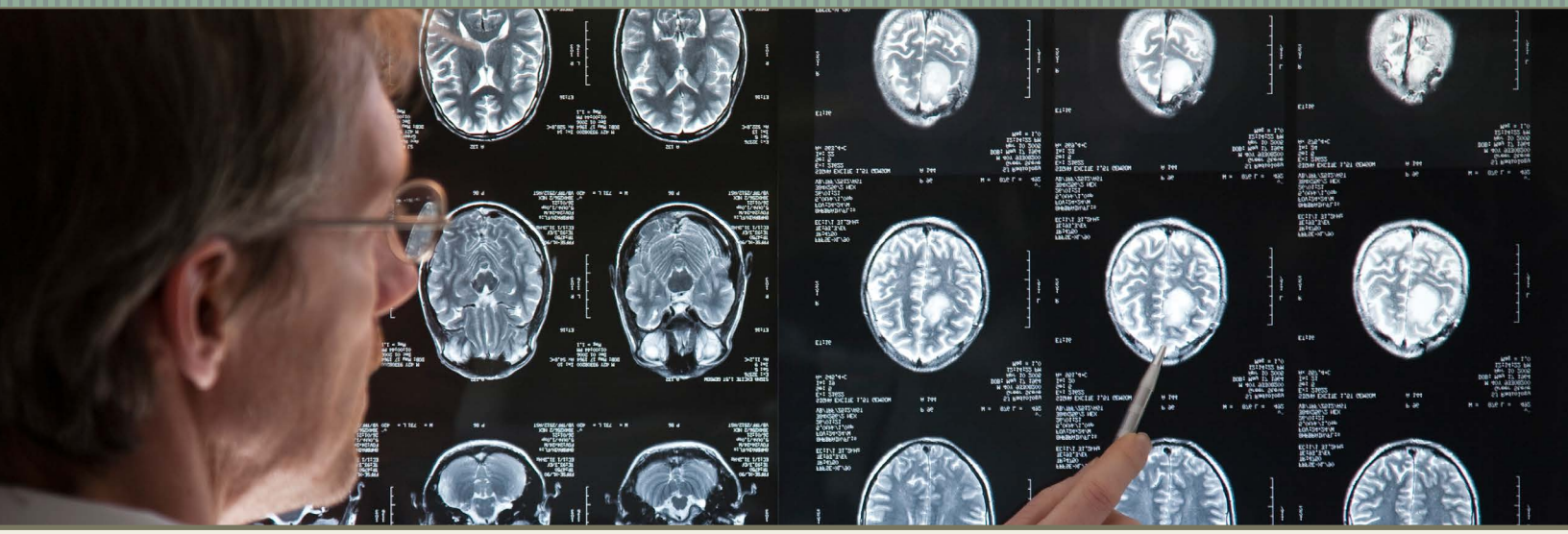
Children's Safety Network

Innovative Practices in Traumatic Brain Injury Prevention



Introduction

Each year, more than one million youth ages 0 through 19 sustain a non-fatal traumatic brain injury (TBI) (NEISS; NEISS –AIP 2007-2009). With the passage of legislation in all states and the District of Columbia to prevent and manage youth sports concussions, awareness of TBI is on the rise.

Recognizing the need to improve the continuum of care and prevention and the complexity of the causes and consequences of TBI, the Children's Safety Network (CSN) and the TBI Technical Assistance Center organized a year-long Community of Practice (CoP) to:

1. Increase collaboration among state Injury and Violence Prevention programs, state Maternal and Child Health programs, and others working on TBI prevention

2. Promote best practices in the prevention, assessment, and management of TBI

Participating States:

Alabama
Alaska
Connecticut
Delaware
Iowa
Kentucky
Minnesota
Missouri
Nebraska
New Jersey
New Mexico
New York
North Carolina
North Dakota
Tennessee

Fifteen state teams comprised of more than 100 people participated in the CoP through monthly webinars, a listserv, a webpage, and state-specific team meetings. The monthly webinars focused on the following topics:

- Abusive head trauma
- Data collection
- Falls prevention and TBI
- Leading causes of TBI among specific populations
- Motor vehicle crashes and TBI
- Program evaluation
- TBI screening among specific populations
- Sports-related concussions
- Substance use and TBI

When the TBI CoP started, the state teams identified specific TBI prevention goals on which they would work. Throughout the year, the teams reported on those goals, adjusting them as necessary. Below are highlights of what they accomplished.

State Accomplishments

Alabama

Sharing information about TBI screening in domestic violence shelters

Studies have shown that more than 90% of all injuries secondary to domestic violence occur to the head, neck, or face region (Monahan & O'Leary, 1999) and that 75% of domestic violence (DV) victims sustained at least one partner-related TBI, and 50% sustained multiple partner-related TBIs (Valera, 2003). Despite the availability of these studies, 10 years ago, the Alabama Department of Rehabilitation Services identified a lack of awareness about the burden of TBI among DV victims and minimal knowledge about the availability of TBI identification, referral, and management services. Despite strong evidence regarding the consequences of brain injury and the susceptibility of DV victims, many women and DV shelter staff were not seeking specialized services. The connections between a woman's risk of continued harm, repeat brain injuries, and an increased likelihood that interventions will be unsuccessful were not yet being made. By leveraging the relationships that the Department of Rehabilitation Services already had with the Alabama Coalitions Against DV (ACADV), the department set out to screen DV victims for TBI, with the aim of increasing DV intervention success and decreasing continued harm.

Now, all DV shelters statewide screen their residents for TBI and refer identified individuals to additional or specialized services as needed. All shelter staff received training on the nuances of screening and working with victims of DV. This intervention was so successful, it was included in the National Coalition for Domestic Violence Manual for Working with Special Populations as a guide for other states to follow.

Through the CoP, Alabama's team leader was able to share information about how the DV shelter TBI screening program originated and explain the screening tools, which are available through the state's website. Several of the CoP teams had not yet begun screening DV victims for TBI and took this as an opportunity to learn. Alabama's CoP team leader has since heard from several states that are now exploring options and opportunities for developing a screening system for DV victims. Through the CoP, Alabama disseminated its innovative strategy and raised its profile as a leader in the field.

Connecticut

Planning and engaging partners to establish a TBI incidence surveillance system

In 1982, several brain injury survivors and their families established the Connecticut Traumatic Brain Injury Association (CTBIA) to increase public awareness of TBI and to push for better services and supports, which evolved into the Brain Injury Alliance of Connecticut (BIAC). In 1999, the executive director of the BIAC met with the Connecticut Department of Public Health (CTDPH) to request data on TBI, leading to the production of a prevalence report covering the years 1996 to 2000. The report identified 64,000 Connecticut residents with a diagnosis of TBI. Working with the state's Department of Education, Bureau of Special Education, 110 children afflicted with TBI were identified in the Connecticut school system.

The CTDPH followed up on their prevalence report with an incidence report covering the years 2000 to 2004, identifying an average annual TBI incidence rate of 2,256. Extrapolated data points to approximately 93,000 individuals living with the consequences of TBI in the state. However, the Bureau of Special Education currently identifies only 114 children enrolled in the TBI category of special education in the school system. Further, each time the issue is explored, a labor intensive incidence or prevalence report must be generated.

BIAC and their partners identified the development of a TBI incidence surveillance system, housed by CTDPH, as a necessary step in gaining easily accessible and timely information on the burden of TBI in the state. More readily available data will make engaging policy makers in the recognition of TBI as a public health threat easier and will help generate the political will needed to provide essential services and resources to children and families affected by TBI.

Although Connecticut already had a core of strong advocates in place, participation in the CoP brought new and diverse stakeholders to the table and brought the need for a surveillance system and the steps required to put the system in place into clearer focus. The CoP team has experienced several significant outcomes:

- The CTDPH is in discussion with the Governor's office about funding to create a Surveillance System
- The CTDPH has included TBI in the State Health Improvement Plan (SHIP) through the following goals:
    - Decrease by 10% the number of hospitalizations resulting from TBI
    - Decrease by 10% the number of Emergency Department visits resulting from TBI
- The Department of Education and Office of Student Supports and Organizational Effectiveness are engaged in the implementation of the Connecticut Concussion Law
- The Connecticut Legislature is developing a Committee to advise the Legislature on how to serve this population.

With time, and thanks to the dedication of Connecticut's CoP team and their wide range of partners, TBI will no longer be a silent epidemic.

Iowa

Created Brain Care Guide to coordinate services for individuals with mild to moderate TBI

In 2012, a summit on pediatric brain injuries was held in Iowa. The stakeholders present at the summit represented a wide array of programs, services, and organizations. They were asked to rank the challenges children, youth, and their families/caregivers face with regard to Acquired Brain Injury. Overall, those present said that the biggest challenge families/caregivers face is pulling together and accessing the necessary resources to treat and manage a moderate-severe brain injury (BI) once it has been sustained.

When the TBI CoP opportunity arose, Iowa created a team which could begin to address this challenge. With secondary and tertiary prevention as their guide, they set out to create a tool which provides information on the services a child might need after sustaining a moderate to severe BI and resources for accessing those services.

The two-page Brain Care Guide is intended to be filled out immediately following treatment for a moderate-severe TBI by any individual (social worker, educator, nurse, physician, etc.) working with the family/caregiver. Recognizing the uniqueness of every individual, their circumstances, and their path to recovery, the first page of the tool provides a comprehensive list of services which the caregiver may need to seek. Service areas listed include health care, rehabilitation, education, family support, transition support, prevention of future injuries, community access, funding sources for services, and coordination of services. The second page acts as a resource guide, providing a quick reference to explanations for common terms, as well as resources which the family may encounter after the BI.

While the tool is predominantly geared towards families and caregivers, it also provides the added benefit of enhancing information sharing among professionals serving the injured individual. The tool is currently being piloted in several hospitals in Iowa for effectiveness and completeness before being rolled out on a wider scale.

The Iowa CoP team is hoping to continue their efforts beyond the yearlong endeavor to improve coordination of care and services for children and youth who sustain a TBI. A similar tool for coordinating the care of mild TBI is under development by the Iowa CoP team.

Minnesota

Developed survey of school nurses to determine needs for concussion education

Seizing upon the opportunity the CoP presented, Minnesota decided to focus the work of its existing Brain Injury Interagency Leadership Council (BI ILC) on the CoP for one year. Each month, the team gathered to watch the CoP webinar collectively and discuss the implications for their work. Through a vote, the team decided to focus their energies on post-concussion recovery, given the impact the injury can have on a child's developing brain if not managed correctly and the current undercounting and underservicing of concussed children.

Given Minnesota's return-to-play legislation, which was passed in 2011, and the Minnesota State High School League's (MSHSL) requirement for education of all coaches and referees, the team decided to focus on the implementation of return-to-learn through which concussed children are reintroduced to their normal school work only when they are deemed ready. The issue of return-to-learn was deeply explored in the CoP, especially by Nebraska which shared information about their return-to-learn legislation and how they are gathering information about gaps in knowledge and behavior among physicians.

After readjusting the composition of the CoP team based on the return-to-learn focus, the team got to work. They set out to ensure consistent messaging across the state regarding the management of concussions and appropriate educational accommodations for recovering students returning to the classroom. The team decided to develop a survey to determine needs for further education on concussions and the best way to provide this information to school nurses. They reached out to school nurses and found them very helpful in identifying which questions needed to be asked and how to word the questions appropriately. The survey will soon be distributed to all school nurses in the state.

Now that the CoP is over, the BI ILC will return to the activities they were previously engaged in with an expanded portfolio addressing issues in return-to-learn and classroom accommodations for students who have sustained a TBI.

Nebraska

Formed concussion coalition

Developing return-to-learn guidelines for physicians and club sports programs

Leading up to the TBI CoP, much work was taking place in Nebraska on the prevention, treatment, and management of TBI. The key players in this work were in contact with one another and agreed that their efforts should be more coordinated, but they had not yet determined how to make that happen. The call for applications for the CoP brought them together, creating the impetus for working together. After submitting an application and talking more regularly with one another, the CoP team saw the need for a larger concussion coalition and began working to build one. Today, the Nebraska Concussion Coalition consists of approximately 30 members, including five of the six TBI CoP team members.

The Nebraska Concussion Coalition aims to change the concussion culture in Nebraska by promoting the management of concussion according to known best practices. The coalition prioritized three actionable issues: (1) the development of return-to-learn policies and procedures; (2) improving physicians' understanding of and commitment to best practices in concussion management; and (3) improving club sports programs' understanding of and commitment to best practices in concussion management.

Nebraska legislation on return-to-learn policies went into effect in July 2014 and sets standards for how and when a student who has sustained a concussion may return to the classroom. One important component of the legislation is the need for clearance of the student by a physician before he/she may return to the classroom. Given this requirement, the Nebraska Concussion Coalition prioritized the improvement of physicians' knowledge of their role in implementing the legislation and best practices in the management of a TBI.

So far, the coalition has held a focus group with physicians to get a sense of their knowledge of the law and of best practices, as well as the way they currently treat concussed patients. The coalition is conducting an environmental scan with the state's medical association to determine physicians' knowledge, attitudes, and behaviors regarding concussions and their management. Based on the results of that environmental scan, the coalition plans to develop an online tool to help physicians learn about the new law, their role in the law, and best practices for the management of concussions.

Nebraska's current sports concussion law does not include club sports. Therefore, the coalition prioritized outreach to and work with club sports associations regarding their knowledge, attitudes, and behaviors related to concussions. Their goal is to identify gaps in knowledge and opportunities for engagement so that coaches, parents, and all members of the club sports community manage concussions according to best practices.

The Nebraska CoP team and resulting coalition found that evaluation is a key instrument for determining goals and for identifying strategies to achieve those goals. With the CoP team in place and the coalition off the ground, they are breaking down silos, improving coordination, and working towards a more efficient and effective concussion management culture in Nebraska.

North Carolina

Developing a statewide TBI prevention plan

North Carolina's Brain Injury Advisory Council is very active, with subcommittees focusing on Prevention as well as Children and Youth, among others, and a large network of connections. Given the knowledge, focus, and reach of this organization, it was a natural fit for them to develop a state-wide TBI prevention plan. The plan aims to clearly identify the leading causes of TBI among children and youth and identify strategies for addressing the leading causes and at-risk populations. The group hopes that the state-wide plan can serve as a model which counties can tailor and adapt to their specific populations, risks, and needs while increasing knowledge about TBI across the broad spectrum of injury prevention. Readers will be given resources to access county level data so that they may target specific needs in their home areas.

To date, the Prevention Committee and the Children and Youth Committee have held several conference calls to discuss the plan and have appointed public health interns to seek examples from other states and craft a first draft of the plan. The TBI CoP served as an excellent source of centralized information for the interns, who were able to identify plans from other states involved in the CoP, access those plans, and ask questions about them. The plan will be reviewed by the two committees and will be circulated to the Brain Injury Advisory Council before being disseminated to stakeholders, such as Safe Kids. Thanks to the CoP, the North Carolina team will have a wide network of outside supporters who can provide input and guidance on data collection, prevention strategies, and communication during the review and finalization of the plan.

Conclusion

Leveraging the resources in each of their states, the CoP teams came together to establish a shared understanding of the causes and prevention of TBI. The teams then identified their own state-specific goals, which included the creation or reinforcement of task forces and coalitions; improvements in data collection and sharing, expansions in education and training; and the development of guidelines, protocols, and prevention plans. The CoP provided information about best practices and opportunities for action and, most importantly, offered a forum in which states could learn from one another. For more information about best practices in TBI prevention or for more information about the TBI CoP, please contact Rebekah Hunt at rhunt@edc.org or at (617) 618-2178.

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