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**Traumatic Brain Injury in the United States  
Assessing Outcomes in Children**

Traumatic Brain Injury in the United States:  
*Assessing Outcomes in Children*

Summary and Recommendations from the  
**Expert Working Group**  
Atlanta, GA  
October 26-27, 2000

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## Executive Summary

This report summarizes the comments, suggestions, and recommendations of a working group convened by the Centers for Disease Control and Prevention (CDC) on assessment of Traumatic Brain Injury (TBI) outcomes in children and youth. It is intended for researchers, public health professionals—including those from state health departments—and advocates interested in furthering research on outcomes of TBI in children.

TBI is often described as the leading cause of disability in children, but data to support this assertion are lacking. We know that each year an estimated 3,000 children and youth die from TBI; 29,000 are hospitalized; and 400,000 are treated in hospital emergency departments. Currently, no population-based studies of the outcomes of TBI among children and youth exist to provide national estimates of TBI-related disability and document the need for services.

On October 26 and 27, 2000, the National Center for Injury Prevention and Control at the CDC held a meeting of researchers, advocates and other professionals from the U.S. and New Zealand to discuss “Methodological Issues in Assessing Outcomes of TBI in Children and Youth.” The primary purpose of this meeting was to determine the feasibility and appropriate methods for conducting population-based follow-up studies of outcomes of TBI in children and youth.

Meeting participants identified key research topics and variables to measure in assessing longer-term outcomes of TBI in children and youth (ages 0-16 years). They reviewed several conceptual models of disability, including the Institute of Medicine Model and the World Health Organization Model, that could provide a framework for designing appropriate studies of TBI outcomes. They also discussed the advantages and shortcomings of available measures for assessing these outcomes. Finally, the working group described the challenges in designing and implementing studies on TBI in children and youth and recommended ways to address those challenges.

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Meeting participants recommended that further research be done to examine physiological responses to brain injury, patterns of recovery and treatment and costs of TBI. The group suggested that the field needs to explore the applicability of various types of research, including qualitative research. Some examples suggested included focus groups and individual interviews. Meeting participants also recommended methods for improving measurement, data analysis and terminology used in the study of TBI.

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# Background

## **Methodological Issues in Assessing Outcomes of Traumatic Brain Injury (TBI) in Children and Youth**

### **Purpose of this Report**

On October 26 and 27, 2000, the Centers for Disease Control and Prevention (CDC) convened an expert working group to discuss "Methodological Issues in Assessing Outcomes of Traumatic Brain Injury in Children and Adolescents." This report documents the comments and suggestions of the working group.

### **Meeting Goal and Objectives**

The goal of the meeting was to determine the feasibility and appropriate methods for conducting a population-based follow-up study of outcomes of TBI in children and youth.

The meeting objectives were to

- Identify key domains and variables to measure in assessing longer-term outcomes of TBI in children and youth (ages 0-16 years).
- Discuss the advantages and shortcomings of available measures for assessing these outcomes.
- Highlight the need for other types of research on TBI in children and youth.
- Discuss methodological issues in assessing TBI outcomes in this population.

### **Meeting Participants and Process**

The eleven participants included researchers, advocates, psychologists, educators and other professionals from the United States and New Zealand. With input from the Brain Injury Association, CDC selected invitees for their potential to contribute to a greater understanding of the important outcomes of TBI in children that need to be studied or the methods appropriate for collecting information about those outcomes. Two of the participants are the developers of key measures of health status in children.

For each objective, CDC staff prepared background materials for discussion; selected meeting participants assisted in these preparations. The meeting began with presentations of preliminary CDC multi-state surveillance data and South Carolina surveillance data to provide background information on the importance of TBI among children and youth as a public health problem (See Appendix B and Appendix C). For the remainder of the first day, participants discussed the background materials. A professional note taker recorded participants' comments and suggestions. On the second day, the moderator presented a synthesis of the suggestions for review and revision by the participants.

This report documents the final summary of the comments and recommendations. For some sections, more detailed definitions, references and other materials have been added to clarify the information from the meeting.

### **TBI as a Public Health Problem in Young People**

Among children and youth aged 0 to 14 years in the U.S.:

Each year traumatic brain injury results in an estimated

- 3,000 deaths
- 29,000 hospitalizations
- 400,000 emergency department visits.\*

Unintentional injury is the leading cause of death, and traumatic brain injury is the type of injury most often associated with death.

The annual total of TBI-related deaths is

- More than 6 times the number the number of deaths related to HIV/AIDS\*
- 20 times the number of deaths from asthma\*\*
- 38 times the number of deaths from cystic fibrosis.\*\*\*

\* CDC

\*\* NCHS, Monthly Vital Statistics Report. Vol. 45, No. 3 (S), September 30, 1996.)

\*\*\* CDC Wonder

TBI is reported to be the leading cause of disability in young people in the U.S., but the evidence is limited. Most studies of the outcomes of TBI in children and youth are based on case series from selected hospitals or rehabilitation facilities, small regional samples or anecdotal reports. Few studies have followed the same group of children over time. (See Appendix B for additional statistics on TBI in children and youth.)

### **The Need for More Research**

*Population-based longitudinal studies* provide data representative of the long-term outcomes of all children and youth in a defined area who have had a TBI. They are necessary to allow generalization to the U.S. population of children and youth with TBI. Currently no population-based studies of the outcomes of TBI among children and youth exist to provide national estimates of TBI-related disability and to document the need for services.

CDC has funded such studies, referred to as "follow-up studies" or "outcomes surveillance," of older adolescents and adults (ages 15 years and older) in two states, South Carolina and Colorado. In each of these studies, a sample of people hospitalized with a TBI is identified and given a telephone questionnaire at yearly intervals to find out about TBI outcomes, including disability. For more information about CDC-funded TBI studies, see Appendix E. When the first of these studies was initiated in 1994, children were not included, in part, because few measures were available. The difficulty of measuring the effects of the injury in the context of naturally occurring developmental changes contributes to the challenge of assessing outcomes of TBI in young people.

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The Brain Injury Association, the Federal Advisory Committee for Injury Prevention and Control and a wide range of researchers and other professionals in the field have long argued for a population-based follow-up study of outcomes of TBI in children. In its October 2000 reauthorization of the TBI Act of 1996, Congress emphasized the need for CDC to support TBI studies among all age groups. This meeting was conducted to obtain advice regarding the feasibility of conducting a CDC-funded study of TBI outcomes in children and youth.

### **A Note about Terminology**

**Child vs. Pediatric:** Meeting participants advocated using the term *child* because *pediatric* is associated with the medical model. Reference to *child* encourages consideration of broader, longer-term issues, not only medical concerns. Researchers and professionals should avoid using *pediatric* especially when referring to longer-term outcomes of TBI in children.

**Youth vs. Adolescent:** Participants referred to the term *youth* over *teenagers* or *adolescents* because it is more widely used in educational and other settings.

**Caregiver vs. Parent:** The term *caregiver* may be more appropriate than *parent* because in many cases the person caring for the child is someone other than a parent.

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# Designing Studies that Assess Longer-Term TBI Outcomes in Children and Youth:

## Conceptual Models, Operational Models and Other Resources

### Objective

This section provides background information about selection of a conceptual model and development of an operational model as well as other resources available to help guide the study design.

### Conceptual Models

Meeting participants mentioned several conceptual models that could provide a framework for designing appropriate studies of TBI outcomes. It is important to select an appropriate conceptual model before finalizing an operational model and selecting specific measures.

- **Institute of Medicine (IOM) Model**  
The original IOM model links the four main components of the disabling process—pathology, impairment, functional limitation and disability. The modified IOM model removes disability from this chain to emphasize that disability is not an individual characteristic but a result of interaction between an individual and his or her environment. (Brandt EN Jr., Pope AM, editors. *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*. Washington, DC: National Academy Press; 1997).
- **World Health Organization (WHO) Model (ICIDH-2)**  
This WHO model of disability addresses both the individual factors, including body systems, impairment, activity, and social participation, and the role of the environment. The model is still under revision and has not yet been adapted for children, although work is in progress. Meeting participants recommended that CDC consider adopting this model, which is being applied to disability research internationally. (ICIDH-2: International Classification of Functioning, Disability, and Health Website. Available at: [www.who.int/icidh/](http://www.who.int/icidh/). Accessed January 10, 2001; Simeonsson RJ, Lollar D, Hollowell J, Adams M. Revision of the International Classification of Impairments, Disabilities, and Handicaps Developmental Issues. *J Clin Epidemiol* 2000;53:113-124.)
- **Family Systems Model**  
This model assesses the family environment, including structural dimensions such as family size and family composition, as well as qualitative aspects such as family stressors, sources of internal and external support, and areas of strength and need. (Kalesnik, J. Family assessment. In Nutall EV, Romero I, et al. editors. *Assessing and Screening Preschoolers: Psychological and Educational Dimensions* (2<sup>nd</sup> ed.). Boston: Allyn and Bacon, Inc; 1999. pp. 112-125.)
- **Developmental Models**  
A developmental model is a framework that recognizes a wide range of factors including the intricate matrix of a changing child and environment, evolving familial and societal expectations, and the link between disrupted and normal development.

(Pynoos RS, Steinberg AM, Wraith R. A developmental model of childhood traumatic stress. In: Cicchetti E, Cohen DJ, editors. *Developmental Psychopathology. Vol 2: Risk, Disorder, and Adaptation.* Wiley series on personality processes. New York: John Wiley and Sons; 1995. pp. 112-125. Brett AW, and Laatsch L. Cognitive rehabilitation therapy of brain-injured students in a public high school setting. *Pediatric Rehabilitation* 1998;2:27-31.) Consideration of developmental models is critical in designing studies of longer-term outcomes of TBI in children so that the studies address not only the effects of the injury but also how these effects relate to development.

Models of disability (IOM or WHO) are the most useful as overall guides for the study design. Family systems and developmental models suggest key areas to be considered for inclusion in the study.

### **Operational Models**

Operational models are one-page summaries of topics and variables to consider in planning studies of outcomes of TBI in young people. Meeting participants reviewed and discussed draft operational models, which were prepared before the meeting. Figure 1 (General Model) and Figure 2 (Service-Related Model) show the topics and related variables recommended by the working group.

These topics and variables were suggested by researchers, advocates and professionals. It is also important to conduct qualitative research, such as focus groups, with families and children or youth with TBI to understand the key issues from their perspectives. Minority populations should be included in qualitative studies to increase understanding of the unique experiences and service needs of these subpopulations.

To date, studies have focused largely on determinants of secondary conditions and adverse outcomes, but studies must also be developed to identify factors related to *good* outcomes.

### **Other Resources**

Meeting participants mentioned several other resources that could be used to guide selection of research priorities. These resources include:

- Healthy People 2010 Health Objectives for children and people with disabilities
- Declarations of children's rights
- HRSA/Maternal and Child Health Bureau rights of the child
- United Nations Convention on the Rights of the Child.

To read portions of these documents, see Appendix C of this report.

### **More About the Domains for Assessing Service Needs**

Parents and advocates report that appropriate services for children and youth with TBI are lacking. Studies of outcomes of TBI among this population should document the needs for services and the barriers to receiving them. For that reason, meeting participants developed a separate operational model specifically for these issues (Figure 2).

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For clarification, a more detailed description of some of the important barriers that were discussed follows below:

- Lack of referrals made by healthcare providers.
- Caregivers not aware of available services.
- Lack of appropriate identification of TBI as the underlying reason for the need for the service or misidentification (e.g., instead of being identified as having a TBI, the child is diagnosed as having a learning disability).
- Lack of appropriate services and service providers with expertise specifically in TBI.
- Lack of insurance or inadequate insurance; e.g., an HMO or PPO may not have appropriate service providers.
- Continuation of pre-injury services; children may tend to receive the same kind of services after the TBI, even if these services are not appropriate for their specific post-TBI problems.
- Lack of acceptance of services because they are not perceived as culturally relevant.
- Lack of appropriate educational services; the Individualized Educational Plan (IEP) does not meet the child / youth's need or schools may tend to identify conditions they know how to manage. Research is needed to determine whether classifying children as having a TBI affects how they are managed in school.

Figure 1: General Operational Model for Outcomes Studies of Traumatic Brain Injury in Children and Youth

Characteristics and Risk Factors		Injury	Treatment	Status at Year One				
Socio-demographic	Pre-injury	TBI event	Post-injury care	Symptoms/ sequelae	Environmental/ personal mediators	Functional limitation	Secondary conditions & other adverse outcomes	Overall outcome
<p><u>Child/youth</u> Age Sex Race/ethnicity Education Health insurance</p> <p><u>Parent/caregiver</u> Age Sex Marital status† Education† Employment Relationship to child/youth</p> <p><u>Family</u> County of residence ZIP code Composition† Family income Housing Rural vs urban†</p>	<p><u>Medical history</u> History of previous TBI(s) Pre-existing medical conditions Alcohol/substance use (youth) General health/quality of life Depressive symptoms</p> <p><u>Development</u> Physical/motor Cognitive Language/communication Social Affective Behavioral (ADD/ADHD) Learning disabilities</p> <p><u>Education</u> Grade Academic achievement Behavior problems Special education services</p> <p><u>Employment and personal income (youth)</u></p> <p><u>Living situation</u> Family environment/function Social support</p> <p><u>Functional status</u></p>	<p>Date Age at injury Severity Multiple trauma Circumstances of injury</p>	<p>Acute Sub-acute Post-acute Rehab† Special ed. Social services</p>	<p>General health Physical/motor Cognitive Language Affective Behavioral Neurologic Mental health† Self-esteem† Post-traumatic stress disorder†</p>	<p><u>Child/youth</u> Personal assistance/supervision Special education Mental health services Rehab/counseling Alcohol/drug abuse treatment Awareness of disability</p> <p><u>Family</u> Information, referral, case management Counseling Social support Family environment/function</p> <p><u>Child/family</u> Health insurance Socialization opportunities Personal/family income</p>	<p>Activities of daily living (ADLs)/ self-care Walking/mobility Instrumental activities of daily living (IADLs) Communication Leisure/play Driving (youth)</p>	<p>Secondary conditions Alcohol/substance use problem (youth) Depressive symptoms Psychiatric problems†</p> <p>Other adverse outcomes</p> <p><u>Child/Youth</u> Decline in grade level Decline in academic performance Special education services Behavior problems Decrease in social participation Problems with peer/family relationships Change in living situation (e.g., nursing home) Change in lifestyle (e.g., decreased exercise)† Repeat injury TBI since discharge Interpersonal violence, neglect Delinquency Incarceration</p> <p><u>Family</u> Caregiver burden Family stress Change in marital status of caregiver Change in caregiver employment† Change in residence† Economic impact† Impact on siblings†</p>	<p>Life satisfaction</p>

\* Environmental/personal mediators includes factors not covered in other categories and services that may influence functional status and/or decrease the likelihood of secondary conditions/other adverse outcomes, and thus affect the overall outcome.

† These factors were added or modified during the meeting.

Figure 2: Operational Model for Studying Service Needs and Use Among Children and Youth with TBI

<b>Factors influencing receipt of services</b>				
<b>Awareness of existing services</b>	<b>Need for services</b>	<b>Barriers to receiving services</b>	<b>Mediating factors</b>	<b>Services received</b>
Need for information Cultural sensitivity* Caregiver lack of knowledge of TBI (e.g., "My child didn't have a brain injury")* Lack of awareness in medical community*	"Measured" need (e.g., child reports difficulty performing activities of daily living) Perceived need (Self-report: child reports need for services) Observed need (Proxy report: caregiver or other reports child's need for services)	<u>Child/Youth/Family Levels</u> Cognitive problems but not physical impairments† Behavior problems† Lack of or inadequate insurance* Low income Lack of transportation Lack of family follow-through Pre-injury services* Lack of eligibility* Lack of acceptance of services* Lack of awareness—not connecting problem to TBI*  <u>Provider/Health/Education Levels</u> Lack of appropriate identification/misidentification* Lack of referral Limited availability of services in the community / waiting lists Lack of support within local education system Lack of specialized services* Lack of awareness—not connecting problem to TBI*	Advocate/case manager to help with referral to services† Service coordination Good social support network† Family income Caregiver education Previous receipt of services Self-advocacy*	<u>Health Care Level</u> Occupational therapy Physical therapy Speech therapy Medical equipment Adaptive/communication/ mobility equipment Cognitive rehab. Behavioral intervention Alcohol/drug abuse treatment Mental health services Information, referral & case management/ service coordination. Preventive services* Respite service*  <u>Education/Community Levels</u> Special education Early intervention Transportation Socialization opportunities Legal assistance Financial assistance Family services, including family support* Services accessed in school*  <u>General Level</u> Quality / appropriateness of services received & available*

\*These factors were added or modified during the meeting.

† From U.S. General Accounting Office. Traumatic Brain Injury: Programs Supporting Long-Term Services in Selected States. February, 1998. Adults with these characteristics encounter substantial barriers in accessing services that will support their reintegration into the community. People with behavior problems are defined as exhibiting unmanageable behaviors such as aggression, destructiveness or participation in illegal behaviors. Without treatment, they are the most likely to become homeless, be committed to a mental institution or be sentenced to prison.



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# Available Measures for Assessing Outcomes of TBI in Children and Youth

## Objective

This section summarizes existing measures for assessing outcomes and describes their applicability to studies of TBI.

## Key Criteria

Meeting participants reviewed key criteria for evaluating the usefulness of currently available measures for assessing outcomes of TBI. These criteria included:

- **Developed for use with children and youth**  
Because the problems resulting from TBI in children are unique, most measures designed for adults cannot be effectively adapted for children and youth.
- **Previously used with children/youth with TBI**  
Potentially useful measures that were not developed specifically for this population need to be validated or, at a minimum, pilot-tested first.
- **Useful for measuring change during longer-term follow-up**  
Some measures have ceiling or floor effects (limitations in their ability to detect more minor or more severe problems, respectively). Ceiling effects in particular may limit the usefulness of a measure to assess changes over time, as recovery occurs. Many measures have only been used to assess status at one point of time; thus, their usefulness for measuring change is not known.
- **Norms/comparison data available for other conditions**  
Measures with norms for the general population or that have been used to document outcomes associated with other conditions are very useful for determining the effects of TBI.
- **Appropriate for the target age group**  
Many more measures have been developed for use with school-aged children and youth than for very young children. The majority of measures developed for children aged 5 years or younger are developmental measures not specifically designed for children with TBI. Longitudinal research that applies the appropriate measures at each developmental level, but that also tracks important milestones and late emerging deficits from early childhood through older ages, will be especially challenging.

## Specific Measures

A wide range of child health and other measures are available. (For tables that summarize the measures, see Appendix A.) However, not all of these measures are useful or appropriate for studying children and youth with TBI.

**Key Measures:** The Child Health Questionnaire (CHQ) and the Pediatric Evaluation of Disability Inventory (PEDI)

Prior to the meeting, participants identified two promising measures for assessing outcomes of TBI in children and youth, CHQ and the PEDI. The working group discussed the characteristics of these measures, which are summarized below.

### **Child Health Questionnaire (CHQ)**

This summary was presented by Jeanne Landgraf, who developed the measure.

<b>Characteristics</b>	<ul style="list-style-type: none"> <li>◦ Serves as a generic quality-of-life instrument.</li> <li>◦ Assesses physical and psychosocial well being.</li> <li>◦ Is appropriate for ages 5-17 years; version for ages &lt;5 is under development.</li> <li>◦ Measures 14 health concepts.</li> <li>◦ Includes 28- or 50-item parent-completed forms.</li> <li>◦ Includes 87-item child-completed form (a short form is currently being developed).</li> <li>◦ Probes for information about the family.</li> <li>◦ Includes normative data and has been used in studies of a wide range of other conditions; thus, it can be used to help estimate the burden of TBI compared to other conditions.</li> </ul>
<b>Strengths</b>	<ul style="list-style-type: none"> <li>◦ Is specifically developed for children and youth. Provides high reliability.</li> <li>◦ Scores can be compared to available norms and benchmarks.</li> <li>◦ Allows for parallel reporting of parents and children.</li> </ul>
<b>Weaknesses</b>	<ul style="list-style-type: none"> <li>◦ The majority of studies to date using the CHQ have used a cross-sectional design.</li> <li>◦ Limited data about sensitivity to change over time are available.</li> <li>◦ No published studies used it with children with TBI/cognitive impairment, but some work is currently planned or being conducted (reported by Keith Yeates and Melissa McCarthy).</li> <li>◦ CHQ may not be as sensitive as condition-specific instruments.</li> <li>◦ Paper and pencil version have normative data; the telephone interview version is scripted, but normative data are not available.</li> </ul>

### ***Pediatric Evaluation of Disability Inventory (PEDI)***

This summary was presented by Stephen Haley, who developed the measure.

Original PEDI	<ul style="list-style-type: none"> <li>◦ Serves as a functional assessment instrument.</li> <li>◦ Is designed for children in active rehabilitation programs or children with severe problems.</li> <li>◦ Is standardized for children between ages 6 months and 7 ½ years.</li> <li>◦ Can also be used in inpatient and outpatient rehabilitation settings with older children who are functioning at lower levels.</li> </ul>
New Version of PEDI	<ul style="list-style-type: none"> <li>◦ Is based on the WHO model of disability.</li> <li>◦ Is being developed for children with brain injury.</li> <li>◦ Is designed for children and youth aged 1 to 18 years.</li> <li>◦ Has an activity scale that extends beyond basic functional skills; intended to examine recovery of basic skills needed for return to the community.</li> <li>◦ Includes a participation scale that emphasizes life roles and assesses levels of participation in the community and school environments.</li> <li>◦ Is designed to be completed by parents or providers; a child-administered form is not available.</li> <li>◦ Is designed for use in the rehabilitation setting.</li> <li>◦ Will allow risk-adjustment to account for variability across institutions.</li> <li>◦ Can be adapted for use in follow-up studies, although not originally developed for such studies.</li> </ul>

### **Selected Clinical Measures**

A wide range of clinical measures is available for assessing outcomes of TBI. The working group discussed the applicability of these measures, some of which were originally developed for use with adults, to studies of children and youth, and the comments are summarized below:

#### ***Glasgow Coma Scale (GCS)***

- Is a useful indicator of severity, but not for children younger than age 5.
- Scores for the same patient vary depending on when they were collected, e.g., GCS scores collected by Emergency Medical Technicians (EMTs) before admission are not as reliable as those collected in the ED or hospital. CDC TBI surveillance guidelines recommend use of the first GCS after admission to ED or hospital.

#### ***Children's Coma Score***

- Is a modification of the Glasgow Coma Score designed to be used in children aged 3 years and younger.
- Eye opening and motor response subscales are identical to the GCS, but the verbal response subscale rates behavior/affect in preverbal populations. (Multilingual Resources Assessment Tools. Available at: [www.multilingualresources.com/assessment.html](http://www.multilingualresources.com/assessment.html). Accessed January 9, 2001).

- Is unclear how widely this score is being used or whether the score represents a significant improvement in the GCS for use with children. More research on this topic is needed.

#### ***Abbreviated Injury Score/Injury Severity Score (AIS/ISS)***

- Are used routinely in the clinical setting.
- Most recent version (AIS 98) is better than previous versions for assessing children.
- Because of the variability within AIS levels, researchers should consider supplementing AIS/ISS with Therapeutic Intensity Level, which is used in some clinical settings to determine severity based on the intensity of treatment required by the patient (according to Nancy Carney).
- The AIS score for the head is highly correlated with GCS and is a useful measure of TBI severity.

#### ***Loss of Consciousness (LOC)***

- Measures the length of time between injury and when the patient regains consciousness.
- Is strongly correlated with outcomes in children and adults and is a key piece of information that should be collected.

#### ***Length of Post-traumatic Amnesia (PTA)***

- Measures the time from when a patient emerges from coma until he or she is no longer disoriented.
- Appears to be strongly correlated with outcome; however, it is difficult to document consistently and accurately within a hospital protocol.
- Inter-rater reliability is low; that is, different people report different lengths of PTA.
- Despite limitations, PTA should be collected and reported as accurately as possible.

#### ***Rancho Los Amigos Scale***

- Is a 7-level scale for assessing early recovery in the brain injury rehabilitation setting.
- Rates behavior, cognitive functioning, and response to the environment.
- Levels range from No Response (Level I) through Purposeful-Appropriate Responses (Level VII). Multilingual Resources Assessment Tools. Available at: [www.multilingualresources.com/assessment.html](http://www.multilingualresources.com/assessment.html). Accessed January 9, 2001).
- May be useful for research on outcomes but to date has not been used widely or evaluated for that purpose.

#### ***Pediatric Trauma Score (PTS)***

- Is a composite injury score in which the injured child receives a score of -1 (severely injured), +1 (moderately injured) or +2 (slightly injured or not injured) in each of six areas—body weight/size, airway, blood pressure, central nervous system activity, open wounds and skeletal injuries.
- (Ford EG, Andrassy RJ. *Pediatric Trauma: Initial Assessment and Management*. Philadelphia: W.B. Saunders Company; 1994).
- Score is not useful for TBI research because it does not separate head injury from injury to other body regions/functions.

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### ***Neuropsychological/psychiatric tests***

- These detailed tests of cognitive and psychological functioning are frequently conducted by trained professionals.
- Results from these tests are important, particularly to document more subtle deficits, but they must be done in a clinical setting.

### **School Performance Assessments**

Assessments of school performance include achievement tests, which measure students' academic performance, and school function assessments, which assess students' ability to behave appropriately in the classroom.

#### ***Achievement tests***

- These tests of academic achievement are not sensitive to TBI-related problems.
- Thinking and reasoning are not assessed.
- Bright students may do well based on previous learning, thus masking TBI-related problems.
- Scores may improve even as behavior worsens.
- Achievement test results, if available for review, might provide some useful information about previous performance; however, meeting participants did not strongly recommend including them in studies assessing longer term outcomes of TBI.

#### ***School function assessments***

- These checklists are specifically designed to assess functioning in the classroom setting.
- They are helpful in detecting problems specific to the classroom, including awareness of hygiene and behavior regulation.
- Meeting participants recommended including at least some key items from school function assessments in studies of outcomes of TBI in children and youth.

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# Recommendations for Additional Research into TBI in Children and Youth

## Objective

This section summarizes participant recommendations regarding the wide-ranging needs for additional research and improved research methods in studies of TBI in children and youth.

## The Need for Qualitative Research

*Qualitative research* facilitates an increased understanding of the experiences of people with TBI, their caregivers, or professionals working with people with TBI from their own unique and personal perspectives. Such information can guide the development of informational materials and questionnaires for epidemiologic studies. Common qualitative research techniques include focus groups and individual interviews. (See Patton MQ. *Qualitative Evaluation and Research Methods* (2<sup>nd</sup> Ed). Newbury Park, CA: Sage Publications, 1990.)

One meeting participant also had experience in conducting in-depth ethnographic, naturalistic studies with children with other health conditions (e.g., a study of children with asthma collected data by allowing them to carry video cameras). Participants recommended exploring the applicability of these methods to studies of TBI.

## Research Topics

### Basic

Basic research addresses physiologic responses to brain injury. Meeting participants noted that further studies are needed to:

- Reveal the underlying mechanisms of recovery
- Identify outcomes due to the injury itself vs. those that are secondary (e.g., neurogenic vs. situational depression).

### Patterns of Recovery

Because recovery after TBI can be lengthy and because the risk of developing secondary conditions changes over time, better information about patterns of recovery from TBI is needed to understand the long-term effects of TBI. Meeting participants noted that further studies are needed to describe:

- The natural history of recovery from TBI. For example, when are secondary conditions most likely to develop?
- Recovery trajectories. That is, how quickly does recovery occur and in what order are skills regained?
- The later emergence of TBI-related problems especially in children. For example, are infants with TBI more likely to have later learning disabilities, such as trouble with reading or math, or behavior problems that are associated with the TBI?

## Treatment

The NIH Consensus Conference on the Rehabilitation of Persons with Traumatic Brain Injury documented the need for improved research on treatment of TBI, including treatment for children. Meeting participants noted the need for further studies about

- The effectiveness of various treatments and the importance of the intensity level of those treatments
- The effectiveness of educational and behavioral interventions
- The implementation of treatment guidelines – Specific issues include how widely the guidelines are being applied and what effects implementation has on TBI outcomes.
- Personal (or person-centered) outcomes – Personal outcomes are the expectations that people with disabilities have for their lives, including what they expect from the services and supports they receive. Many service providers have adopted personal outcomes as a measure of quality of their services. (The Council on Quality and Leadership in Supports for People with Disabilities, Towson, MD. 410-583-0060)

## Costs

Few studies have looked at the cost of TBI, especially among children. Cost data can help focus greater attention on a public health problem such as TBI. Meeting participants noted that further studies are needed to document:

- The costs of TBI in children, including reduced quality of life, compared with costs for other child health conditions (e.g., asthma, HIV)
- The economic impact of TBI on children, their families, and society.

## Issues of Measurement and Data Analysis

Among the greatest challenges to conducting high-quality research on outcomes of TBI in children are limitations in existing outcome measures and analytic approaches as well as the lack of standard terminology to describe the outcomes. Meeting participants offered the following recommendations to improve measurement, analysis, and terminology:

- Conduct studies to assess the validity of existing measures for use in follow-up studies (i.e., sensitivity to individual changes over time) and apply improved methods for testing item validity.
- Use new types of measures including cognitive measures for use by school psychologists and applicable to consumers; a global measure of cognitive function that assesses memory; a cognitive screening tool for surveillance; a TBI-specific outcomes measure;<sup>1</sup> a severity measure for comparing the burden of TBI with that of other conditions; and improved measures of the environment and its relationship to disability.
- Develop a standard terminology to describe and document service needs and barriers.
- Develop new analytic approaches including application of growth curve analysis to detailed studies of the relationship between development and recovery from TBI.

<sup>1</sup> To expedite development of this measure, it would be preferable to apply enhancements to existing measure(s) to address the limitations of those measures (e.g., add to an existing measure an appropriate assessment of cognitive functioning) as opposed to developing an entirely new measure.

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## Other Methodologic Issues in Assessing TBI Outcomes in Children

### Objective

The objective for this section is to review key issues to consider in conducting studies of TBI outcomes in children and youth.

Meeting participants had a wide range of experiences in obtaining information from children with TBI, their families and schools. These sections document participants' ideas about the challenges of designing and implementing a study of outcomes of TBI in children and youth and how they should be managed.

### Considerations for Defining the Study Population

#### Degree to which the Study Population Represents the General Population

Meeting participants discussed how representative the study population would be if children were selected for follow-up using the same approach used in CDC follow-up studies of older adolescents and adults. That approach, which identifies cases from surveillance systems using hospital discharge data sets, has some important limitations:

- It may underestimate problem outcomes because those who can still be identified and followed after one-year post-hospital discharge tend to have more resources and more stable lives (for adults followed in the Colorado follow-up system, about 35% are lost to follow-up within one year).
- It probably does not include an adequate subsample of children from low-income families.
- It does not include children seen in the emergency department (ED) but not admitted to hospital. The majority of children with TBI are seen only in the ED.

### Sampling Frame

Participants discussed an appropriate sampling frame for selecting cases for follow-up studies of children. They determined that the sampling frame should include both children treated and released from the ED and children discharged from the hospital. The population should then be stratified by severity before selecting the sample.

### Information from Parents / Caregivers and Schools

Participants also discussed whether the study should collect information from parents / caregivers or schools:

#### *Parent / caregiver:*

- A study should include assessments of both the parent (caregiver) and older children (age 8 to 10 or older). Parents and children may differ in reporting, especially about the social experiences of the child, with the parent reporting that the child has more friends and fewer problems with peer interactions than the child reports.



**School:**

- A study should incorporate school assessments of the child's abilities, if possible.
- Parents' and teachers' understanding of the child's individual educational plan (IEP) may differ, so getting both perspectives is important.
- Parents tend to rate their child's school performance higher than do school personnel. The more time that has elapsed since the injury, the higher parents tend to rate pre-injury performance (including school performance).
- Interviews of teachers could yield some valuable information, especially for younger children who have one teacher only.
- Information from school records may also be useful; however, school records may not be complete, and schools are inconsistent in classifying children's disability. For example, a child with a brain injury may be classified as having a learning disability, not a TBI. School records may not be a thorough source of information about grade retention and services received, but these areas are important, so a study should obtain information about them using other methods if necessary.
- Other school-related information of interest includes drop-out rates, achievement on statewide standardized tests and transfers to alternative schools.
- Whether obtaining information requires IRB approval from each school might vary by location, so researchers should check before beginning the study.

**Appropriateness of Telephone Interviews for Children / Youth Follow-up Studies**

Instead of using in-person interviewing, which is very expensive, CDC has used telephone interviewing to collect information in its follow-up studies of older adolescents and adults. Meeting participants discussed the appropriateness of this approach for studies among children and youth.

**General Issues**

Before beginning telephone interviewing, researchers should investigate telephone coverage among the proposed study population because low-income families may not have telephones. Researchers might also consider newer alternatives such as Internet administration, but Internet coverage among low-income families is likely to be even lower than for telephones.

**Telephone vs. In-Person**

Studies show that responses vary according to mode of administration (telephone vs. in-person and, for in-person interviews, whether the interview is conducted by a doctor/nurse or other type of interviewer). People tend to report fewer impairments when they are interviewed in-person than when they are interviewed by telephone. Therefore, researchers might need to compare responses from in-person and phone interviews in a sample of participants to evaluate reliability.

**Interviewing Children by Telephone**

Studies suggest that interviewing by telephone may not be appropriate for children and youth younger than age 13. TBI-related deficits and problems such as fatigue and limited attention span may make phone interviews with young people more difficult.

### **Suggestions for Enhancing Telephone Administration**

- Pilot the questionnaire and revise based on results and experience before beginning the main study.
- Consider mailing the parent questionnaire before the interview to give them time to think about their answers.

### **Appropriate Interview Length**

- Questionnaires for use with children and youth with TBI should be as short as possible to minimize fatigue among participants. Questionnaires for use with their parents may be longer but should also be kept as short as possible.
- Interviews should not exceed 45 minutes for adolescents while approximately 60 minutes is appropriate for parents. Meeting participants suggested that questionnaires for use with children should be pilot tested to determine the appropriate interview length.
- Meeting participants also suggested pilot testing a longer version for use with adolescents or parents to see how they respond. Families of children with TBI may be very invested in outcomes and often like to have someone to talk with. Some meeting participants reported surprise at the willingness of parents to be interviewed for longer than 60 minutes.

### **Effective Follow-up Interviews**

Longitudinal studies of TBI outcomes involve an initial interview sometime after TBI, then tracking participants and re-interviewing them periodically, often at one-year intervals. Of particular concern is the potential for loss to follow-up because the families move or no longer agree to be part of the study. Meeting participants offered these suggestions for follow-up with children who have TBI:

#### **Timing of Follow-Up**

- Begin interviewing earlier than one year after the injury (optimally at 3-6 months). This approach could help decrease loss to follow-up because the family is less likely to have moved from the address found in the medical record. This approach would also provide useful information about patterns of early recovery.
- Consider beginning active surveillance and follow-up while people are still in the hospital. Follow-up beginning at one year is not timely enough to meet the needs of people with TBI to be identified early and linked to information that can help them get the services they need. Meeting these needs requires a case management approach, even if it is cost- and resource-intensive. The principal investigator for the South Carolina follow-up study of older adolescents and adults estimates that double the funding it currently receives from CDC would be required to initiate active surveillance of TBI. To decrease the cost and improve the feasibility of conducting more active surveillance, researchers should consider limiting surveillance to the few hospitals that see the majority of child TBI cases—for example, Level I trauma centers and children's hospitals.
- Consider alternative approaches to tracking, especially for very young children, such as early intervention tracking systems that follow very young children (younger than age 3) who have TBI or other disability (e.g., in Rhode Island).

### Length of Follow-Up

A single year of follow-up is insufficient to document important outcomes. Ideally, a study should follow children as long as possible through as many developmental transitions as possible to try identifying late-emerging problems resulting from TBI. Based on experience with the currently funded CDC studies of outcomes in older adolescents and adults, three- to five-year follow-up is feasible considering estimated cost and loss to follow-up.

### Tracking

To reduce loss to follow-up, researchers should test a mechanism for routinely contacting participant families, such as sending a postcard at frequent intervals to track changes of address.

### Advantages of and Selected Methods for Comparison Groups

Meeting participants strongly recommended including a comparison group as part of any follow-up study of outcomes of TBI in children to strengthen the study design and improve the usefulness of the findings. A comparison group completes the same questionnaire as the follow-up study participants, and researchers compare their responses with those of the children with TBI. The comparison group need not be the same size as the group of children with TBI. Methods of selecting a comparison group vary. Meeting participants discussed the pros and cons of each method, as summarized below:

#### Non-TBI Trauma Comparison Group

This approach entails selecting a population of children who were injured but did not have a TBI, matched by age and sex with the TBI children. The approach helps control for risk factors for injury that are similar between the two groups. The comparison group should be matched by socio-economic status to the TBI group.

- Researchers should consider the length of time following the trauma in selecting the comparison group. If the concern is adjusting for pre-injury risk factors only, selecting children who have recovered from the trauma may be more appropriate.
- Keeping non-TBI trauma controls involved in the study requires much effort, especially if they will be interviewed more than once, because they are not as invested in it as family members.
- ***Meeting participants strongly recommended this approach.***

#### Friend Comparison Group

This approach involves selecting one similar-aged friend for each child with a TBI. The “friend control” completes the questionnaire. The approach helps control for social environment and school context, but friend controls might not have the same pre-injury risk factors.

- Defining “friend” may be difficult for very young children. Also, many children lose their friends after the TBI, so identifying a friend control may be difficult.
- Keeping friends involved in the study requires effort because they are not as invested in it as family members.
- ***Meeting participants recommended this approach as useful but with several limitations.***

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### **Sibling Comparison Group**

This approach involves selecting a brother or sister of the child with TBI to serve in the comparison group. The approach helps control for family environment factors, but matching on age and sex may be impossible or there may not be any siblings.

- Siblings may not be a good comparison group because, as part of the family of the child with TBI, they also feel effects of the trauma.
- *Meeting participants did not recommend this approach.*

### **Age- and Sex-Matched Comparison group**

This approach involves selecting a sample of children from the general population, matched by age and sex. The approach allows comparison of the normal developmental trajectory with the trajectory for children with TBI.

- *Meeting participants recommended this approach.* They also suggested that the optimal study would include both an age- and sex-matched comparison group and a non-TBI trauma comparison group.

## Other TBI Issues

Research on outcomes of TBI is only one component of a broader effort to improve the lives of children with TBI. Meeting participants also noted the need for improved education and awareness of TBI as a public health problem and the need for more CDC research. To address those needs, participants offered the following suggestions:

### Education and Awareness

In the TBI Act Reauthorization of 2000, CDC has been given expanded authorization for an education and awareness campaign. The campaign should consider:

#### Increasing overall public awareness

- A recent Harris poll, commissioned by the Brain Injury Association, revealed that the American public greatly underestimates the magnitude and importance of TBI ([www.biausa.org/harrispollresults.htm](http://www.biausa.org/harrispollresults.htm). Accessed January 24, 2001).
- All educational efforts should strive to use standard terminology to increase understanding and improve communication about TBI.

#### Raising awareness in the medical and TBI communities

- The campaign should educate the medical and TBI communities that so-called “mild” TBI can result in serious, long-term deficits. A relatively large number of children have problems after mild TBI.
- A group of neuropsychologists, now at the University of Pittsburgh, has developed a computer-based sports sideline screening for symptoms of concussion. The National Football League (NFL) first used the screening, and now some college and high school sports use it, which has generated a lot of attention from parents.

#### Increasing the awareness of parents and caregivers

- Parents and caregivers also need to better understand what they can expect after a child has a TBI, especially a less severe TBI.
- Cultural sensitivity is critical.
  - Efforts to develop materials that increase awareness should begin with focus groups to understand children's and families' perspectives and the language that is meaningful to them.
  - Educational efforts should be sensitive to the different information needs of parents of children whose disability resulted from a sudden change (i.e., TBI) and of parents of children with developmental disability. An education campaign should try to ensure that the information about possible outcomes of TBI in children does not result in negative self-fulfilling prophecies. For example, children with mild-to-moderate TBI may have cognitive deficits, but they are still capable of learning.

### Dissemination

CDC should distribute educational materials as widely as possible, including through the HRSA Maternal and Child Health Bureau Clearinghouse, which distributes a wide range of materials on children's health.

### CDC Research Efforts

Meeting participants offered the following additional suggestions for steps the CDC should take to improve knowledge about TBI outcomes in children.

- **Continue to collect data while ensuring more widespread dissemination.**  
CDC should continue to increase awareness of the TBI problem by collecting and sharing data about the incidence and prevalence of TBI and TBI-related disability. Information should be in a form that can be distributed by health professionals to people with TBI and their families. For example, CDC should publish more brochures like the concussion brochure (*Facts about Concussion and Brain Injury*, [www.cdc.gov/ncipc/tbi](http://www.cdc.gov/ncipc/tbi). Accessed January 24, 2001).
- **Support, promote and conduct additional research.**  
CDC should make its surveillance data sets more widely and readily available to other researchers and professionals, including via the Internet.

CDC needs to identify research gaps and issue requests for proposals (RFPs) to address those gaps. Future CDC studies should document:

- the disproportionately low funding for TBI compared with the burden of TBI
- poor coverage of services by insurance companies
- the percentage of children with TBI receiving services and the percentage not receiving them
- the need for appropriate educational programming for children and youth with TBI.

# Appendix A

## Overview of Outcome Assessments Available for Use with Children and Youth with TBI

### Quality of Life

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
CHIP (Child Health & Illness Profile)	Assess physical & mental health	11-17	Child / youth	Self-administered	153	30-45	Yes	Yes	----	12, 15, 22	Can be used to assess change over time	Utilization questions within the health status scale; requires professional interpretation
CHQ (Child Health Questionnaire)	Assess physical, emotional & social well-being	5-17	Parent	Self-administered	28 or 50	----	Yes	Yes	Yes	6, J. Landgraf	Specifically developed for children/youth; well normed; used in other pediatric populations; allows parallel child & parent reports; telephone interview scripted	Limited data on sensitivity to change; under 5 version not yet normed; may not be as sensitive as condition-specific instrument; paper-&-pencil version normed but telephone interview not normed
		10/12 & older	Child		87							
		5 & younger	Parent		87							
COOP Charts (Dartmouth Primary Care Cooperative Info. Project)	Assess functioning and health-related quality of life	8-12	Child	Self-administered	9	----	Yes	Yes	----	12		Floor and ceiling effects; relies on sample size for power
		13-18	Youth		14							
PedsQL (Pediatric Quality of Life Inventory)	Assess health-related quality of life	8-18	Child/youth Parent	Child: interview Youth & parent: self-administered	15 core, 30 disease-specific	----	Yes	Yes	----	25		
QWB (Quality of Well-Being)	Assess quality of life	12 and older	Youth	Structured interview	----	15	For adults	Yes	----	3, 8		Weighted based on population preferences; adapted from adult measure; low parent/ youth correlation; not designed for a neurological population

--- Information was not found.

\* Measure was discussed during the meeting.

\*\* General topic was discussed during the meeting.

## Epidemiology

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
NHIS (National Health Interview Survey)	Assess prevalence of certain health-related conditions in the US	1988 Child Supp: 0-18	Parent	Structured telephone interview	65	-----	-----	-----	yes	12, 21		
		1994 Disability Supp: 0-18	Parent	Structured telephone interview	-----	-----	-----	-----	-----			
OCHS (Ontario Child Health Survey)	Assess prevalence of emotional & behavioral disorders	4-16	Parent	Interview & self-administered	304	-----	Yes	Yes	-----	12		
		12-16	Youth		169	-----						

## Behavioral / Cognitive

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*BASC (Behavior Assessment System for Children)	Measure anxiety, depression, aggression, coping, social relationships	2.5-18	Parent/teacher	Self-administered	130	10-20	Yes	Yes	-----	14	Normed; relatively brief	
		8-18	Child/youth	Self-administered	152 child 186 youth	30-45						
*BRIEF (Behavior Rating Inventory of Executive Function)	Assess executive functioning including self-monitoring, organizational control, & individual planning	5-18	Parent & teacher	Self-administered	86	10	Yes	Yes	Yes	10	5-18 year parent version normed; more specific than some other measures	2.5-5 year parent and 11-22 year youth versions still being normed; rather long
		2.5-5	Parent	Self-administered								
		11-22	Youth	Self-administered								
*CBCL (Child Behavior Checklist)	Assess children's competencies & behavioral/emotional problems	1.5-5	Parent	Self-administered	99	-----	Yes	Yes	Yes	1, 20		Designed to assess psychopathology; may not be appropriate for brain injured population; quite long; can give inconsistent results
		4-18	Parent	Self-administered	118							

--- Information was not found.

\* Measure was discussed during the meeting.

\*\* General topic was discussed during the meeting.



Behavioral / Cognitive continued												
*FS-II(R) (Functional Status II(R))	Assess behavioral response to illness that interferes with normal social roles	0-16	Parent	Structured interview	long: 43 short: 14	----- -----	Yes	Yes	----- -----	12, 15, 23	Can be used repeatedly to document change	Designed for lower end of the functional continuum; permission must be obtained from authors

## Functional

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*PEDI (Pediatric Evaluation of Disability Inventory)	Measure capability & performance of functional activities	0.5-7.5	Parents and/or physicians	Interview or direct observation	41	45	Yes	Yes	Yes	2, 9 S. Haley	Incorporates more cognitive, behavioral, & safety components than WeeFIM	Primarily a rehab instrument; limited age range
*PEDI II (Pediatric Evaluation of Disability Inventory, Version II)	Measure ADLs, social/ behavioral activities & community participation	0-18	Clinical staff Parent	Self-administered	44	45	Planned	Planned	Designed for TBI	S. Haley	Focuses more on community participation than PEDI; some questions may be useful for TBI surveillance	Still in development; questionable inter-rater reliability; too detailed for surveillance; focuses on rehab, more severe injuries, people who receive services
*SIB (Scales of Independent Behavior)	Assess adaptive & maladaptive behavior	0-80+	Parent	Structured interview or checklist	long: 259 short: 40	45-60 15-20	Yes	Yes	-----	11, 18, 19	Global index of independence; considers initiation of activity	
*VABS (Vineland Adaptive Behavior Scales)	Survey activities the child/youth habitually demonstrates in the environment	0-18	Parent	Semi-structured interview	297	30-60	Yes	Yes	Yes	11, 16	Short form has global index of independence	Complicated interview process
*WeeFIM (Functional Independence Measure for Children)	Assess functional independence by focusing on dependence	0.5-7	Parent	Interview or direct observation	18	15-20	Yes	Yes	Yes	9, 15, 24	Can be used repeatedly to document change	Difficult to teach to interviewers with no rehab experience; designed for inpt assessment of kids with serious injury; ceiling effect; underrepresents cognitive defects

--- Information was not found.

\* Measure was discussed during the meeting.

\*\* General topic was discussed during the meeting.

**Educational/Vocational/Recreation**

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*PPSC (Play Performance Scale for Children)	Assess play performance	0.5-16	Parent or clinician	Self-administered	Single scale	2	Yes	Yes	-----	13, 15	Assessment can be done by non-professionals; easy to administer, analyze & interpret	Used primarily in oncology studies
*PSO (Post-Secondary Outcomes)	Assess educational & vocational status	post-high school	Youth & parent	Structured interview	-----	-----	-----	-----	Designed for TBI	Bonnie Todis		
*SFA (School Function Assessment)	Assess ability to perform functional tasks necessary for the academic & social aspects of education	K-6th grade	-----	Interview / evaluation	-----	-----	-----	Yes	-----	7	May have useful elements	Long

**Family Functioning**

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
*FAD (McMaster Family Assessment Device)	Assess global family functioning	na	Parents / family members	Self-administered	53	15-20	Yes	Yes	Yes	9, 27		Not designed to measure impact on family; not sensitive to change over time
*FBII (Family Burden of Injury Interview)	Assess burden of pediatric TBI on families	na	Parent	Interview	27	-----	Yes	Yes	Yes	4, 27	Sensitive to change over time	May not be applicable to non-TBI groups; rather long
*IOF-G (Impact on the Family Scale, Version G)	Measure impact of pediatric disability on family	na	Parent	Interview	34	-----	-----	Yes	Yes	15, 27	Brief, useful; designed to be more sensitive to change	Difficult to get; may not be as useful as FBII

--- Information was not found.

\* Measure was discussed during the meeting.

\*\* General topic was discussed during the meeting.

**\*\*Depression**

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used in child / youth TBI studies?	Ref.	Strengths	Weaknesses
BDI (Beck Depression Inventory)	Evaluate depressive symptoms	Youth	Youth	Self-administered	21	5-10	Yes	Yes	-----	17, 20		Measuring depression may not be as important in children/ youth as in adults
CDI (Child Depression Inventory)	Assess frequency of depressive symptoms	8-17	Child / youth	Self-administered	27	-----	-----	Yes	-----	26		Measuring depression may not be as important in children/ youth as in adults
CES-D (Center for Epidemiological Studies Depression Scale)	Measure current depressive symptoms	Youth	Youth	Self-administered	20	-----	Yes	Yes	-----	9		Measuring depression may not be as important in children/ youth as in adults

**\*\*PTSD**

Title	Purpose	Age Range (yrs)	Parent or child response	Administration mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Used In child / youth TBI studies?	Ref.	Strengths	Weaknesses
CAPS-CA (Clinician Administered PTSD Scale, Child/ Adolescent version)	Measure PTSD-related symptoms	7-18	Child/ youth	Structured interview	33	30-120	-----	-----	Yes	5	Can assess impact of symptoms on functioning; extremely detailed and thorough	Requires a longer time period than other assessments; requires administration by a trained professional
CPTS-RI (Child Posttraumatic Stress Reaction Index)	Measure PTSD-related symptoms	6-17	Child/ youth Parent	Semi-structured interview	20	20-45	Yes	Yes	Yes	5, 28	Relatively brief and easy to administer	Does not inquire about all DSM-IV symptoms; parent version not yet validated
TESI (Traumatic Events Screening Inventory)	Assess trauma history	4-18	Child/ youth Parent	Semi-structured interview Interview or self-administered	15 19	10-30 10-30	Yes	Yes	Yes	5		Requires administration by a trained professional

--- Information was not found.

\* Measure was discussed during the meeting.

\*\* General topic was discussed during the meeting.

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## Appendix B

### Traumatic Brain Injury in Children and Youth as a Public Health Problem: An Overview

Presented by Dr. David Thurman, CDC

This section features copies of the slides from Dr. David Thurman's presentation. The surveillance data (beginning with Slide 2) are from selected states for the information available at the time of the meeting; therefore, the data should be considered preliminary.

#### Slide 1 - Estimated Impact of TBI on Children Aged 0-14 Years in the United States

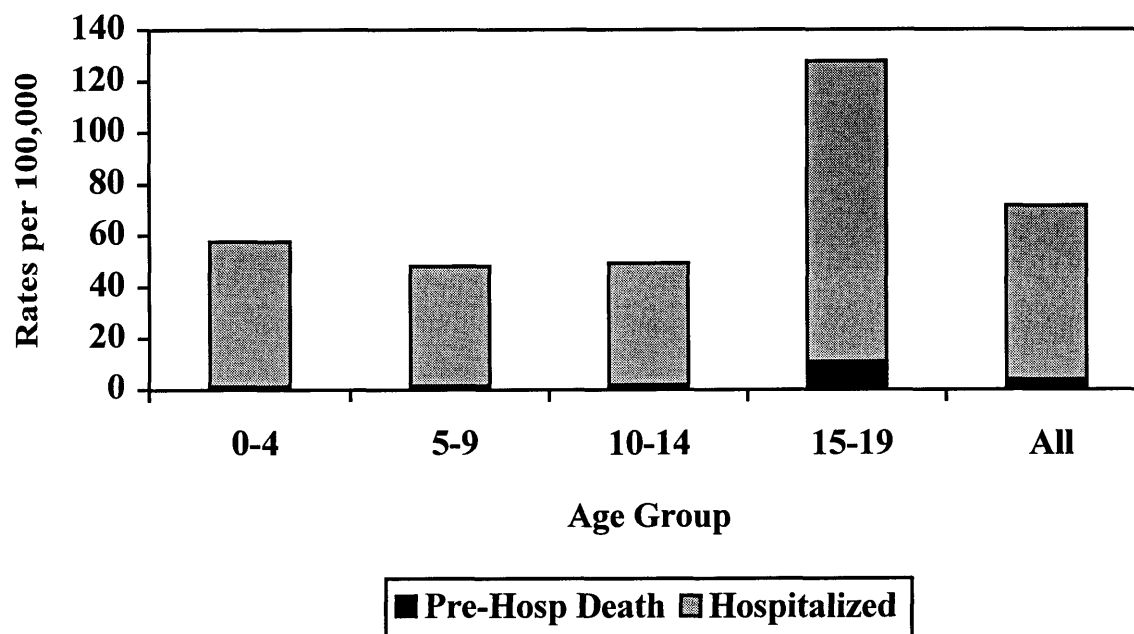
- 3,000 deaths (NCHS, 1994)
  - 29,000 hospitalizations
  - 400,000 ED visits (NHAMCS, 1996)
  - Unknown number with long-term disability
- 

#### Slide 2 - Preliminary Surveillance Findings for TBI-Related Hospitalizations & Deaths –1997

##### TBI Surveillance--Background

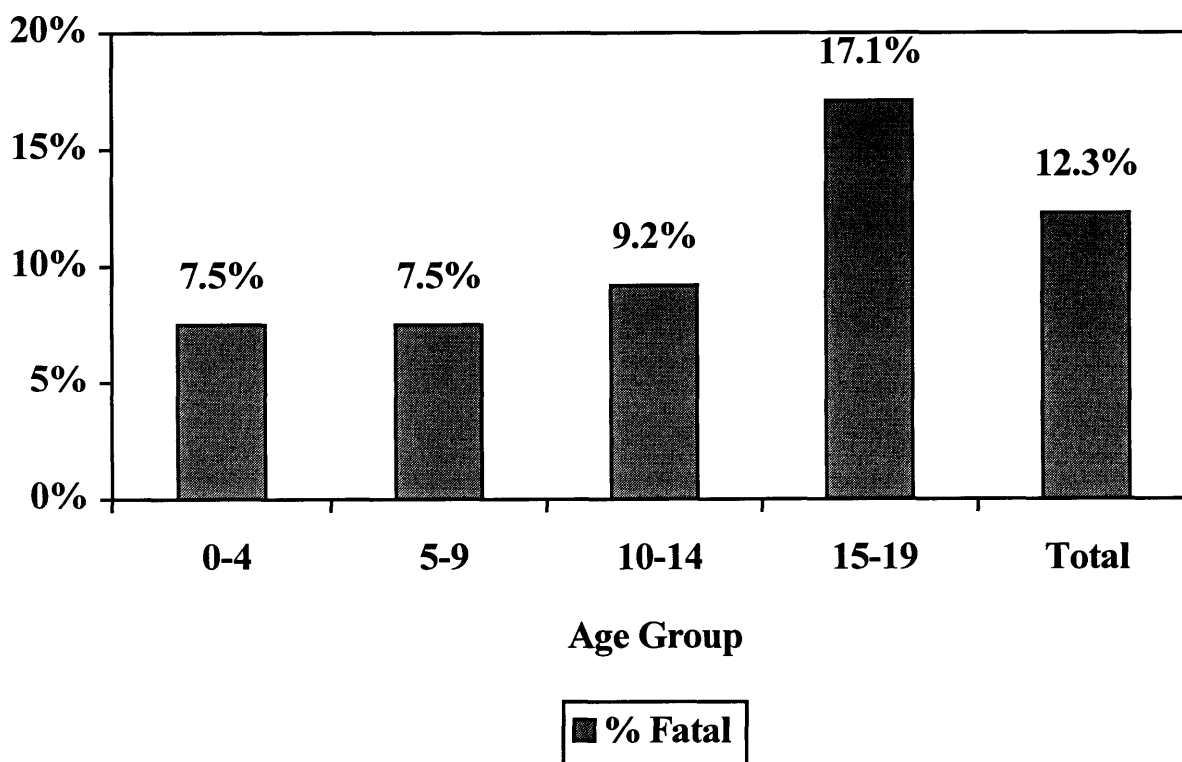
- CDC collects data on TBI-related injuries from 15 states.
- *Clinical case definition:* Injury to the head associated with decreased consciousness, amnesia, neurologic abnormalities, skull fracture, intracranial lesion or death.
- *Data case definition:* ICD-9 codes 800-801, 803-804, 850-854 and (for fatalities only) 873.
- *Data sources:* Vital records, hospital discharge data and medical records (for a sample of cases).
- *Data elements:* Demographic, nature of injury (ICD-9 N-codes), cause of injury (ICD-9 E-codes), severity, and outcome.
- *For this presentation, unless otherwise noted, data are from Minnesota, Missouri, South Carolina and Utah*

Slide 3 - Figure 1: Rates of TBI in Children and Youth by Age Group &amp; Care Level, 1997



TBI death and hospitalization rates were highest among those aged 15-19 year

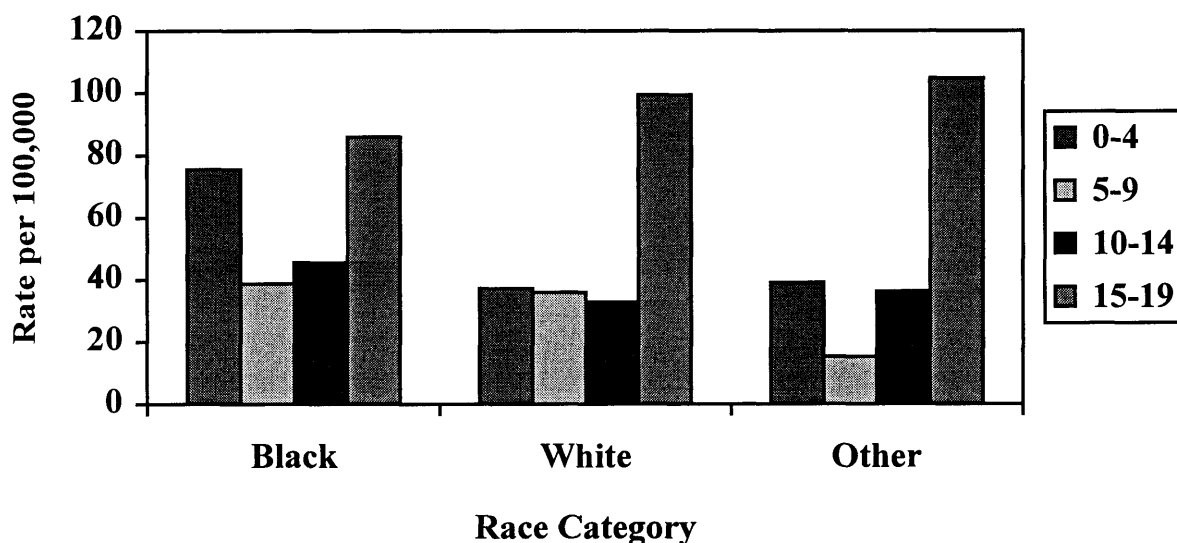
Slide 4 - Figure 2: TBI in Children and Youth: Percent with Fatal Outcomes, 1997



The percent of TBIs that were fatal increased with age.



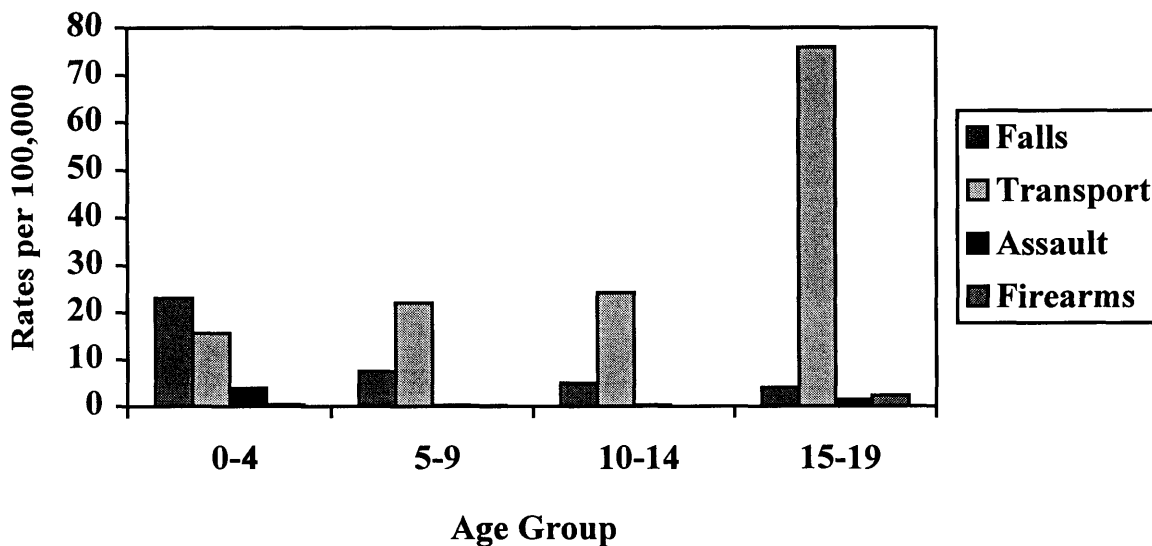
Slide 5 - Figure 3: TBI Rates in Children and Youth by Age and Race, 1997



*(Approximately 28% of cases were of unknown race)*

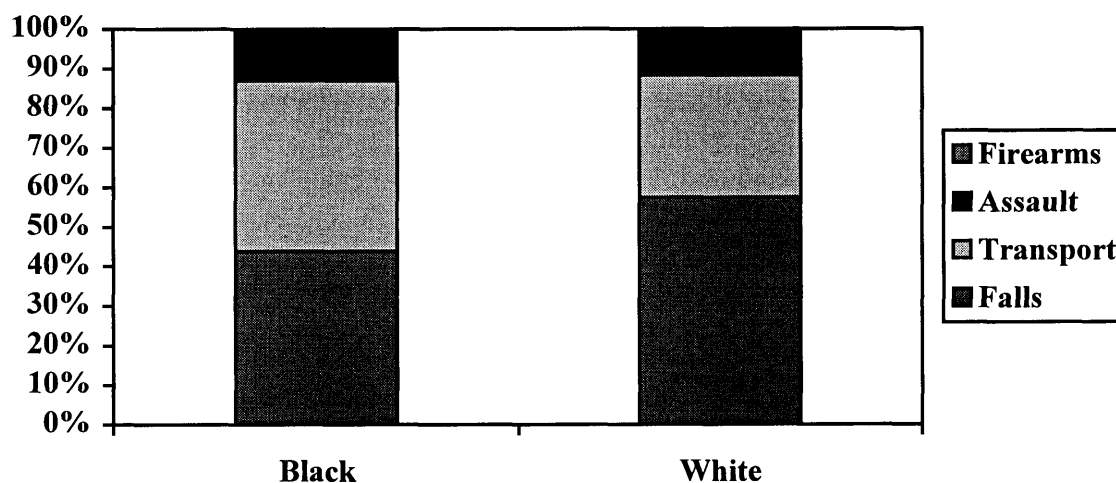
- For all categories of race, the highest TBI rates were among youth, aged 15-19 years followed by children aged 0-4 years.
- The TBI rate in black children aged 0-4 years was approximately twice as high as for the same-aged white or other race children.

Slide 6 - Figure 4: Rates of TBI in Children and Youth by Age Group and External Cause of Injury, 1997



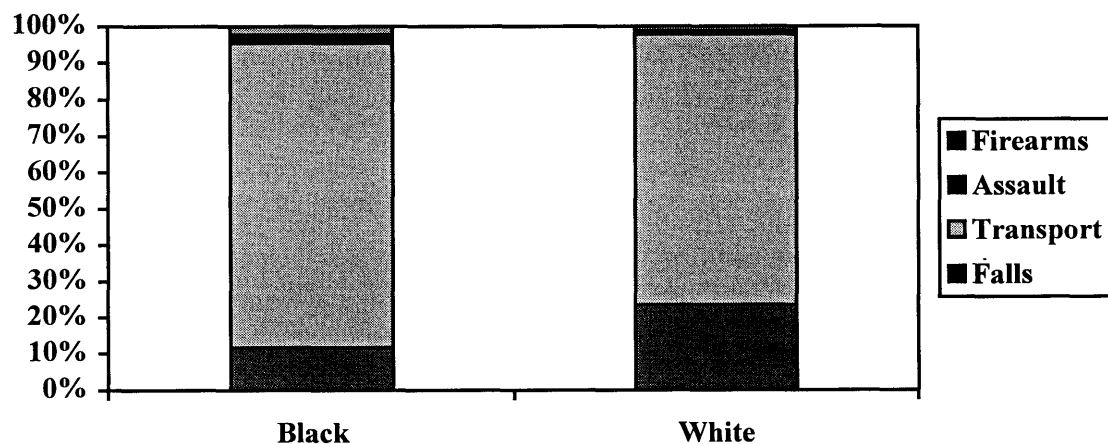
- The rate of TBI from falls decreased with increasing age.
- The rate of TBI from transportation incidents was more than three times as high for youth aged 15-19 years as for children in the younger age groups.
- The rate of TBI from firearm-related injuries was highest among 15-19 year-olds.
- The rate of TBI from non-firearm assaults was highest among 0-4 year-olds.

Slide 7 - Figure 5: TBI in Children Aged 0-4 Years: Proportion by Cause & Race, 1997



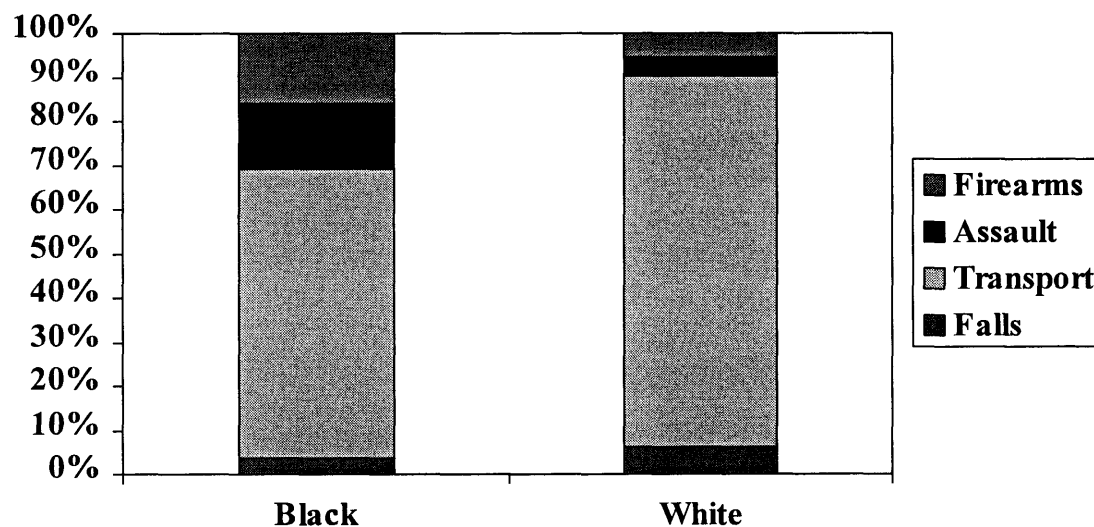
For children aged 0-4 years, falls were the leading cause of TBI, followed by transportation and assaults; however, transportation-related TBIs accounted for a greater proportion among black children than among whites.

Slide 8 - Figure 6: TBI in Children Aged 5-14 Years: Proportion by Cause & Race, 1997



Transportation incidents were the cause of a majority of TBIs in 5-14 year-olds.

Slide 9 - Figure 7: TBI in Youth Aged 15-19 Years: Proportion by Cause and Race, 1997



Transportation was the leading cause of TBIs, but compared to those aged 5-14 years, a greater proportion were due to assaults and firearm-related injuries, particularly among blacks.

## Appendix C

### TBI in Children and Youth

### Data from the South Carolina Surveillance System

Presented by Dr. Anbesaw Selassie, Medical University of South Carolina

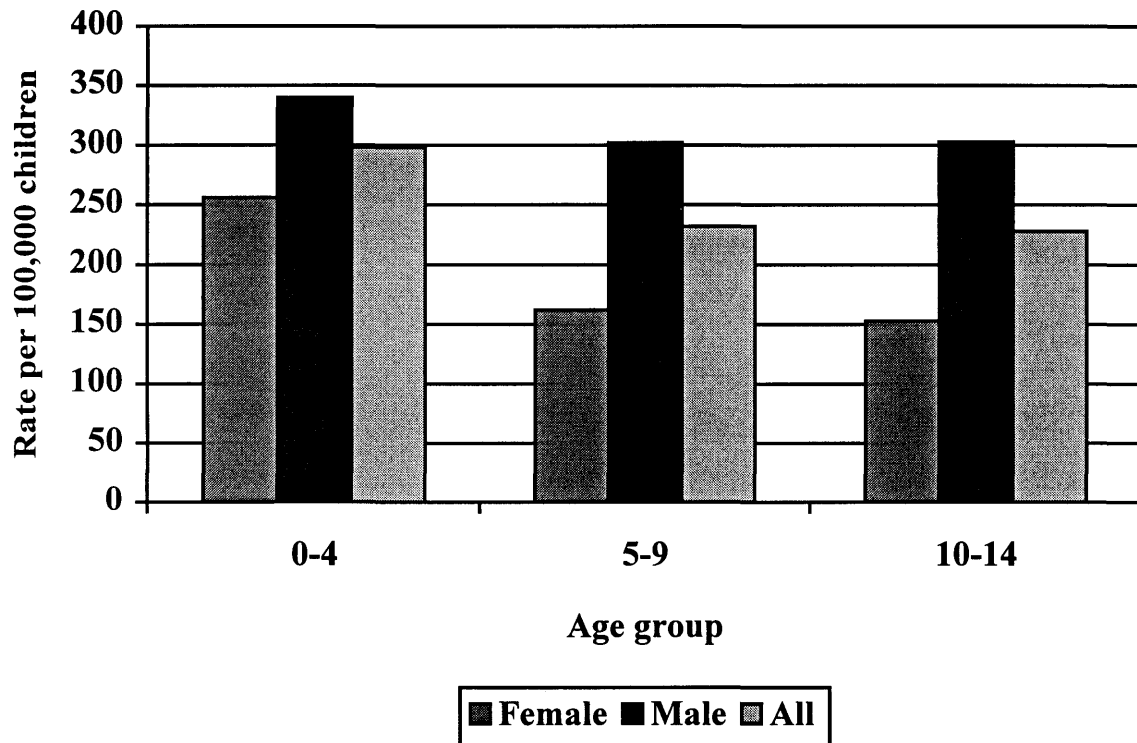
The following are copies of the lecture slides from Dr. Anbesaw Selassie's presentation:

#### Slide 1 - Table 1: Distribution of TBI in Children Treated and Released from Emergency Departments—South Carolina, 1996-1999

Age Group (yrs)	Female		Male		All	
	Number	Percent (%)	Number	Percent (%)	Number	Percent(%)
0-4	1008	42	1395	58	2403	40
5-9	623	34	1192	66	1815	31
10-14	564	33	1168	67	1732	29
All	2195	37	3755	63	5950	100

- Males 0 to 4 years of age had the greatest number of TBI-related ED visits.
- Among 0 to 14 year-olds, the total number of TBI ED visits (5,950) was more than 4 times the number of TBI-related hospital discharges (1,451--see Table 2).

Slide 2 - Figure 1: Annual Rate of TBI in Children Treated and Released from Emergency Departments - South Carolina, 1996-1999



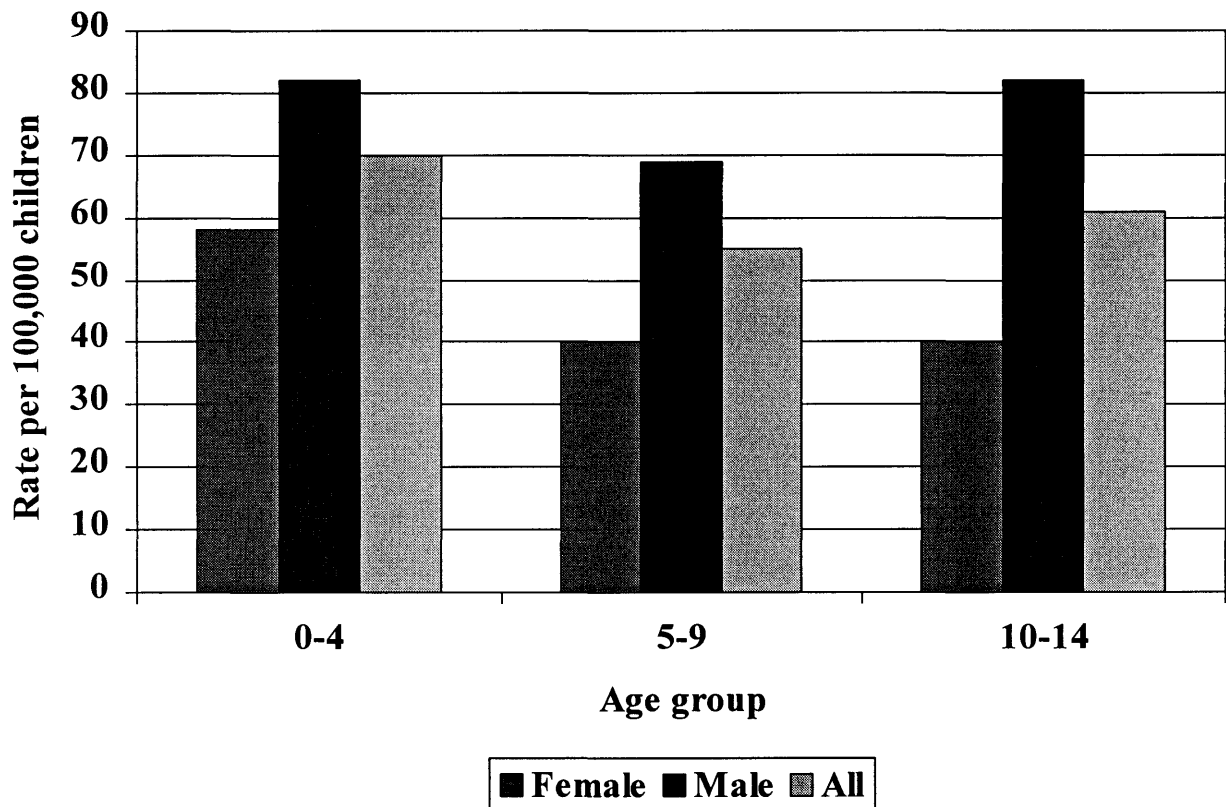
- The annual rate of TBI-related ED visits was greatest among children aged 0-4 years (298 visits per 100,000).
- The rate of TBI-related ED visits was similar for children aged 5-9 years and 10-14 years (232 and 228 per 100,000, respectively).
- For all age groups, males had higher rates of TBI-related ED visits, and the difference increased with age.

Slide 3 - Table 2: Distribution of TBI in Children Discharged from Acute Care Facilities—South Carolina, 1996-1999

Age Group (yrs)	Female		Male		All	
	Number	Percent (%)	Number	Percent (%)	Number	Percent(%)
0-4	230	41	336	59	566	39
5-9	152	36	271	64	423	29
10-14	146	32	316	68	462	32
All	528	36	923	64	1451	100

As for ED visits, the greatest number of TBI-related hospital discharges occurred in males aged 0 to 4 years.

Slide 4 - Figure 2: Annual Rate of TBI in Children Discharged from Acute Care Facilities - South Carolina, 1996-1999



- The highest rate of hospitalization was for children aged 0-4 years (70 per 100,000), followed by 10 to 14 year-olds (61 per 100,000), and 5 to 9 year-olds (55 per 100,000).
- The rate of hospitalization for males was greater than for females at all ages.

Slide 5 - Table 3: Type of TBI in Children Treated and Released from EDs - South Carolina, 1996-1999

ICD-9-CM BASED TYPE OF BRAIN INJURY	0-4		5-9		10-14		All	
	N	%	N	%	N	%	N	%
CLOSED CEREB CONTUSION	3	19	5	31	8	50	16	0
CLOSED CEREB LACER& UNSPEC HEM	62	51	30	25	30	25	122	2
CLOSED UNSPEC IC TBI	1631	47	1053	30	795	23	3479	58
CONCUSSION	436	24	605	33	774	43	1815	31
DURA-ARACH HEMORRHAGE	40	43	23	24	31	33	94	2
FRACTURE SKULL, BASE	39	41	21	22	34	36	94	2
FRACTURE SKULL, VAULT	90	70	21	16	17	13	128	2
MULT SKULL&FACE FRACTURE	2	33	1	17	3	50	6	0
PENETRATING TBI	18	32	21	37	18	32	57	1
UNQUAL SKULL FRACTURE	82	59	35	25	22	16	139	2
All	2403	40	1815	31	1732	29	5950	100

- Concussions were the second most frequent diagnosis for TBI-related ED visits after unspecified closed head injuries.
- Skull fractures were more common among children aged 0 to 4 years compared to other age groups.



Slide 6 - Table 4: Type of TBI in Children Discharged from Acute Care Facilities - South Carolina, 1996-1999

ICD-9-CM BASED TYPE OF BRAIN INJURY	0-4		5-9		10-14		All	
	N	%	N	%	N	%	N	%
CLOSED CEREB CONTUSION	10	26	15	39	13	34	38	3
CLOSED CEREB LACER& UNSPEC HEM	56	29	60	31	76	40	192	13
<i>CLOSED UNSPEC IC TBI</i>	<i>102</i>	<i>33</i>	<i>97</i>	<i>31</i>	<i>109</i>	<i>35</i>	<i>308</i>	<i>21</i>
CONCUSSION	76	28	98	36	97	36	271	19
<i>DURA-ARACH HEMORRHAGE</i>	<i>127</i>	<i>49</i>	<i>52</i>	<i>20</i>	<i>80</i>	<i>31</i>	<i>259</i>	<i>18</i>
FRACTURE SKULL, BASE	59	41	43	30	43	30	145	10
FRACTURE SKULL, VAULT	96	77	16	13	13	10	125	9
PENETRATING TBI	19	25	34	45	23	30	76	5
UNQUAL SKULL FRACTURE	21	57	8	22	8	22	37	3
All	566	38	423	29	462	32	1451	100

- Intracranial hemorrhages were the third most common TBI-related discharge diagnosis after unspecified closed head injuries and concussions.
- Although less common than for ED visits, concussions accounted for nearly 1 in 5 TBI-related hospitalizations.

**Slide 7 - Table 5: Distribution of Predicted † Disablement from TBI in Children Treated and Released from ED Facilities - South Carolina, 1996-1999**

Age (Yrs)	Probable		Possible		Unlikely		All	
	Num.	%	Num.	%	Num.	%	Num.	%
0-4	55	2	126	5	2222	92	2403	40
5-9	30	2	82	5	1703	94	1815	31
10-14	46	3	107	6	1579	91	1732	29
All	131	2	315	5	5504	93	5950	100

† Prediction based on an algorithm that incorporated severity, disposition, and type of injury. ROC curve C-Statistic expressing "Association of Predicted Probabilities and Observed Responses" is 0.86 for probable and 0.68 for possible disablement categories.

- These figures represent conservative estimates.
- For additional information, contact Dr. Anbesaw Selassie (please refer to the list of participants).

**Slide 8 - Table 6: Distribution of Predicted † Disablement from TBI in Children Discharged from Acute Care Facilities - South Carolina, 1996-1999**

Age (Yrs)	Probable		Possible		Unlikely		All	
	Num.	%	Num.	%	Num.	%	Num.	%
0-4	50	9	250	44	266	47	566	40
5-9	20	5	203	48	200	47	423	29
10-14	52	12	223	48	187	40	462	29
All	122	8	676	47	1451	45	1451	100

† Prediction based on an algorithm that incorporated severity, disposition, and type of injury. ROC curve C-Statistic expressing "Association of Predicted Probabilities and Observed Responses@ is 0.86 for probable and 0.68 for possible disablement categories.

- These figures represent conservative estimates.
- For additional information, contact Dr. Anbesaw Selassie (please refer to the list of participants).

# Appendix D

## Other Resources

In addition to this report, the following resources can help researchers select topics for research studies of TBI outcomes in young people.

### **HRSA/MCHB Principles for Meeting the Needs of the Child** **Bright Futures Children's Health Charter**

Throughout this century, principles developed by advocates for children have been the foundation for initiatives to improve children's lives. Bright Futures participants have adopted these principles to guide their work and meet the unique needs of children and families into the 21<sup>st</sup> century.

- Every child deserves to be born well, to be physically fit and to achieve self-responsibility for good health habits.
- Every child and adolescent deserves ready access to coordinated and comprehensive preventive, health-promoting, therapeutic, and rehabilitative medical, mental health and dental care. Such care is best provided through a continuing relationship with a primary health professional or team and ready access to secondary and tertiary levels of care.
- Every child and adolescent deserves a nurturing family and supportive relationships with other significant persons who provide security, positive role models, warmth, love and unconditional acceptance.
- A child's health begins with the health of his parents.
- Every child and adolescent deserves to grow and develop in a physically and psychologically safe home and school environment free of undue risk of injury, abuse, violence or exposure to environmental toxins.
- Every child and adolescent deserves satisfactory housing, good nutrition, a quality education, an adequate family income, a supportive social network and access to community resources.
- Every child deserves quality childcare when her parents are working outside the home.
- Every child and adolescent deserves the opportunity to develop ways to cope with stressful life experiences.

- Every child and adolescent deserves the opportunity to be prepared for parenthood.
- Every child and adolescent deserves the opportunity to develop positive values and become a responsible citizen in his community.
- Every child and adolescent deserves to experience joy, have high self-esteem, have friends, acquire a sense of efficacy and believe that she can succeed in life. She should help the next generation develop the motivation and habits necessary for similar achievement.

Reference: [www.brightfutures.org](http://www.brightfutures.org)

Bright Futures is sponsored by MCHB, HRSA and, in part, supported by unrestricted educational grants from Pfizer Pediatric Health. Bright Futures material is produced by NCEMCH and is not copyrighted.

## **Selected Articles from the United Nations Convention on the Rights of the Child**

### **Article 2**

1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parents' or legal guardians' race, color, sex, language; religion, political or other opinion; national, ethnic or social origin; property, disability, birth or other status.

### **Article 6**

2. States Parties shall ensure to the maximum extent possible the survival and development of the child.

### **Article 23**

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible

social integration and individual development, including his or her cultural and spiritual development

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

#### **Article 24**

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

#### **Article 28**

1. States Parties recognize the right of the child to education and, with a view to achieving this right progressively and on the basis of equal opportunity, they shall, in particular:

- (a) Make primary education compulsory and available free to all;
- (b) Encourage the development of different forms of secondary education, including general and vocational education, make them available and accessible to every child and take appropriate measures such as the introduction of free education and offering financial assistance in case of need;
- (c) Make higher education accessible to all on the basis of capacity by every appropriate means;
- (d) Make educational and vocational information and guidance available and accessible to all children;
- (e) Take measures to encourage regular attendance at schools and the reduction of drop out rates.

#### **Article 29**

1. States Parties agree that the education of the child shall be directed to:

- (a) The development of the child's personality, talents and mental and physical abilities to their fullest potential;

#### **Article 31**

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.

2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

Reference: [www.unicef.org/crc/crc.htm](http://www.unicef.org/crc/crc.htm) Accessed January 24, 2001

## **Selected Healthy People 2010 Goals and Objectives**

### **Goal 1: Increase quality and years of healthy life.**

#### **Access to Medical Care**

**Objective 1-6:** Reduce the proportion of families that experience difficulties or delays in obtaining health care or do not receive needed care for one or more family members.

**Objective 1-15:** Increase the proportion of persons with long-term care needs who have access to the continuum of long-term care services.

#### **Disability and Secondary Conditions**

**Objective 6-1:** Include in the core of all relevant Healthy People 2010 surveillance instruments a standardized set of questions that identify “people with disabilities.”

**Objective 6-2:** Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy or depressed.

**Objective 6-4:** Increase the proportion of adults with disabilities who participate in social activities.

**Objective 6-5:** Increase the proportion of adults with disabilities reporting sufficient emotional support.

**Objective 6-6:** Increase the proportion of adults with disabilities reporting satisfaction with life.

**Objective 6-7:** Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles.

Target: For persons 21 years and younger—total elimination.

**Objective 6-9:** Increase the proportion of children and youth with disabilities who spend at least 80% of their time in regular education programs.

**Objective 6-10:** Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.

**Objective 6-11:** Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.

**Objective 6-12:** Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.

**Objective 6-13:** Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

**Maternal, Infant and Child Health**

**Objective 16-22:** Increase the proportion of children with special health care needs who have access to a medical home [for the provision and coordination of care].

**Objective 16-23:** Increase the proportion of Territories and States that have service systems for children with special health care needs.

**Mental Health and Mental Disorders**

**Objective 18-7:** Increase the proportion of children with mental health problems who receive treatment.

**Public Health Infrastructure**

**Objective 23-2:** Increase the proportion of Federal, Tribal, State and Local health agencies that have made information available to the public in the past year on the Leading Health Indicators, Health Status Indicators, and Priority Data Needs.

**Objective 23-5:** Increase the proportion of Leading Health Indicators, Health Status Indicators, and Priority data Needs for which data—especially for select populations—are available at the Tribal, State, and Local levels.

Reference: <http://www.health.gov/healthypeople/Document>. Accessed January 25, 200; or U.S. Department of Health and Human Services. Healthy People 2010. 2<sup>nd</sup> ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.



## Appendix E

### Overview of Traumatic Brain Injury Surveillance Activities Funded By The Centers for Disease Control and Prevention

#### I. Basic Surveillance: Defining the Magnitude of the Problem, Identifying Causes and High Risk Groups

In 1995, CDC funded TBI surveillance efforts in 4 states and developed *Guidelines for Surveillance of Central Nervous System Injury*.<sup>3</sup> These surveillance efforts expanded with the implementation of Public Law 104-166, the Traumatic Brain Injury Act of 1996. Under the TBI Act, the CDC has developed a uniform reporting system to answer questions about the incidence and causes of TBI deaths and hospitalizations. The surveillance program currently supports data collection in the following 15 states:

Alaska	California	Maryland	Nebraska	Rhode Island
Arizona	Colorado	Minnesota	New York	South Carolina
Arkansas	Louisiana	Missouri	Oklahoma	Utah

#### II. Outcomes Surveillance: The Colorado and South Carolina Traumatic Brain Injury Follow-up Systems

In 1995, CDC funded a follow-up study in Colorado to describe TBI-related disability, use of services, and other outcomes. A similar project was begun in South Carolina in 1998 including people with TBI aged 15 years or older. These projects:

1. Each year, select a representative sample of people identified by surveillance who have been hospitalized and survived with a TBI
2. Locate each person in the sample within one year of their injury
3. Contact them and obtain consent to do a telephone interview
4. Interview each person about a wide range of outcomes and service needs (approximately 40 minutes); proxies are interviewed if the person is unable to participate themselves
5. Track each person and interview them again at 2 and 3 years post-injury
6. Analyze and report the results

#### Project Strengths

- *Population-based* findings with the potential to generalize results to all people aged 16 years or older who have been hospitalized with a TBI
- Wide range of outcomes assessed using both standardized and nonstandardized measures
- Focus on “macro” outcomes relevant to policy-makers
- Potential to build a case for the needs of people with TBI
- The addition of a comparison group to the SC study to better delineate the impact of TBI

**Project Limitations**

- Outcomes are assessed in limited detail.
- Self-report may not be valid among people with decreased awareness of problems.
- Loss to follow-up is high (approx. 35% at one year, 10-15% at years 2 and 3).
- Do not include people with less severe TBI seen in the ED or not receiving medical care.
- Do not include children and adolescents.

**III. Future Directions: Adding Children and Adolescents to the TBI Outcomes Surveillance Projects**

Obtaining population-based TBI outcomes data for children and youth is a high priority for the Advisory Committee of the National Center for Injury Prevention and Control, the Brain Injury Association and a wide range of experts and professionals who participated in the CDC-sponsored TBI in Public Health Meeting in April 1999. The TBI Act Reauthorization of 2000 also highlights it as a priority activity.