



**NATIONAL COLLABORATIVE
ON CHILDREN'S
BRAIN INJURY
NCCBI**



**Drew Nagele, Pennsylvania
Ann Glang, Oregon
Stephen Hooper, North Carolina
Karen McAvoy, Colorado**

DISCLOSURES



Presenters have no interests to disclose.

PESG and IBIA staff have no interest to disclose.

This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with IBIA. PESG, IBIA, and all accrediting organization do not support or endorse any product or service mentioned in this activity.

LEARNING OBJECTIVES



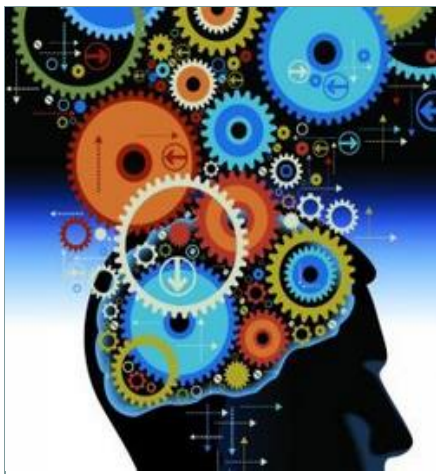
- At the conclusion of this activity, the participant will be able to:
 - Describe the factors that result in under-identification of children in the TBI special education classification.
 - Demonstrate a wide variety of decisions and options for assisting children in returning to school and becoming successful in their learning careers after sustaining a concussion.
 - Describe the elements of infrastructure that schools need to have in place to optimize education for children with brain injury.

OBTAINING CME/CE CREDIT



- If you would like to receive continuing education credit for this activity, please visit:

<http://ibia.cds.pesgce.com>



NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY NCCBI



Introduction to NCCBI

Drew Nagele, PsyD, CBIST

Beechwood NeuroRehab

DNagele@Woods.org

NCCBI HISTORY



- The work of NCCBI began with a Children's Brain Injury Summit held in PA in August of 2011
- Group of professionals working with pediatric brain injury with a focus on the school/community environments including:
 - State Departments of Education (DOE)
 - Health Resource Services Administration (HRSA)
 - HRSA grantees with relationships with their state DOE
 - National Institute on Disability and Rehabilitation Research (NIDRR)
 - Researchers in pediatric brain injury
- Purpose: conduct a high level assessment of accomplishments, needs & gaps with regards to children with brain injury in education setting

NCCBI HISTORY



- **Primary themes emerged including;**
 - under-identification
 - lack of coordination for transition from hospital/rehab to school/community
 - lack of training for school personnel both pre-service and in-service
 - lack of evidence based practices
 - lack of funding to support these initiatives
- **Group decided to write up the findings of this meeting in various white papers which have been published**

NCCBI HISTORY



- Concurrent to the summit, other groups were starting to focus attention to children and brain injury through task forces and committees
- Idea of NCCBI was to merge these efforts, collaborate and not duplicate
- The first meeting of the Collaborative was held in March 2012
- Represents a grass roots effort
- Goal: To develop recommendations for building statewide capacity to support students with brain injury

NCCBI PURPOSE



Although there are significant gaps across all service domains for children/youth with brain injury, NCCBI will focus first on community, family, and rehabilitation issues in relation to school services. At this time, the goals of the NCCBI are to:

1. identify critical gaps in educational services,
2. make policy and research recommendations, and
3. share information, tools, and resources on supports for children with TBI in the school setting.

<http://cbirt.org/nccbi/>

NCCBI MEMBERSHIP



Membership includes:

- Family Members
- State Department of Education Staff
- State Lead Agencies on Brain Injury Directors
- Federal Agency Staff
- National Brain Injury Organization Leaders
- Researchers

Brain Injury in Youth

Supports for School Success

<https://youthbraininjury.obaverse.net>

- Community of Practice – an interactive online resource community
- designed by those currently working in the field of education and brain injuries
- purpose of the site is to share ideas, discuss issues, and generate strategies for those who educate, advocate for, and support children and adolescents with brain injury in schools

BRAIN INJURY IN YOUTH CoP SUPPORTS FOR SCHOOL SUCCESS



- **Concussion** – definition, prevention, identification, assessment, management, return to learn, symptom based accommodations, building state infrastructure & policy, concussion resources
- **Educational Interventions and Accommodations** – behavior, online learning for educators, resources for the classroom, strategies to support students, working with families
- **Identification, Screening, and Assessment Practices** – identification processes, assessment, IEP and 504, resources

COMMUNITY OF PRACTICE



Current Google Analytics:

- Total Number of CoP Members: 531
- Organization/Occupation
 - Health Care (Rehabilitation, Hospitals, or Physical Therapy)
 - Education (School Districts, Higher Education, Education, or Service Districts)

COMMUNITY OF PRACTICE



Website Traffic

Feb 2016 - March 2017

New Users:

1280

Total Visitors:

2903

Pageviews:

14,256

Top Pages

Forums

Identification, Screening, and Assessment Practices

Educational Interventions and Accommodations

COMMUNITY OF PRACTICE



What are the Top CoP Comment/Forum Topics?

Comment/Forum Topics

- concussion resources
- WIOA pre-transition employment services
- training resources for teachers
- rehab facilities
- return to learn resources

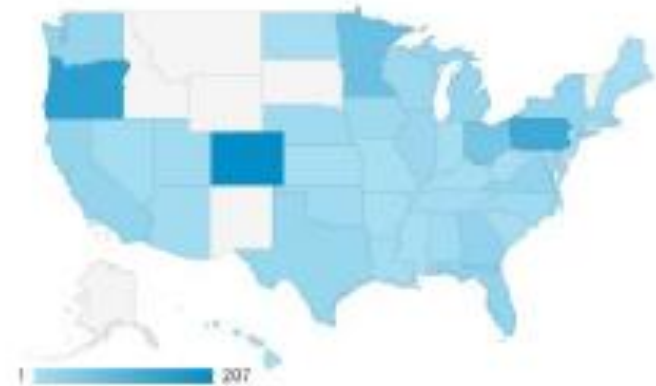
COMMUNITY OF PRACTICE



Where do CoP users come from?

Demographics - Top locations

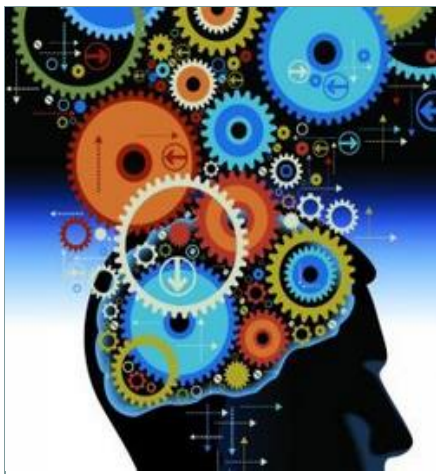
Colorado
Oregon
Pennsylvania
Minnesota
Ohio
California



NCCBI CURRENT INITIATIVES



- **Infrastructure – Dr. Ann Glang**
 - Brain Injury Elements to Optimize Education
- **Policy - Dr. Stephen Hooper**
 - Under-identification of Children with Brain Injury
- **Concussion – Dr. Karen McAvoy**
 - Return to Learn Consensus Guidelines



NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY NCCBI



Infrastructure Development

Ann Glang, PhD
University of Oregon
AGlang@UOregon.edu

INFRASTRUCTURE DEVELOPMENT



- Survey of state directors of special education
- NCCBI white papers on statewide infrastructure components
- Engagement with NASDSE, OSEP and state Departments of Education

EDUCATION FOR CHILDREN WITH BRAIN INJURY



- Surveyed State Directors of Special Education (N = 43)
- How does your state identify and provide educational and support services to children with brain injury?

Glang, Ettel, Todis et al., 2015

Survey of special education directors



Over half of respondents: TBI count in our state is inaccurate

Why are children mis-identified?

- Lack of awareness
- Poor communication between hospital-school
- Under-reporting by parents
- Use of other disability categories for eligibility

What disability category is used?



- TBI (40%)
- OHI (12%)
- Specific learning disability (9%)
- Emotional disturbance (6%)
- Intellectual disability (5%)
- Multiple disabilities (5%)

PUBLICATIONS



- Dettmer, Ettel, Glang & McAvoy, 2014. *Building statewide infrastructure for effective educational services for students with TBI: Promising practices and recommendations*. The Journal Of Head Trauma Rehabilitation.
- Gioia, Glang, Hooper & Eagan-Brown, 2015. *Building statewide infrastructure for the academic support of students with mild traumatic brain injury*. Journal of Head Trauma Rehabilitation.

NCCBI RECOMMENDATIONS: STATEWIDE INFRASTRUCTURE FOR STUDENTS WITH TBI



- Identification, screening, and assessment practices
- Systematic communication between medical and educational systems
- Tracking of child's progress over time
- Professional development for school personnel

Dettmer, Ettel, Glang & McAvoy, 2014

NCCBI RECOMMENDATIONS: STATEWIDE INFRASTRUCTURE (MILD TBI)



- Training of the interdisciplinary school team
- Professional development
- Identification, assessment, and progress monitoring protocols
- Intervention strategies
- Communication among medical, school, and family team members

DISSEMINATION

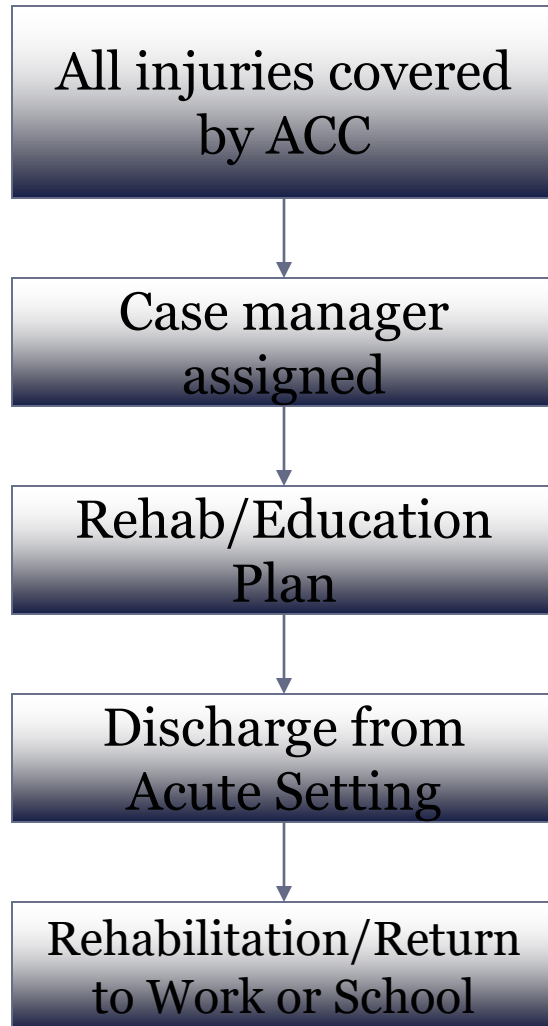


- Engagement with National Association of State Directors of Special Education (NASDSE)
- Office of Special Education Programs (OSEP)
- State Departments of Education

NZ perspective (A. McKinlay, PhD)



ACC National insurance: Services Covered



- Hospital, Medical Centre, Work Place, Family Doctor, Ambulance
- Comprehensive assessment; development of individualised education plan

NZ Perspective-Children with TBI



- Children are under-reported and misidentified
 - TBI diagnosis does not flow from the acute setting
 - Emphasis on recovery of mobility

- Interventions developed for other disabilities may be inappropriately applied
 - Children with TBI are lumped in with all other childhood disabilities

Educator interviews



- N = 10 classroom teachers in New Zealand
- Semi-structured interviews
- Topics covered – source of funding, differences, and teaching strategies.

Preliminary findings



- None of the educators was aware that ACC was a source of funding
- Many had difficulty defining difference between TBI and other disorders
- Most said that children with TBI compete with children with other disabilities for funding.

Northern Ireland: Educational professionals' understanding of TBI (M. Linden, PhD)



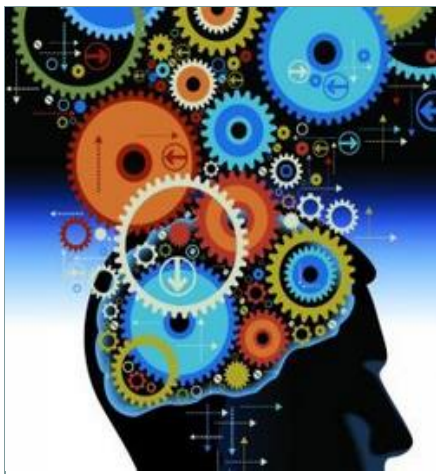
- 386 educational professionals responded to a questionnaire in the UK.
- Responsible for the care of 116,000 pupils
- 20 had received “training” in TBI
- 163 had some knowledge of TBI
- 100 had experience of teaching a child with TBI

N. Ireland educator survey



- Q ‘Children who have had one brain injury are more likely to have a second (True).’ **98.8% disagreed or didn’t know.**
- Q ‘It is common for children with brain injuries to be easily angered (True).’ **83.5% disagreed or didn’t know.**
- Teachers in the UK have a statutory obligation to meet the needs of children under their care, and they are failing.

Linden, MA., Braiden, H-J., & Miller, S. (2013). Educational professionals’ understanding of childhood traumatic brain injury. *Brain injury*, 27(1):92-102



NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY NCCBI



Under-identification

Stephen R. Hooper, Ph.D.

University Of North Carolina

School Of Medicine

Stephen_Hooper@Med.UNC.Edu

UNDER-IDENTIFICATION OF STUDENTS IN THE TBI SPECIAL EDUCATION CLASSIFICATION



Drew A. Nagele, Beechwood NeuroRehab, Pennsylvania

Stephen R. Hooper, University of North Carolina

Kristin Hildebrant, Disability Rights Ohio

Melissa McCart, University of Oregon

Ann Glang, University of Oregon

Judy Dettmer, Colorado Brain Injury Program

THE PROBLEM



- Following a TBI, the return-to-school component of their recovery can present significant challenges to the student, family, and educational system (Prasad et al., 2016)
- These challenges include:
 - Cognitive and learning needs
 - Lower adaptive functions
 - Social-behavioral difficulties
 - Lower rates of participation in social activities
 - Physical impairments

THE PROBLEM



- For children with moderate to severe brain injuries, these challenges actually may change, or perhaps increase, over time (Rivara et al., 2012)
- Given that <4% of hospitalized children receive inpatient rehabilitation, the burden of rehabilitation typically falls to the family and the school
 - This reinforces the importance of accurately identifying and serving these students

THE PROBLEM



- In the United States, the Individual with Disabilities Education Act (IDEA, 1990) has included a TBI Classification for students who require special education services in the public schools
- Unlike several other special education classifications (e.g., ASD, LD), the number of students identified under this classification has remained stable, or even gotten smaller over the years
- National estimates indicate that approximately 145,000 children ages birth to 19 are living with significant disabilities from a TBI (Zaloshnja et al., 2008), but the total number of students receiving special education services under the TBI Classification was less than 26,000
 - ~ this suggests that as many as 119,000 potential students are not being served under this classification

THE PROBLEM



- Following a brain injury, consideration for special education services is an essential first step to accessing appropriate and needed educational services
- When potential impairments are not recognized following an injury and/or when those impairments are attributed to other types of disabilities (e.g., LD), there is significant risk for educational services to be poorly aligned with a student's educational needs

STUDY PURPOSE



- The primary purpose of this study is to examine the magnitude of the discrepancy between the number of children who sustain moderate to severe injuries versus the number of children who have been identified as receiving special education services under the TBI Classification
- Analyze potential reasons for this discrepancy

METHODS



- State-reported statistics on the number of students identified under the TBI Classification for 2010
 - This was the last year that agency statistics aligned for direct comparison
- State population statistics for 2010 from US Census data for ages 5 to 24 years
- By using this Census figure against the CDC's estimates of national TBI incidence, we derived an estimated incidence for moderate to severe brain injuries for each state
 - This represented the population that would be most likely be eligible for special education services

METHODS



- Since these numbers only represent one year of data, to get from incidence to prevalence, we multiplied the incidence data by the number of school cohorts from K to 12 (i.e., 13 years)
- We recognized that not all students with moderate to severe TBI would have a long-term disability as a result of their TBI
- To be conservative in our estimates, we utilized the Selassi et al (2008) projection that about 19% of students with moderate to severe TBI would have long-term disabilities substantial enough to receive special education services
- We then compared that adjusted number of children with TBI with the number of students identified under the TBI classification

RESULTS



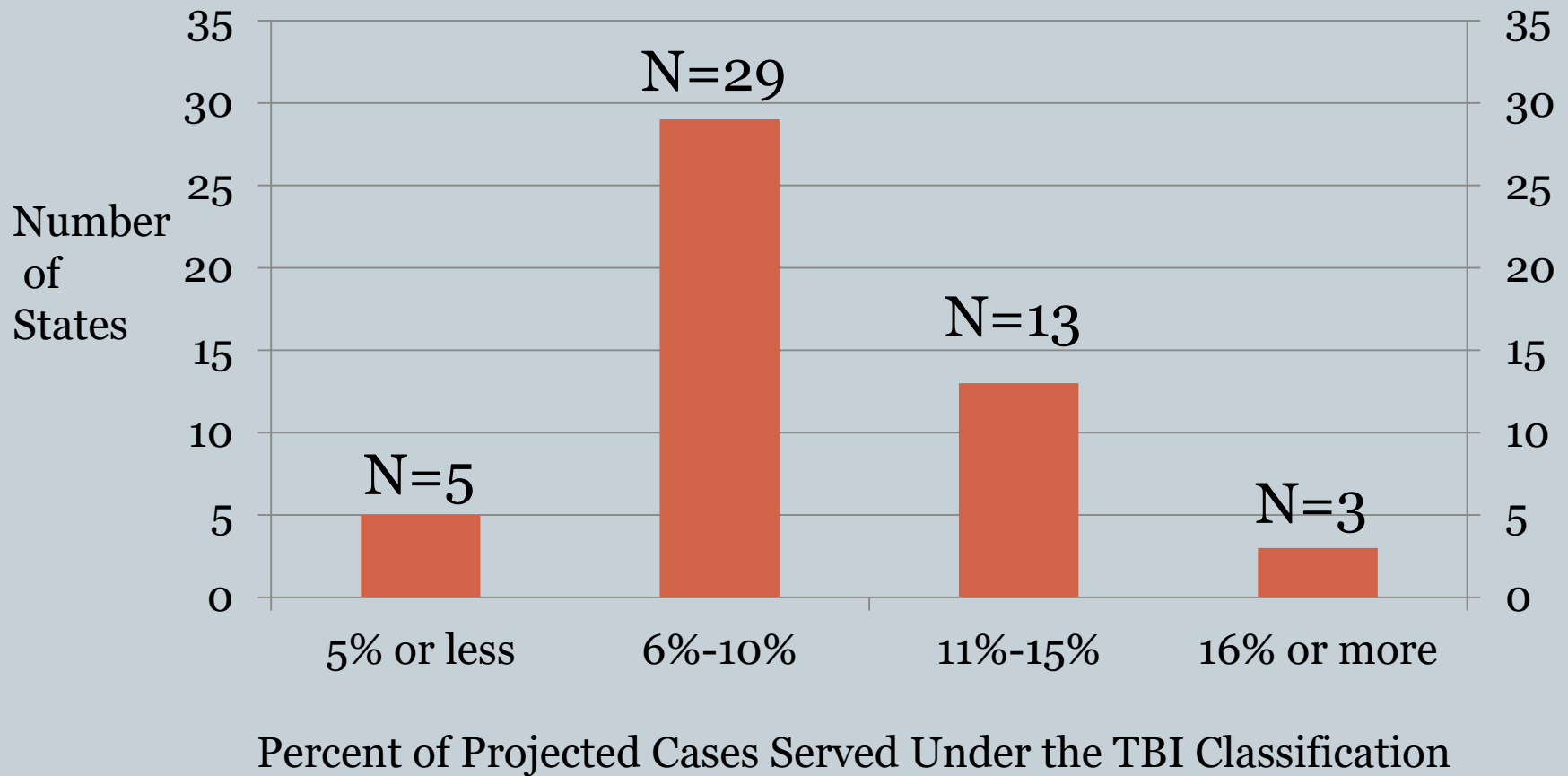
- Only one state meets or exceed the expected numbers based on our calculations, and the rest were significantly lower
 - Massachusetts had a rate of 169%, in large part because of their broad-based definition of TBI.
- All other states were under-identifying students for special education services under the TBI Classification following a TBI.
- These rates ranged from 0% in Wyoming to 17% in Ohio and Nebraska.
- Total number of students identified across all states was ~25,000, which represents only 11.6% of the projected 217,000 students who should be classified as TBI.
 - Conversely, this leaves about 192,000 students, or 88.4% of students who have not been served under the TBI Classification

RESULTS



State	Percentage of Projected TBI Classification
1. Massachusetts	169%
2. Nebraska	17%
3. Ohio	17%
4. New Jersey	15%
5. Colorado	14%
6. New Mexico	13%
7. Utah	12%

NUMBER OF STATES CLASSIFYING STUDENTS PROJECTED TO HAVE LONG-TERM DISABILITY UNDER THE TBI CLASSIFICATION



POSSIBLE REASONS FOR THE DISCREPANCIES



- According to State special education directors (Glang et al., 2015):
 - Lack of awareness about TBI as a disability
 - Lack of communication between hospital and school
 - Identification of students with TBI under different classifications
 - Under-reporting of injuries by parents
 - Narrow definition of TBI that excludes other forms of brain injuries.

POSSIBLE REASONS FOR THE DISCREPANCIES



- **Other reasons include:**
 - A large number of preschool and school-age children are just not receiving services following a TBI.
 - ✦ Awareness of issues pertaining to TBI remains poorly developed.
 - ✦ Public health screening, particularly in educational settings, is almost non-existent.
 - Lack of school capacity to identify students who have sustained a TBI (e.g., assessment, tracking progress of recovery, providing appropriate services and interventions for learning and behavioral challenges).
 - Poor counting strategies for services provided to students following a TBI.
 - ✦ ~60% of students are being served in other special education classifications, such as OHI, SLD, Behavior/Emotional Disturbed
 - “Injuries lying silent” issue; the later effects of brain injuries.
 - The confusion of services to students following a concussion.

POSSIBLE SOLUTIONS



- Special Education Directors suggested (Glang et al., 2015):
 - Increase staff awareness of TBI
 - Increase parent awareness of TBI
 - Increase identification of students through screening programs
 - ✦ This will require screening tools and strategies with satisfactory positive and negative rates.
 - Provide initial AND ongoing staff professional development
 - Program evaluation

CONCLUSIONS



- There are significantly low rates of students being served under the TBI classification across the country versus those who likely would be eligible based on estimated rates of hospitalization.
- This raises critical questions about how states are identifying and serving students who may have special needs following a moderate to severe brain injury.
- There are a number of possible reasons for this discrepancy, and associated solutions, and each of these reasons and solutions will require a systematic approach to closing this gap.
- While many students may be receiving adequate special education services following a TBI, the current magnitude of this discrepancy continues to raise significant concerns about how students with moderate to severe brain injuries are being served in the public school setting.



NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY (NCCBI)

**1st National Consensus for Return To Learn
Following Concussion**

Karen McAvoy, PsyD
Rocky Mountain Hospital for Children
Karen.McAvoy@HealthOneCares.com

Brenda Eagan Brown, MEd
Brain Injury Association of PA
EaganBrown@BIAPA.org

THE PROBLEM:



International Consensus papers have recommended physical and cognitive rest post-concussion followed by a gradual re-introduction of activity.

Cognitive rest:

- What does cognitive rest look like?
- How much cognitive rest is needed?
- When/How does the student return to school?
- When/How does the student return to learn?

RESEARCH SHOWS...



- 70% of students with a concussion show resolution of symptoms within 28 days of injury (Zemek 2016).
- Students randomly assigned to 5 days of strict rest vs. 1-2 days of rest followed by a gradual return to activities (school and social activities) had a poorer outcome (higher symptoms over a longer period of time). (Thomas 2015)
- Academic dysfunction may be evident for up to 1 month post-injury (Wasserman 2016)
- Best Practice:
 - The American Academy of Pediatrics Clinical Report on Return to Learning recommends that a student return to school when symptoms are “tolerable, intermittent and amenable to rest” (Halstead 2013).

The Dilemma



Students with a concussion:

- often feel well enough to return to school within days to 1 - 2 weeks post-injury
- While, at the same time, symptoms typically persist for up to 4 weeks.
 - Thirty percent of the time, symptoms may persist longer than 4 weeks

**Students need NOT wait to be
“symptom-free” to return to
school/learn**

THE CHALLENGE



Schools are discovering that for numerous social, emotional and physical recovery reasons, concussed students are returning to school sooner rather than later, much improved but still symptomatic.

Yet, surveys of educators show that school psychologists, special education teachers, classroom teachers and high school principals have little knowledge or comfort level with this population.

(Ettel 2016; Heyer 2014)

Absolutes...



The overwhelming majority of students with a concussion will return to school/return to learn at some point post-injury (typically within days or weeks and typically while still symptomatic) and each student's recovery will be unique.

Schools need to gain knowledge and comfort on the topic of concussion... for **EVERY** student (not just athletes and not just athletes who fall under Return to Play - RTP - legislation) requires educational support.

THE SOLUTION: RTL GUIDELINES



NCCBI took on the task of leading the Delphi Process for consensus on RTL:

Comprised of 2 Rounds

- Round 1 June 2016
- Round 2 October 2016 – Consensus achieved by January 2017

Final RTL Consensus manuscript readied for submission and publication in a peer review journal by Spring 2017

19 NATIONAL ORGANIZATIONS AGREED TO BE PART OF THE DELPHI PROCESS

1. American Academy of Neurology (AAN)
 2. Sports Neuropsychology Society (SNS)
 3. National Association of School Psychologists (NASP)
 4. National Athletic Trainers' Association (NATA)
 5. National Federation of High School Associations (NFHS)
 6. American Physical Therapy Association (APTA)
 7. High School RIO
 8. National Collaborative on Children's Brain Injuries (NCCBI)
 9. National Association of State Head Injury Administrators (NASHIA)
 10. American Academy of Pediatrics (AAP)
 11. Department of Defense (DVBIC/DOD)
 12. American Medical Society for Sports Medicine (AMSSM)
 13. National Association of School Nurses (NASN)
 14. Brain Injury Association of America (BIAA)
 15. United States Brain Injury Alliance (USBIA)
 16. North American Brain Injury Society (NABIS)
 17. American Academy of Pediatric Neuropsychology (AAPN)
 18. Zurich Sports Concussion Consensus authors
 19. National Association of State Directors of Special Education (NASDSE)
- Consulting on content:*
United States Department of Education
Center for Disease Control (CDC)

15 NATIONAL ORGANIZATIONS COMPLETED ROUND 1 AND ROUND 2

1. National Association of School Psychologists (NASP)
 2. National Athletic Trainers' Association (NATA)
 3. National Federation of High School Associations (NFHS)
 4. American Physical Therapy Association (APTA)
 5. High School RIO
 6. National Collaborative on Children's Brain Injuries (NCCBI)
 7. National Association of State Head Injury Administrators (NASHIA)
 8. American Academy of Pediatrics (AAP)
 9. Department of Defense (DVBIC/DOD)
 10. American Medical Society for Sports Medicine (AMSSM)
 11. National Association of School Nurses (NASN)
 12. North American Brain Injury Society (NABIS)
 13. American Academy of Pediatric Neuropsychology (AAPN)
 14. Zurich Sports Concussion Consensus authors
 15. National Association of State Directors of Special Education (NASDSE)
- Consulting on content:*
United States Department of Education
Centers for Disease Control & Prevention (CDC)

GUIDING QUESTIONS



1. What are the important aspects of concussion and school management that health care professionals, educators, students and parents should be educated about, as part of their potential future involvement/ *communication* with school based concussion interdisciplinary teams?

GUIDING QUESTIONS



2. What are the main facets of a systematic "promising practices" plan for Return to Learn (RTL) following concussion that promotes management of all students who experience concussion?
 - 2a. How should schools monitor symptom resolution for Return to Learn/School?
 - 2b. How should schools monitor academic performance in Return to Learn process.
 - 2c. How are school-based services constructed for students following a concussion? What is the evidence base?

GUIDING QUESTIONS



3. Does RTL for concussion need to be legislated?
 - 3a. How do state concussion laws and the educational needs of all students interact?

PRELIMINARY FINDINGS FROM THE DELPHI PROCESS



Data is still being analyzed at the time that this powerpoint needed to be submitted for CME review.

Preliminary data will be shared at the IBIA conference.

REFERENCES

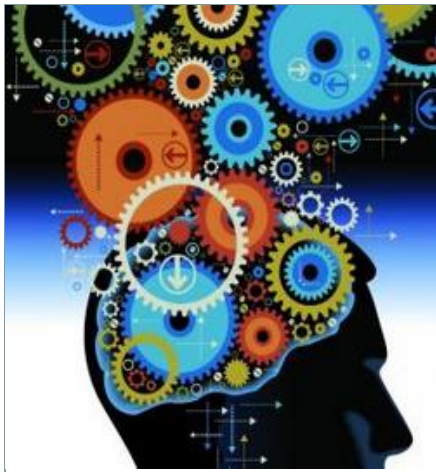


- Zemek, R., et al. (2016) Clinical Risk Score for Persistent Postconcussion Symptoms Among Children With Acute Concussion in the ED. *JAMA*. 2016;315(10):1014-1025. doi:10.1001/jama.2016.1203
- Thomas, DG, Apps, JN., Hoffmann, RG., McCrea, M., Hammeke, T. (2015) Benefits of Strict Rest After Acute Concussion: A Randomized Controlled Trial. *Pediatrics*, DOI: 10.1542/peds.2014-0966
- Wasserman, EB, et al. (2016). Academic Dysfunction After a Concussion Among US High School and College Students. *American Journal of Public Health*. doi: 10.2105/AJPH.2016.303154
- Halstead, M. et al. (2013). CLINICAL REPORT Returning to Learning Following a Concussion. *Pediatrics* doi:10.1542/peds.2013-2867

REFERENCES



- Ettel, PhD, NCSP,D., Glang, A. E., Todis, B., & Davies, S. C. (2016) Traumatic Brain Injury: Persistent Misconceptions and Knowledge Gaps Among Educators. *Exceptionality Education International*, 26, 1-18. Retrieved from <http://ir.lib.uwo.ca/eei/vol26/iss1/1>
- Heyer, G. et al., (2015) High School Principals' Resources, Knowledge, and Practices regarding the Returning Student with Concussion. *J Pediatr* 2015;166:594-9)



NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY NCCBI



QUESTIONS

<http://cbirt.org/nccbi/>

<https://youthbraininjury.obaverse.net>