

POPULATION SPECIFIC FACT SHEET

What to Know When Assisting a Consumer with a Traumatic Brain Injury (TBI)

This fact sheet is intended to help Navigators identify what issues are unique to consumers with TBI

Q1. What do I need to know about traumatic brain injury (TBI)?

A. A traumatic brain injury (TBI) is a bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain. The Centers for Disease Control and Prevention (CDC) estimates there are 2.5 million TBI emergency department (ED) visits, hospitalizations, and deaths in the U.S. each year. These numbers do not include persons who do not seek medical care, had outpatient or office-based visits, or those who received care at a federal facility, such as persons serving in the U.S. military or veterans.

The leading causes of TBI are falls among very young children and older adults (high-risk groups), motor vehicle-related crashes, blunt trauma, and assaults. An increasing number of TBIs are reported as the result of sports and recreation activities. Military personnel are also at significant risk for TBI. Blast injuries, which result from over-pressurization forces (blast waves), also cause TBIs but may be undiagnosed or misdiagnosed should a person not lose consciousness or present other immediate symptoms.

TBI is the leading cause of death and disability in children and young adults in the United States, but everyone is at risk.

No two brain injuries are alike. Many factors contribute to outcome after TBI, including the age at the time of injury, severity of injury, presence of drugs and/or alcohol, pre-injury functioning, and access to emergency medical services and rehabilitation. Regardless of the severity of the injury, a TBI can affect cognition (thinking skills), behavior, emotion, and motor function. Common symptoms include difficulties with memory, attention, learning, decision making, reasoning, and concentration. Family members and friends may note changes in personality. The person with a TBI may also exhibit irritability, aggression, and/or be unable to modify behavior to fit varying situations. The person may be unable to distinguish problems or be aware of his or her symptoms. Other signs and symptoms include headaches, fatigue, sleep disturbances, problems with hearing, vision, or speech, and difficulty with balance or coordination. All of these resulting problems may affect one's ability to conduct activities of daily living, return to work/school, and to live a healthy and productive life.

Post-concussion syndrome refers to a collection of symptoms that some people develop after they have had a concussion. Symptoms of post-concussion syndrome can include headache, dizziness, and memory and concentration problems. Symptoms usually clear within three months after the initial injury. Treatment is aimed at relieving these associated symptoms.

Q2. What type of health care providers does someone with a TBI need to have access to?

A. Depending on the type and severity of injury, individuals who sustain a TBI may require emergency medical services, surgical or medical care, and rehabilitation as well as neuropsychological assessment and counseling, case management, and personal or attendant care services. Care may be provided on an inpatient or outpatient basis at hospitals, residential rehabilitation facilities, day treatment centers, and through home health care.

The most common care providers include:

- Neurosurgeon
- Neurologist
- Psychiatrist (doctor of rehabilitation medicine)
- Therapists - physical, occupational, respiratory, and speech
- Neuropsychologist
- Social worker
- Nursing
- Primary care physician

Patients with TBI frequently require specialists, such as:

- Optologist
- Neuro-optometrist
- Nutritionist/Dietician
- Ophthalmologist
- Pain Management Specialist
- Sleep medicine
- Substance abuse counselor specializing in TBI

Longer term, other specialists may be needed to address chronic conditions that can result from TBI. These include:

- Cardiology
- Endocrinology
- Gastroenterology
- Pulmonology
- Psychiatry
- Urology

Q3. What are some of the prescription needs that someone with a TBI may have?

A. Drug interventions addressing TBI-related conditions include: anticonvulsants/antiepileptic drugs, antidepressants, anti-anxiety agents, neuroleptics, anti-Parkinson agents, psychostimulants, anticholinergic agents, antihypertensive,

narcotic antagonists, and Botox® to prevent the release of chemical transmitters that cause muscles to contract.

For further information regarding prescription medication benefits see Fact Sheet #5.¹

Q4. What type of therapies (physical, occupational, speech, etc.) and/or devices (durable, disposable, etc.) would someone with TBI potentially require?

A. For many people, rehabilitation is a lifelong process. They may continue to benefit from rehabilitation therapies to maintain skills and to learn new skills or compensatory strategies to help with independence and community integration. Therapies include speech-language; cognitive; behavioral; recreational; occupational; and physical therapies. Cognitive rehabilitation consists of a group of therapies used to manage deficits in thought processes and behavior (e.g., comprehension, perception, and learning). Physical rehabilitation focuses on enhancing different forms of mobility by improving physical factors such as strength and endurance, as well as providing assistive devices that facilitate independence.

There are many “home made” solutions to assist with cognitive problems, such as smart phones, timers, checklists, voice recorders and so forth to remind people about taking medication, adhering to appointments, and helping with activities of daily living. In addition, wheelchairs and walkers help with mobility; assistive or adaptive computer hardware and software, such as voice recognition programs will help people with mobility and vision problems; and motion detectors and door alarms will help with individuals who wander.

For further information see Fact Sheet #4 on rehabilitation and habilitation services and devices² and Fact Sheet #10 on medical supplies.³

Q5. What other services and supports, which are not generally medically arranged therapies and devices, are typically required by persons with TBI? Are these arranged and financed in some private health insurance plans or in some Medicaid programs?

A. Chore services, in-home care, personal care, support groups, therapy, transportation, home and vehicle modifications, socialization, complementary and alternative treatments (CAM), including acupuncture, chiropractic care, and massage for pain management, respite, transitional living and training, personal emergency response, and skills training.

¹ <http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-5/>

² <http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-4/>

³ <http://www.nationaldisabilitynavigator.org/ndnrc-materials/fact-sheets/fact-sheet-10/>

Twenty-three (23) states administer 27 Medicaid Home and Community-based Services (HCBS) brain injury waiver programs. These tend to be small in numbers and expenditures, but cover some of the traditional waiver services afforded to other populations requiring long-term services and supports. Almost half of the states have dedicated and/or state funding to also pay for some type of supports, although services are limited.

At least one state (Texas) covers cognitive rehabilitation as a mandated insurance benefit.

Q6. Are there any other unique medical needs that someone with TBI should consider when evaluating a health plan?

A. Access to service providers and professionals with expertise in TBI. There are many areas of the country whereby healthcare professionals experienced and trained in TBI are limited. Telehealth and telerehab, should these capacities exist, may help with the delivery of health and rehabilitative services.

Q7. Are there any type of accommodations I should consider when I'm planning to meet with someone with a TBI?

A. Yes, individuals with TBI generally have cognitive problems with regard to memory, attention, and concentration. Navigators assisting someone with a TBI should help them with writing down any instructions, including any appointments with them. Navigators should also avoid “yes” or “no” type of questions when obtaining information as persons who have sustained TBIs may not be able to discern the type of information being requested or may not be aware of how the question pertains to them. Navigators should also avoid distracting noise in the interview setting. Length of time in helping an individual should also be considered due to fatigue, attention, lack of insight and other limitations that may impact the ability to participate in an appointment that is too long. Accommodations to help with these situations include giving adequate breaks, speaking clearly and slowly, repeating questions, reducing environmental distractions, and offering information in alternative formats.

For further information see the Disability Guide.⁴

⁴ <http://www.nationaldisabilitynavigator.org/ndnrc-materials/disability-guide/>

Q8. Are there any resources you would recommend for obtaining additional information about TBI?

A. The following organizations and agencies can provide more information about TBI:

- Brain Injury Association of American: <http://www.biausa.org/>
- Centers for Disease Control and Prevention, National Center for Injury Prevention and Control: <http://www.cdc.gov/TraumaticBrainInjury/>
- Model Systems Knowledge Translation Center: <http://www.msktc.org/>
- National Association of State Head Injury Administrators: www.nashia.org
- National Institute on Disability, Independent Living and Rehabilitation Research: <http://www.acl.gov/programs/NIDILRR/>
- National Institutes of Health, National Institute of Neurological Disorders and Stroke: <http://www.ninds.nih.gov/>

American Association on Health and Disability (AAHD)
National Disability Navigator Resource Collaborative (NDNRC)
110 N. Washington Street, Suite 328J
Rockville, MD 20850
301.545.6140/contact@aahd.us

www.nationaldisabilitynavigator.org

Copyright © 2015 – American Association on Health and Disability