

Attachment 11: Statewide Action Plan for Utah's with Traumatic Brain Injury and Their Families

Introduction

The Utah State Action Plan for Traumatic Brain Injury is a dynamic document and reflects the on-going efforts of the Utah Traumatic Brain Injury Grant, years 2003-2013. The Action Plan is a collaborative effort with the Utah Department of Health, Utah Brain Injury Council, the State of Utah: Department of Human Services-Division of Services for People with Disabilities, Utah State University, the Brain Injury Association of Utah. Funding for the development of this Plan is supported in part by the Health Resources and Services Administration, Maternal and Child Health Bureau (HRSA-MCH) grant number H21MC07896. Matching funds for the Plan have been generously contributed by several state agencies, including; Department of Health, Division of Aging and Adult Services, Juvenile Justice Services, Utah State office of Rehabilitation, Bureau of Children with Special Health Care Needs, Division of Child and Family Services, and the Division of Services for People with Disabilities.

The Plan has been developed to ensure a system that is culturally competent, comprehensive, community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of Traumatic brain injury services and addresses the needs of individuals with TBI as well as family members. Traumatic brain injury (TBI) has numerous definitions. For the purposes of this document the following definition will help to define the target population.

Traumatic Brain Injury is the result of an external force causing damage to the brain caused by an impact, internal damage, or loss of oxygen. Depending on the amount of damage to the brain, symptoms of Traumatic Brain Injury are classified as mild, moderate or severe. Although not always visible, Traumatic Brain Injury may cause enduring physical, emotional, intellectual, and social changes for the survivor.

Traumatic brain injury, often referred to as TBI, is a complex injury with a broad spectrum of symptoms and disabilities. It is most often an acute event similar to other injuries but, that is where the similarity between traumatic brain injury and other injuries ends. A brain injury is different from a broken leg. A person's mobility is limited by the broken leg, but their personality and mental abilities remain unchanged. Broken bones and other physical injuries usually heal and regain full function. Brain injuries do not heal like other injuries. Recovery is a functional recovery, based on mechanisms that remain uncertain. No two brain injuries are alike and the consequence of two similar injuries may be very different. Symptoms may appear right away or may not be present for days or weeks after the injury. One of the consequences of brain injury is that the person often does not realize that a brain injury has occurred. A brain injury can affect all aspects of life.

The Centers for Disease Control and Prevention (www.biausa.org) estimates that at least 5.3 million Americans currently have a long-term or lifelong need for help to perform activities of daily living as a result of a TBI.

- Approximately 1.4 million people sustain a TBI each year in the United States.
- An estimated 5.3 million Americans currently live with disabilities resulting from a traumatic brain injury.
- Of the 1.4 million people that sustain a TBI, 50,000 die, 235,000 are hospitalized, and 1.1 million are treated and released from an emergency department.
- An estimated 62.3 per 100,000 adults age 15 and over are living in the community with enduring functional impairments due to TBI.
- The leading causes of TBI are; falls, 28%; motor vehicle accidents, 20%; colliding with moving or stationary object/sports, 19%; and assaults, 11%.
- Blasts are a leading cause of TBI for active duty military personnel in war zones.

Traumatic Brain Injury in the State of Utah

The number of Utah residents with documented TBI increases every year. The reported rate is significantly low due to misdiagnosis, non-reporting, and accident victims who do not seek medical attention. In 2006, 2,505 Utahns suffered TBIs.

- Of those 1,638 were males and 867 were females
- A rate of 9.6 per 10,000 population

- 445 cases were fatal
- 208 brain injuries are documented monthly
- Adults over 60 years of age suffered the highest rates of TBI at 20.4 per 10,000 population
- Falls were the most common cause of these injuries.

The impact on the state is reflected in multiple but equally difficult areas to measure such as: reduction in workforce and employment, increased medical costs for state sponsored programs (Medicaid), increased reliance on state sponsored social programs, divorce, substance abuse, and criminal justice involvement.

Utah recognizes that proper treatment of TBI requires a full spectrum of care and services from initial evaluation and treatment through community inclusion. Barriers to a comprehensive system of care is a fragmented system caused by the disconnect between multiple agencies and service providers and the overall lack of understanding of what is a Traumatic Brain Injury. Additionally, family involvement is not always recognized as a critical component; but must be incorporated due to the impact on the family system and the need to maintain family support for the good of the TBI survivor.

Background

Grant History

Utah began to address the issues of its fragmented system and lack of TBI awareness through a series of grants- beginning with the Utah TBI Planning Grant, in July 2001. The grant brought together diverse TBI stakeholders and constituents resulting in the establishment of the State TBI Advisory Board. The major accomplishments of the grant were the completion of a Statewide Needs and Resource Assessment conducted by the Utah Department of Health and Center for Persons with Disabilities and the development of an initial Action Plan for a comprehensive system of services. The Action Plan was organized around four content areas identified as high priorities by the Needs Assessment.

In 2003, Utah received a three-year TBI Implementation grant. The Department of Human Services, Division of Services for People with Disabilities was designated by the Coordinating Council for People with Disabilities as the Lead Agency for Implementation Grant. The grant's Action Plan priorities included: improving access to care, community services and supports; developing systems change for sustainability; and developing and disseminating TBI educational training materials. Additionally this grant supported identification of "best practices" in the areas of case management practices, social/recreational activities for individuals, use and availability of assistive technology devices, and transition planning. These best practices were integrated into the three TBI Community Workgroup Action Plans.

In 2007, Utah received a three-year TBI Partnership grant which continued the direction mapped from prior grant experiences. Three working subgroups of the Utah Brain Injury council were formed to expand the responsibilities for implementing the statewide action plan. Two additional pilot communities were established in Box Elder and Davis counties, for a total of 5 exemplary local collaboratives. The pilot communities focused on identification of resources, awareness training and family support.

Accomplishment Highlights

The efforts supported by the TBI grant opportunities have allowed Utah to increase the efficiency and effectiveness of TBI service delivery by establishing a coordinated and integrated statewide system. Utah has addressed many of the challenges faced by persons who have experienced a traumatic brain injury including: access to community services and supports, increased dissemination of TBI information, education and awareness training, expanded state and local services, development and continued enhancement of an information and referral system, and identification of sustainable funding sources. Additionally, service providers are better informed regarding the unique needs of persons with TBI and are able to provide services that are more appropriate and effective. Significant educational information has been developed consisting of first responders information cards, TBI foundational training, mental health specific TBI training, brochures, community resource guides, Train-the-Trainer TBI foundation training, and physician awareness training and expansion of Utah's Medical Home website to include TBI specific information.

Pilot Communities

System development at the community level has resulted in the formation of five pilot communities across the state. These pilot communities are located in Cache County, Davis County, Box Elder County, Washington County, and the Uintah Basin. The pilot communities have formed local advisory groups consisting of brain injury survivors, state agency representation, local providers, advocacy groups, educators, law enforcement, and mental health. Each group has developed resource guides, first responder cards, brochures, and support groups specific for their communities.

BIAU

The BIAU website continues to address the needs of individuals with TBI and their families. The association celebrated twenty-five years of services this year. BIAU actively advocates for the prevention of brain injury and raise awareness in the community through collaboration with other groups, state agencies and legislators toward governmental change. The organization provides information, resources, and support to persons with brain injuries, their families, and the community. In 2008, 4,254 calls were received on the information help line. How many used the website?

Utah Traumatic Brain Injury Fund

The Traumatic Brain Injury (TBI) Fund was established in 2008 by the Utah Legislature as a restricted special revenue fund. The fund consists of gifts, grants, donations, and any other funding from private sources. The fund is administered through the Utah Department of Health. Fund monies may be used to:

- Educate the general public and professionals on the treatment and prevention of TBI;
- Provide access to evaluations and coordinate short-term care to assist an individual in identifying services or support needs, resources, and benefits for which the individual may be eligible; and
- Develop and support an information referral system for persons with a traumatic brain injury and their families.

Core Components of Utah's TBI infrastructure

The U.S. Department of Health and Human Service, Health Resources and Services Administration requires the following four core components be established in each state's TBI infrastructure

TBI Advisory Board: Utah Brain Injury Council (UBIC)

Utah established a Statewide Advisory Board with the initial 2001 planning grant. Over the course of the grant activities the advisory has broadened its mission and adopted the name Utah Brain Injury Council. UBIC provides oversight to the TBI Project and has representation of key State Agencies with an interest in TBI, such as State Departments of Health, Rehabilitation, Human Services, Education, Transportation, Veterans Administration, and Labor. This board also has strong representation from individuals with TBI and family members. Additionally, the council has representatives from organizations that advocate for or serve individuals with TBI including: Primary Children's Medical Center, Gentiva, Rehab Without Walls, Disabled Rights Action Committee, Indian Health Services, Legislative Coalition for People with Disabilities, Disability Law Center, Brain Injury Association of Utah, Center For Persons With Disabilities, and Phoenix Services. The Council meets quarterly to advocate for, facilitate and guide the implementation of a permanent and sustainable stateside TBI system.

Lead Agency: Utah Department of Human Services, Division of Services for People with Disabilities (DSPD)

In May 2003 the Utah Department of Human Services Division of Services for People with Disabilities was designated as the TBI Lead Agency for Utah. The agency has provided leadership and coordination for TBI grant activities. DSPD has supported the Statewide Action Plan to assist the state in expanding and improving its capacity to increase state and local capacity, which, in turn, would enhance access to comprehensive and coordinated services for individuals with TBI and their families. In September 2009, the Department of Human Services-Division of

Services to People with Disabilities determined that due to severe budget reductions, that the TBI initiatives could best be moved forward under the direction of the Utah Department of Health.

Statewide Needs and Resources Assessment

Under the direction of the Lead Agency and in coordination with the Center for Persons with Disabilities a second statewide needs and resources assessment was completed in 2007. Four sample groups were identified: individuals with TBI, family members / significant others of individuals with TBI, identified TBI service providers and potential TBI service providers, and state agencies. The major concerns found by the Needs and Resource Survey summary and analysis included: *elements of systems change, provider education and training, increased information and services (with emphasis for young children and their families), and services and supports related to: cognitive/mental health/behavioral, community skills training, and employment.*

The Needs and Resource Assessment asked questions across the spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI. Information was obtained from One hundred seventy-seven (177) individuals with TBI and eighty-eight (88) Family Member/Significant Other. Three primary areas of need were identified by this group (1) need for increased information and services, (2) the need for cognitive/mental health/behavioral supports and community skills training, and (3) the need for employment related supports and services. State agencies and private provider of services for individuals with TBI surveys were completed or partially-completed.

Seventy service providers were contacted with thirty-eight survey successfully completed. Case Management/service coordination, family support and education/training were the primary services by direct service providers (N=12). The agencies survey (N=26) were providing a combination of support and referral services. All service providers and agencies interviewed identified areas of significant unmet needs such as: cognitive therapy, mental health, behavioral supports, social and community skills training, and education and related services and supports.

The focus groups were made up of the Cottonwood Support Group and the Sugarhouse Support Group. Each support group is made up of survivors and family members. In addition to family members and survivors, the Cottonwood Support Group was attended by an IHC support team. Their input was included in the focus group results.

Individual interviews were also conducted with key state agencies to examine the services currently available to individuals with TBI, the process to identify individuals with TBI within their service population, and how services and supports are tailored to address the needs of individuals with TBI.

Comprehensive Statewide Plan

Action Planning Process

This plan reflects the contributions of time, expertise, and resources from a broad variety of stakeholders, including persons with brain injury, parents, and other family members, government officials, health and advocacy organizations, public and private providers, state and local agencies, and others with a vested interest in brain injury issues. This Action Plan is intended to be a dynamic document that will evolve over time with the development of a comprehensive system of TBI services and supports in Utah. Primary needs, concerns and priorities were identified through the Needs and Resource assessment process. The UBIC used the identified needs and priorities to identify the direction for revision to Action Plan.

Contributing Partners

A primary grant activity was to decrease the fragmented service system and increase communication and collaboration between service and advocacy systems. Utah's success in its development and sustained effort of its comprehensive statewide plan is dependent on the collaboration of the partnerships developed through the grant

activities. The following is a list of resources/services contributed by partners related to TBI needs that ensures a full spectrum of care and services.

State Agencies

Department of Health

- Children with Special Health Care Needs
- Bureau of Long Term Care
- Administer Utah TBI Fund
- Violence and Injury Protection Programs
 - TBI Surveillance Project
- Multi-culture Coordinator
- Administer Medicaid and CHIP

Division of Services for People with Disabilities

- Acquired Brain Injury waiver
- Self-study Brain Injury Training Kit for ABI support coordinators
- MR/RC waiver: acquire brain injuries prior to the age of 18
- Services TBI on waiting for services

Utah State Office of Education

- Individuals with Disabilities Education Act, Part B services
- 504 Services
- TBI training for educators

Veterans Administration

- Property Tax Abatement
- Purple Heart Tuition Waiver
- Purple Heart Tuition Waiver
- Bus/Trax Reduced Fare Cards

Indian Health Services

- Navajo Area Indian Health Service
- Fort Duchesne Indian Health
- Phoenix Area Indian Health Services, Tri- State

Utah State Office of Rehabilitation

- Utah Center for Assistive Technology
- Division of Disability Determination
- Division of Rehabilitation Services
- Independent Living
- Employer Network Listing
 - Workability

Juvenile Justice Services

- Youth Support Services
- Evaluation and Treatment Planning
- Case Management

Department of Human Services

- Division of Substance Abuse and Mental Health
 - Consumer Outreach Program
 - Prevention and Treatment

Public and Private Service Providers

Intermountain Healthcare

- Primary Children's Medical Center
- EMS Outreach Education
- Patient Education
- Inpatient Services, Rehab Services

Phoenix Services

- Support Living
- Support Employment

Gentiva, Rehab Without Walls

- Home Health Care

Advocacy Organizations

Legislative Coalition for People with Disabilities

- Advocate for Public Policy

Center for Persons with Disabilities

- Advocacy, Education, Policy, Research and Services Agency
- Certified Brain Injury Specialist Training

Brain Injury Association of Utah

- BIAU Website: resource and contact information, services and supports
- Annual Family & Professional Conference
- Helpline, Resource Library
- Legislative Advocacy
- Community Education

Disability Law Center

- Protection and Advocacy Agency

Disabled Rights Action Committee

- Advocacy Services

UTAH STRATEGIC PLAN FOR TRAUMATIC BRAIN INJURY

Note: *Objectives that are asterisked are part of the 2009 proposal.*

Area: Infrastructure and Systems

Goal One: Foster meaningful improvement in the TBI service delivery system of public and private agencies and providers that achieves person-centered and family-centered service and support, is guided by system-wide ownership, establishes strong leadership that influences policy and procedures and maintains the necessary leverage to promote implementation of the Statewide TBI Action Plan.

**Objective 1.1* With the Lead Agency, a full-time TBI Director, and a TBI Ombudsman, continue to engage state and community-level private and public agencies, families, individuals with TBI, and health/medical and education professionals to expand and improve TBI services and supports.

**Objective 1.2* Continue expanding the role of the Utah Brain Injury Council (UBIC) in guiding policy development, prioritizing needs, and promoting the successful implementation of the Statewide TBI Plan through the activities of 3 functional working groups and increase the family/members/individuals with TBI representation and the racial and ethnic diversity of UBIC by 30% over 4 years.

**Objective 1.3* Under the direction of the UBIC provide education for policy makers, funding organizations, and other interested parties by ensuring that TBI issues are included in the agendas of existing statewide groups who educate policy makers and funding organizations.

**Objective 1.4* Implement *Action Agendas* between the Lead Agency (UDOH) and local, state, federal, and private agencies/entities serving individuals with TBI that specify collaborative activities designed to increase/enhance the services and supports.

**Objective 1.5* Identify and obtain additional fiscal support for the TBI Fund and for the sustainability of the TBI infrastructure, and community supports and services.

Area: Coordinated and Comprehensive Community Services

Goal Two: Every individual with TBI in Utah will have access to a full array of coordinated and comprehensive *community services*.

**Objective 2.1:* Develop and implement a population-specific *Action Agenda* to address supports and services including training, technical assistance, and information dissemination on a state and community level for the following targeted populations:

- **Children ages birth-4*

- *Service members and veterans of Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF)
- Other groups as identified by UBIC

Objective 2.2 Increase the availability of employment rehabilitation, supported employment, and employment opportunities for individuals with TBI through training supported employment providers, job coaches, employment counselors, and human resources directors for large employers.

Objective 2.3: Expand the number of community-based social, recreational, and support opportunities for children, adolescents, and adults with TBI.

***Objective 2.4:** Provide case managers across agencies and communities who are providing services to individuals with TBI and their families with a virtual resource center.

***Objective 2.5** Develop functional relationships (including *Action Agendas*) with at least 10 agencies/entities providing services for American Indian and Latino populations in Utah and within the 4-corners area and well as individuals with TBI from these populations and provide requested information, training, and technical assistance.

Area: Awareness, Education, and Training

Goal Three: Continue to refine, expand, and deliver TBI *awareness, and education, and training* to individuals with TBI, families, providers, health care professionals, educators, and the general public.

***Objective 3.1** Conduct a statewide campaign to inform the public about TBI and the resources available.

***Objective 3.2** Develop new or significantly revised educational (training) materials suitable for agencies serving incarcerated juveniles, *veterans, *young children (birth to 4), secondary students, entering college students, and other audiences identified by UBIC.

Objective 3.3 Provide educators with 3 additional training modules and 12 technical assistance activities in providing instructional accommodations for secondary students with TBI and those who have been incarcerated with TBI.

***Objective 3.4** Expand the capacity of the www.medicalhomeportal.org website to provide additional information about TBI diagnosis and treatment of young children (ages birth -4) for physicians, health care professionals, and families including a self-study CME module for physicians regarding TBI in young children.