

# **NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY (NCCBI)**



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# NCCBI HISTORY



- The work of NCCBI began with a Children's Brain Injury Summit held in PA in August of 2011.
- Group of professional working with pediatric brain injury with a focus on the school/community environments including:
  - State Departments of Education (DOE)
  - HRSA grantees with relationships with their state DOE
  - HRSA
  - 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 a white paper format to be 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

# PAST INITIATIVES/PUBLICATIONS



- White Paper: (2014) *Building statewide infrastructure for effective educational services for students with TBI: Promising practices and recommendations.* The Journal Of Head Trauma Rehabilitation.
- White Paper: (2015) *Building statewide infrastructure for the academic support of students with mild traumatic brain injury.* Journal of Head Trauma Rehabilitation.

# CURRENT INITIATIVES



- Brain Injury Community of Practice
- Policy
- Quality Indicators
- Return to Learn Consensus Paper
- Family-School Partnership



# **NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY (NCCBI)**



**INFRASTRUCTURE DEVELOPMENT  
ANN GLANG**

# 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

# UNDER-IDENTIFICATION



- 55% of respondents report that TBI count for their state is inaccurate
- Factors influencing under-identification:
  - Lack of awareness about TBI
  - Lack of communication between hospital and school

# WHY IDEA COUNTS ARE NOT ACCURATE



- Factors influencing under-identification (cont):
  - Students identified under different eligibility categories
  - Parents under-report injuries
  - Narrow definition of TBI that excludes other forms of acquired brain injury

# 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

# 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

# CAPACITY BUILDING



- Quality Indicator Assessment Tool
- Engagement with NASDSE, OSEP and state Departments of Education

# **NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY (NCCBI)**



**COMMUNITY OF PRACTICE &  
POLICY INITIATIVES  
DREW NAGELE**



# Brain Injury in Youth

Supports for School Success

<https://youthbraininjury.obaverse.net>

- a nationwide 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

# COMMUNITY OF PRACTICE



Currently has 3 Practice Groups:

<https://youthbraininjury.obaverse.net/2/collection/index.php?group=2>

- Identification, Screening, and Assessment Practices
- Educational Interventions and Accommodations
- Concussion

# COMMUNITY OF PRACTICE



## Current Google Analytics:

- Total Number of CoP Members: 440
- Organization/Occupation
  - Health Care (Rehabilitation, Hospitals, or Physical Therapy)
  - Education (School Districts, Higher Education, Education, or Service Districts)

# COMMUNITY OF PRACTICE



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<b>Website Traffic</b>	Feb'16	May '16	Aug'16
New Users:	545	167	39
Total Visitors:	781	359	89
Page views:	4,118	1,885	396

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# COMMUNITY OF PRACTICE



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## Top Pages (2/1/2016 - 8/31/2016)

Page views

Forums

154

Identification, Screening and Assessment Practices

97

Educational Interventions and Accommodations

96

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# COMMUNITY OF PRACTICE



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## **Comment/Forum Topics (2/1/2016 - 8/31/2016)**

concussion resources  
executive functioning  
training resources for teachers  
rehab facilities  
return to learn resources

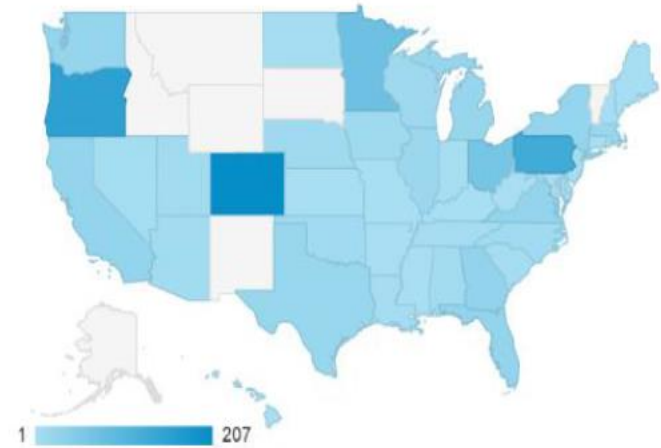
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# COMMUNITY OF PRACTICE



## Demographics

Colorado	359
Oregon	299
Pennsylvania	244
Minnesota	171
Ohio	99
California	70



# NCCBI Policy WorkGroup



- Meets via teleconference on a regular basis to map out policy agenda addressing brain injury and schools
- Analyzes data about incidence and prevalence of brain injury as it pertains to identification of students with brain injury
- Makes recommendations to Federal and State agencies that impact school policy regarding services for brain injury
- Makes recommendations for connecting Medical Rehabilitation with Educational Supports & Services to improve practices in programming for students with brain injury



# NCCBI Policy WorkGroup



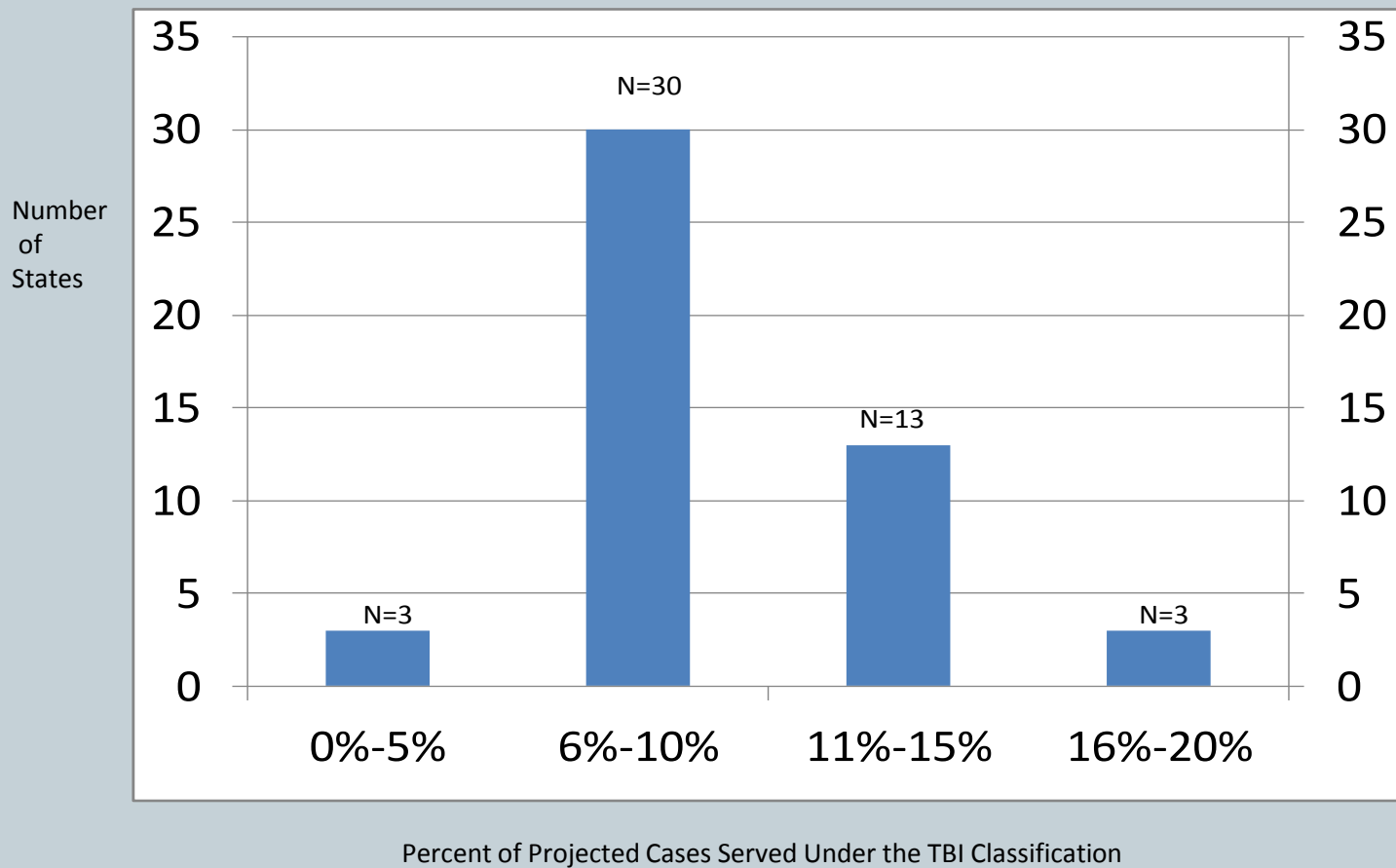
Specific initiatives addressed to date include:

- Under-identification of brain injury in schools, with recommendations to improve identification
- Analyzing the impact of the new Every Student Succeeds Act as it pertains to students with brain injury, and
- Developing opportunities for transition through the Work Force Innovation Act Re-Authorization, utilizing Work Based Learning Experiences.

# NCCBI Policy WorkGroup



## Under-identification findings:



# **NATIONAL COLLABORATIVE ON CHILDREN'S BRAIN INJURY (NCCBI)**



**RETURN TO LEARN  
CONSENSUS PAPER  
BRENDA EAGAN BROWN  
KAREN MCAVOY**

# The Problem:



There is a lack of consensus among education and health care professionals in determining who should take the lead regarding Return to Learn (RTL) following a student concussion and what appropriate management strategies to employ.

# Delphi Process for Consensus



- ✓ **NCCBI workgroup established**
- ✓ **Comprised of 3 Rounds**
- ✓ **Online electronic survey process**

Round 1 - June 2016

Round 2 – September 2016

Round 3 – October 2016

Final Return to Learn Consensus manuscript will  
be submitted for publication -Spring 2017

# 20+ National Organizations Recruited

1. **American Academy of Neurologists**
  2. **Sports Neuropsychology Society**
  3. **American Association of School Administrators**
  4. **National Association of School Psychologists**
  5. **National Association of Athletic Trainers**
  6. **National Federation of High School Associations**
  7. **American Physical Therapy Association**
  8. **RIOS**
  9. **National Collaborative on Children's Brain Injuries**
  10. **National Association of State Head Injury Administrators**
  11. **American Medical Society for Sports Medicine**
  12. **National Association of School Nurses**
  13. **Brain Injury Association of America**
  14. **United States Brain Injury Alliance**
  15. **North American Brain Injury Society**
  16. **American Academy of Pediatric Neuropsychology**
  17. **Zurich Sports Concussion Consensus authors**
  18. **American Academy of Pediatrics**
  19. **Centers for Disease Control & Prevention**
  20. **DVBIC/DOD**
- Consulting on RTL Consensus:***
- **National Association of State Head Injury Administrators**
  - **United States Department of Education**

# Survey of Concussion Experts on Return to Learn (RTL) Management

## *Research Questions*

- 1. What are 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?**

# Survey of Concussion Experts on Return to Learn (RTL) Management



**2. What are the main facets of a systematic "promising practices" plan for Return to Learn 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 the Return to Learn process?**

**2c. How are school-based services constructed for students following a concussion? What is the evidence base?**



# Survey of Concussion Experts on Return to Learn (RTL) Management



**3. Does Concussion RTL need to be legislated?**

**4. How do state concussion laws and the educational needs of all students interact?**