Children & Youth with TBI: Federal & State Resources

--- National Association of State Head Injury Administrators ---

Overview
According to the Centers for Disease Control and Prevention (CDC) each year a traumatic brain injury (TBI) among children and youth aged 0 to 14 years results in an estimated:
- 3,000 deaths
- 29,000 hospitalizations
- 400,000 emergency department

The two age groups at highest risk for TBI are 0 to 4 year olds and 15 to 19 year olds. Falls are a leading cause of TBI in young children, while motor vehicle crashes are a major cause of TBI in youth and young adults. Most injuries occur as the result of motor vehicle crashes -- pedestrian, bicyclist, or passenger. Other causes include sports-related injuries, and physical abuse including Shaken Baby Syndrome.

CDC defines traumatic brain injury (TBI) as “a blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. Not all blows or jolts to the head result in a TBI. The severity of a TBI may range from “mild,” i.e., a brief change in mental status or consciousness to “severe,” i.e., an extended period of unconsciousness or amnesia after the injury.”

Resulting Problems
The severity of injury, location of injury and other factors will determine resulting problems that may affect learning, behavior, personality, mood, sensory, physical functioning, including fatigue, headaches and mobility problems. These problems will affect academic performance, such as learning and remembering new things, initiating and carrying out tasks, and integrating new and old learning.

Children and youth with TBI are often left with long-lasting and significant problems that impact their ability to learn and to perform in the school environment, post-high school education or vocational training, and later in the workplace and community.

Needs
Children and youth may need differing services and supports at varying points after injury. They may need specialized rehabilitation, therapies, accommodations and supportive services to meet their cognitive, behavioral and emotional needs. Families may need information, support, respite and assistance with care giving.

This assistance may be provided by multiple health care providers, education, disability and social services or human services agencies. Communication and coordination of services among these agencies are key to ensure that services and assistance are provided seamlessly and effortlessly.

Federal Programs
There is an array of federal programs that provide funding for services or, with modifications or training, could be providing appropriate services to children and youth with TBI. This may also require changes in program eligibility requirements and a desire to serve these children and youth.

In some states, the lead TBI agency and advisory board are working to increase services and supports, including coordinating resources from hospital to home, school and community.
Education

IDEA
The Education of All Handicapped Children Act of 1975 (P.L. 94-142) is the hallmark legislation that required Free and Appropriate Public Education for all children with disabilities to be provided in the least restrictive environment. The 1990 reauthorization changed the title to the Individuals with Disabilities Education Act (IDEA) and added traumatic brain injury to the list of Federal disability categories for reporting purposes. IDEA provides early intervention, special education and related services to infants, toddlers, children and youth with disabilities.

Early Intervention Services
The Program for Infants and Toddlers with Disabilities (Part C of IDEA) assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities from birth through age 2 years. In most states the lead agency is the health department. Other states have designated the education, rehabilitation, human or social services agency as the lead agency.

Parents Act
IDEA authorizes Parent Centers in each state to provide training and information to parents of infants, toddlers, children and youth with disabilities and to professionals who work with them. The Parent Centers work to improve outcomes for children ages birth-26 years with all disabilities -- emotional, learning, cognitive and physical.

Transition Services
IDEA requires transition services, beginning at age 14, to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living or community participation.

Rehabilitation Act
The Rehabilitation Act Amendments of 1992 also included transition services as defined by IDEA and more clearly identifies the responsibilities of the vocational rehabilitation (VR) system to special education students to facilitate the transition of students with disabilities from the special education system to the VR system.

Section 504
Section 504 of the Rehabilitation Act prohibits schools from discriminating against a student with a disability, if the school is receiving federal funding. Section 504 requires school districts to refer a student for an evaluation for special education or modifications or accommodations for regular education, if the student, because of the disability, needs such services.

No Child Left Behind Act
The No Child Left Behind (NCLB) Act contains provisions to help students with disabilities to achieve and close the gap with their peers. One provision requires assessments to be adapted and accommodations made for students with disabilities as defined in IDEA.

Health Related Services

Medicaid
Medicaid is a federal-state matching entitlement program designed to help fund health and medical services for low-income individuals, including children and parents, the elderly and people with disabilities. Mandatory services that states must provide include inpatient and outpatient hospital services, physician and Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services for children under age 21.

Optional services include a broad range of disability-related services, such as prescription drugs, case management, rehabilitation, personal care services and home and community-based waiver services. Medicaid Waivers offer services and benefits that are above and beyond the Medicaid state plan of services to people with certain health conditions. States generally administer several Medicaid waivers for different populations.
Katie Beckett Waiver
The Katie Beckett Waiver, also known as the Deeming Waiver or the 2176 Model Waiver, enables severely disabled children from birth to eighteen years of age with a chronic disability to be cared for at home and be eligible for Medicaid based on the individual’s income and assets alone. Depending on the state’s waiver Medicaid will pay for physician, hospital, therapy, prescriptions, respite care, diapers, vision and dental care, and in some states, the waiver entitles children to a life-time of unlimited therapy.

School-Based Medicaid
The Medicaid program provides support for Medicaid eligible children who are also eligible for special education services with specific healthcare needs that affect their educational performance as identified in their Individualized Education Program (IEP). These services must be covered in the state Medicaid plan and listed in the child’s IEP. Services include therapies, transportation, social work and medical equipment.

SCHIP
The State Children’s Health Insurance Program (SCHIP) provides health coverage for uninsured children in families whose incomes are too high to qualify for Medicaid, but too low to afford private insurance. States are given flexibility in designing their SCHIP eligibility requirements and policies within broad federal guidelines.

Medicaid Buy-In
As part of the Deficit Reduction Act of 2005, Congress included the Family Opportunity Act (FOA), to enable families with a child with a disability, and whose income is above the Medicaid eligibility level, to be able to buy-in to Medicaid. This coverage may be the person’s only health care coverage or a supplement to private insurance.

Maternal and Child Health Services
The Maternal and Child Health (MCH) Services Block Grant (Title V of the Social Security Act), provides funding to states for a wide range of maternal and child health programs, including injury prevention, to improve the health of all mothers, children, and their families.

Children with Special Health Care Needs
The Children with Special Health Care Needs Program provides funding through the MCH Title V Block Grant to states to provide services to children with extraordinary medical needs, disabilities and chronic health conditions. Services include diagnosis and routine treatment and monitoring; life-sustaining technology, treatment and medicines.

Family Voices
Family Voices is a national network of families with children and youth with special health care needs and/or disabilities. Families are provided tools to make informed decisions, advocate for improved public and private policies and build partnerships among professionals and families.

Emergency Medical Services for Children
The Emergency Medical Services for Children (EMSC) program was created in recognition that children have special needs when they are critically ill or injured. The program provides training and education in pediatric emergency health care, and influences the development of pediatric emergency equipment and standards.

Rehabilitation and Supports

HRSA Federal TBI Program
The TBI Act of 2006, as amended in 2008, authorizes funding to the US Health Resources and Services Administration (HRSA) to assist states in developing, expanding and improving service delivery for individuals with TBI of all ages. The program is administered by HRSA, which awards grants on a competitive basis to states to help address identified gaps in services in their states.

States use grants to conduct needs and resource assessments, develop state action plans and to expand services to unserved or underserved individuals with TBI of all ages.
Legal Advocacy

The Developmental Disabilities Act
The Developmental Disabilities & Bill of Rights Act of 1975 created Protection & Advocacy (P&A) agencies to pursue legal, administrative, and other appropriate remedies under all applicable federal and state laws to protect and advocate for the rights of individuals with developmental disabilities.

TBI Act
The TBI Act 2000 Amendments included authorization for funding to HRSA for state Protection & Advocacy Systems to provide legal and other advocacy services for individuals with TBI of all ages.

Registry and Surveillance
The TBI Act of 1996, as amended, authorized funding to CDC to conduct data collection and follow-up studies in states to determine incidence and prevalence, to link people with TBI to information and to prevent TBI-related disabilities.

In 2000, CDC convened a working group on the assessment of TBI outcomes in children and youth, and then published a report of their findings. CDC funded Johns Hopkins University to conduct a three-year evaluation of methods used to measure physical and psychosocial health outcomes of children with TBI.

State Programs and Initiatives
Education
A number of states have developed training for educators, including pre-service training and in-service training. The Kansas State Department of Education implemented the TBI Project in 1987, which has served as a model for many states, including Oregon, Nebraska, Hawaii, Tennessee, Iowa and Pennsylvania. In addition to training educators, these states have implemented resource teams to assist school districts. For the most part these states have used education funds to support these services, with Oregon expanding its program with a HRSA Federal TBI grant.

The Pennsylvania Brain STEPS school-reentry program was started with MCH Title V funds administered by the state health department in partnership with the Department of Education. Other states have also developed resources, including the Minnesota Department of Education which developed teacher competencies for TBI for special education teachers in addition to a guide and fact sheets.

Care Coordination
The Alabama Department of Rehabilitation, Children's Rehabilitation Services developed PASSAGES to assist children and youth with TBI and their families in the transition from the hospital to the home and then to the community. Care coordination is central to the program. The program was developed with a HRSA Federal TBI grant.

Family and Community Supports
State Developmental Disabilities programs serve individuals with developmental disabilities. In some states children and youth with TBI are eligible for these services, which include personal assistance, habilitation and training, adaptive equipment, home modifications, respite care and service coordination.

National Association of State Head Injury Administrators
4330 East West Highway, Suite 301
Bethesda, MD 20814
301-656-3500 (Phone)
301-656-3530 (Fax)
nashia@nashia.org

Kenneth H. Currier, Executive Director
Prepared by Susan L. Vaughn, Director of Public Policy

NASHIA assists state government in promoting partnerships and building systems to meet the needs of individuals with brain injuries and their families.