 2: Not Hispanic or Latino	3: Unknown or Not Reported

Injuries or Illnesses

Injury or Illness Please check all that apply	Age	Outcomes
<input type="checkbox"/> Blow to Head (egg sports, playing, biking, falling, getting hit by an object, etc.)	At what age(s) _____	Check all that apply: <input type="checkbox"/> Concussion <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Whiplash	At what age(s) _____	Check all that apply: <input type="checkbox"/> Concussion <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Car accident (resulting in any degree of injury or lack of injury)	At what age(s) _____	Check all that apply: <input type="checkbox"/> Concussion <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school

Code: _____

Injury or Illness Please check all that apply	Age	Outcomes
<input type="checkbox"/> Assault/Violence (child abuse, fights, firearm injury)	At what age(s) _____	Check all that apply: <input type="checkbox"/> Concussion <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Sustained High Fever	At what age(s) _____	Check all that apply: <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Brain Tumor	At what age(s) _____	Check all that apply: <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Anoxia (definition: lack of oxygen caused by such events as a near drowning experience or suffocating experience)	At what age(s) _____	Check all that apply: <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Meningitis	At what age(s) _____	Check all that apply: <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Encephalitis	At what age(s) _____	Check all that apply: <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state <input type="checkbox"/> Missed school <input type="checkbox"/> Resulted in no problem
<input type="checkbox"/> Seizures (example: epilepsy)	At what age(s) _____	Check all that apply: <input type="checkbox"/> Loss of consciousness, "for how long" _____ <input type="checkbox"/> Coma, "for how long" _____ <input type="checkbox"/> Confusion or altered mental state

Please tell us about your child's learning styles and behaviors

Learning Style or Behavior	Not Applicable?	Circle the number on the scale which best describes your child:					
		No Problem				Extreme	
	<input type="checkbox"/> N/A	1	2	3	4	5	6
Focusing and maintaining attention	<input type="checkbox"/> N/A	1	2	3	4	5	6
Getting started on activities, tasks, chores, homework and the like, on his or her own	<input type="checkbox"/> N/A	1	2	3	4	5	6
Being understood (speech is easy to understand, speaks clearly)	<input type="checkbox"/> N/A	1	2	3	4	5	6
Understanding others	<input type="checkbox"/> N/A	1	2	3	4	5	6
Coping with change or transitions	<input type="checkbox"/> N/A	1	2	3	4	5	6

Code: _____

Learning Style or Behavior	Not Applicable?	Circle the number on the scale which best describes your child:					
		No Problem				Extreme	
Monitoring own progress on homework, assignments, chores, and the like	<input type="checkbox"/> N/A	1	2	3	4	5	6
Solving everyday problems (example: thinking of different options when something is not working for him/her.)	<input type="checkbox"/> N/A	1	2	3	4	5	6
Waiting for his or her turn in a game	<input type="checkbox"/> N/A	1	2	3	4	5	6
Learns from past mistakes or behavior	<input type="checkbox"/> N/A	1	2	3	4	5	6
Thinks before speaking or acting	<input type="checkbox"/> N/A	1	2	3	4	5	6
Listens without interrupting others often	<input type="checkbox"/> N/A	1	2	3	4	5	6
Handles a change in plans	<input type="checkbox"/> N/A	1	2	3	4	5	6
Demonstrates good judgment	<input type="checkbox"/> N/A	1	2	3	4	5	6

Listens without interrupting others often	<input type="checkbox"/> N/A	1	2	3	4	5	6
Handles a change in plans	<input type="checkbox"/> N/A	1	2	3	4	5	6
Demonstrates good judgment	<input type="checkbox"/> N/A	1	2	3	4	5	6
Learns new things easily	<input type="checkbox"/> N/A	1	2	3	4	5	6
Remembers lists	<input type="checkbox"/> N/A	1	2	3	4	5	6
Remembers day-to-day events	<input type="checkbox"/> N/A	1	2	3	4	5	6

Symptoms

If your child has experienced any of the following symptoms, rank the severity of those symptoms.

+ Please check all that apply:

Symptom	Not Applicable?	Circle the number on the scale which best describes your child:					
		No Problem			Extreme		
	<input type="checkbox"/> N/A	1	2	3	4	5	6
Headaches and/or Migraines (sudden, not responsive to medications, can last for more than a day)	<input type="checkbox"/> N/A	1	2	3	4	5	6
Loss of muscle coordination (can look like awkward movements, problems with balance, slowed reactions, uncoordinated running and catching)	<input type="checkbox"/> N/A	1	2	3	4	5	6
Blackouts/ Fainting	<input type="checkbox"/> N/A	1	2	3	4	5	6
Confusion	<input type="checkbox"/> N/A	1	2	3	4	5	6
Blank staring/Day dreaming	<input type="checkbox"/> N/A	1	2	3	4	5	6
Dizziness	<input type="checkbox"/> N/A	1	2	3	4	5	6
Change in vision (blurred vision, double vision, depth perception)	<input type="checkbox"/> N/A	1	2	3	4	5	6
Fatigue (tires easily, is often tired)	<input type="checkbox"/> N/A	1	2	3	4	5	6
Seizures	<input type="checkbox"/> N/A	1	2	3	4	5	6
Slurred speech	<input type="checkbox"/> N/A	1	2	3	4	5	6
Has trouble finding the "right" word	<input type="checkbox"/> N/A	1	2	3	4	5	6

Educational Impact

Medical documentation/credible history simply confirms the **presence** of the TBI. It does not or cannot automatically establish the “impact” of the TBI. Confirming that an injury has occurred does not shed light upon the affect of the injury on subsequent physical, educational, behavioral, emotional, social outcome. Once medical documentation has been established, CDE requires that school teams continue to proceed through the protocol to establish “educational impact”.

Establishing Educational Impact

- Functional Assessment/Observation
- Focused Assessment

Functional Observation

- Teacher, parent and student interview
- Functional school setting observation

Functional Community-Referenced Assessment

1. Interview
2. Observation
3. Summary

Formal “Focused” Assessment

- Cognitive
- Neuropsychological
- Achievement
- Speech Language
- Occupational Therapy/Physical Therapy
- Adaptive
- Emotional/Behavioral/Executive Functions

Why it Matters

Under-Identification Cycle

1. Students are under-identified so TBI appears as a “low incidence” disability
2. Numbers drives money, there is a lack of funding for TBI
2. This feeds into a lack of awareness and lack of training for school personnel
3. Which develops a cycle of failure for these students

The Importance Of Accurate Identification

- Student receives appropriate interventions
- Prevent a cycle of failure
- Allows the student to begin developing self advocacy skills
- Accurate identification ensures more appropriate funding and subsequent service provision



BrainSTEPS



Brain Injury School Re-Entry Model

The BrainSTEPS Program

- Funded by a Title V, federal Maternal Child Health Block Grant, from the PA Department of Health.
- Partnered with the PA Department of Education, Bureau of Special Education
- Implemented by the Brain Injury Association of Pennsylvania - September 2007



What is BrainSTEPS?

- The BrainSTEPS School Re-Entry Program establishes brain injury consulting teams available to families and schools throughout Pennsylvania.
- Consulting teams are extensively trained in the educational needs of students returning to school following brain injury.
- Teams will work with local school staff to develop educational programs, academic interventions, strategy implementation, and monitoring of students.



Team Membership

Members based:

- Schools
- Educational Intermediate Units
- Medical Rehabilitation Centers
- Community Agencies/Institutions
- Families



BrainSTEPS Encompasses Acquired Brain Injuries

- **Traumatic Brain Injuries**
- **Non-Traumatic Brain Injuries**



BrainSTEPS Objectives

1. Increase awareness of children and youth with brain injury who are served by the school system
2. Provide training and technical assistance to schools, families and healthcare providers in the early identification of children with TBI



BrainSTEPS Objectives

3. Partner with Pennsylvania brain injury hospitals & rehabilitation providers to promote effective communication & consistent/familiar contacts between healthcare providers and educators to facilitate successful transition
4. Explore and direct families to community resources

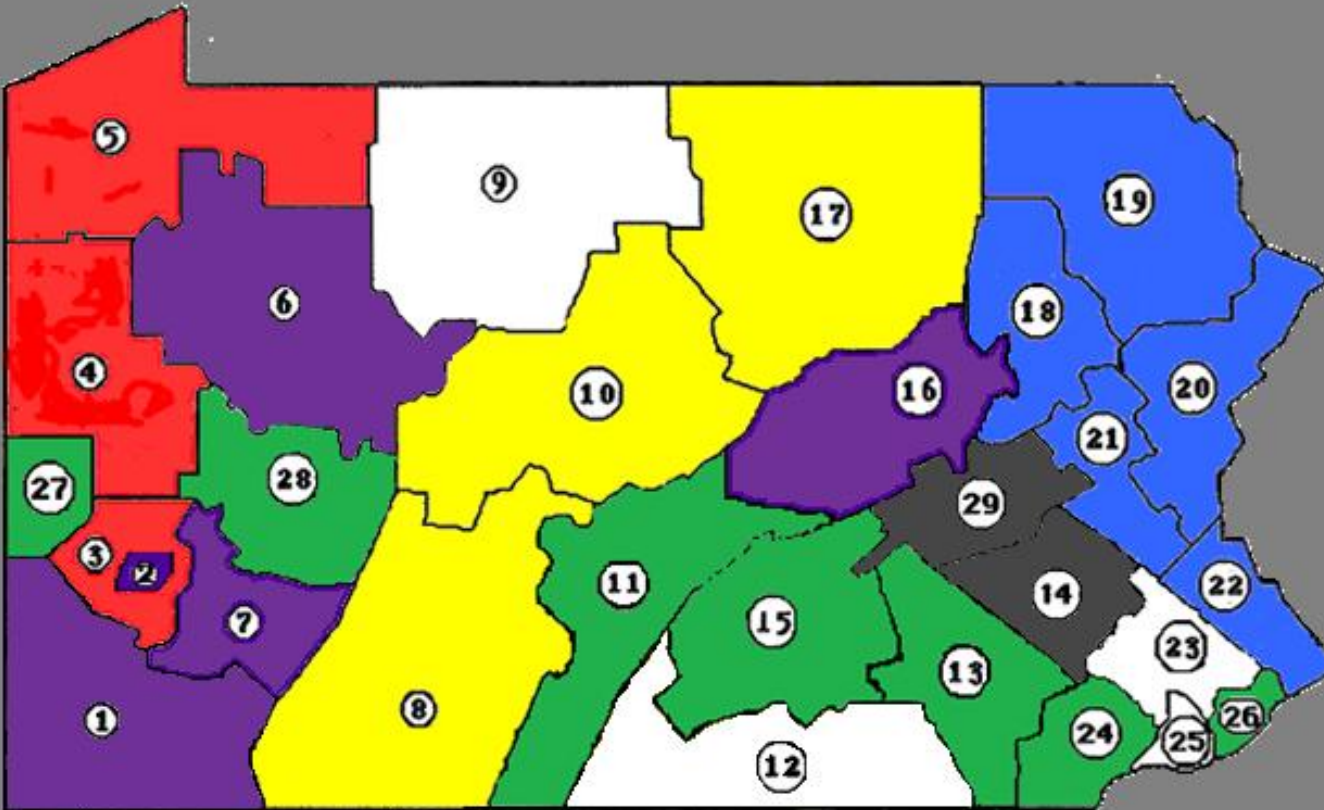


BrainSTEPS Objecti



5. Participate in the student's Individualized Education Program (IEP) planning process or Regular Education planning process.
6. Offer consistent ongoing consultation with teachers regarding educational program.
7. Train area schools on the effects of a brain injury when a student in their school has been identified

24 BrainSTEPS Teams



Red, Yellow, Blue, Green, Purple = Trained & Functioning BrainSTEPS Teams

White = Teams will be Trained & Functioning in the next year.

BrainSTEPS Team Members (2008-2009 School Year):

250+



What Can You Do?

- 1. Ensure that ALL children who are diagnosed with BRAIN INJURY in your school district receive information on the BrainSTEPS Program**
- 2. Invite BrainSTEPS team members to present to your staff on the BrainSTEPS Brain Injury School Re-Entry Program – it's FREE!**





Brain STEPS TEAM CONTACT LIST 2008-2009

When a child who attends a Pennsylvania public school has experienced educational effects following a brain injury, locate their county of residence and contact the coordinating Brain STEPS Team.

For General Information about the Brain STEPS Program Contact:

Brenda Eagan Brown, M.S.Ed., CBIS, Program Coordinator

Brain Injury Association of Pennsylvania

Email: eaganbrown@biapa.org

Phone: 724-944-6542



Intermediate Unit or School District Team	Pennsylvania Counties Served by Brain STEPS	Brain STEPS Team Leaders	Referral Phone Number	Referral Email Address
Allegheny IU #3	Allegheny	Kristen Haynes Erin Peterson	412-394-5787 412-394-5807	kristen.haynes@aiu3.net erin.peterson@aiu3.net
Midwestern IU #4	Butler Lawrence Mercer	Susan Black	724-458-6700 x253	susan_black@miu4.k12.pa.us
Northwest Tri-County IU #5	Crawford Erie Warren	Annette Eccles	814-734-5610 x8459	annette_eccles@iu5.org
Appalachia IU #8	Blair Bedford Cambria Somerset	Carol Hoover Mike Brink	814-940-0223 814-262-7392 x307	choover@iu08.org mbrink@iu08.org
Central IU #10	Centre Clearfield Clinton	Jeff Holter	814-342-0884	jholter@ciul10.org
Tuscarora IU #11	Fulton Huntingdon Juniata Mifflin	Mary Whitaker-Meyers Erin McManamon	814-542-2501	mmyers@tiul11.org emcmanamon@tiul11.org
Lancaster-Lebanon IU #13	Lancaster Lebanon	Anita Heller Anne Hohenwarter	717-606-1713 717-394-1252	anita_heller@iu13.org anneh@acadiaarehab.com
BLAST IU #17	Bradford Lycoming Sullivan Tioga	Mark Nevill	570-323-8561	mnevill@iul17.org
Lincoln IU #12	Adams Franklin York	Lincoln Intermediate Unit 12 Brain STEPS Referral Phone Line	1-888-487-1544 x5067 717-624-4616 x5067	
Canton School District	Bradford	Allison Polly	570-673-3983	apolly@canton.k12.pa.us
Capital Area IU#15	Cumberland Dauphin Perry Northern York	Ann Hoffman Elizabeth Panek Rich Billings	717-732-8400 x8584 x8670 717-531-7306	ahoffman@caiu.org epanek@caiu.org rbillings@caiu.org



For More Information on the BrainSTEPS Program

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