National Center on Advancing Person-Centered Practices and Systems

August 2019 Webinar Question and Answer Summary and Resources List

Considering Brain Injury: Why Being Brain Injury Informed is a Critical Component of Person-Centered Thinking, Planning, and Practice

Question: I am looking at the qualifications for several acquired brain injury (ABI) Waivers in my state, and there are some functional needs requirements to apply. Anne [one of the presenters] was told that she is "too high functioning for services." How do you get around that?

Susan Vaughn: Each state develops its own criteria, policies, procedures, including Medicaid eligibility and functional assessment requirements to determine eligibility for long-term services and supports funded in part by Medicaid. A Medicaid waiver program is designed to serve individuals who would otherwise be in institutional/nursing home settings. Some states allow cueing/accommodations with regard to ability to carry out activities of daily living, while other states require direct hands on care to carry out activities of daily living, such as bathing, in order to qualify. Working with the state Medicaid agency and any other state agencies involved in the administration of the waiver program may help to educate them about the types of supports individuals need in order to living in the community as opposed to institutional settings. State trust fund and/or general revenue funded programs also have considerable differences with regard to purpose, program eligibility and services provided. Some states will cap the amount a person may use within a year or lifetime or other restrictions—so people again, need to work with those programs for accommodating and expanding eligibility requirements.

Anastasia Edmonston: The qualifications do vary from state to state. When bumping up against this kind of thing, I usually suggest folks contact their Brain Injury Association or state Brain Injury Alliance, go to https://www.biausa.org/find-bia to find your local Brain Injury advocacy group.

It might also be worth connecting with your state's Protection and Advocacy Organization. Go to https://www.ndrn.org, the National Disability Rights Network, to find out how to contact your local Disability Rights Network. The local DRNs receive grant funding from the Federal TBI Program. Here is the webpage to find your state's DRN https://www.ndrn.org/about/ndrn-member-agencies/

Last but not least, it never hurts to bring gaps in services to the attention of your elected officials. Here is a link for reaching out to state and federal officials. once you find your state's contacts, look for contact information for Constituent Services. https://www.usa.gov/elected-officials

Kelly Lang: In my experience, answer the questions in the Functional Needs Assessment as best as possible. Give examples of where assistance is needed. If reminders are required to shower, then say so. Personal hygiene may be included as an item/category. It may be surprising what information is considered by the agency. I worried my daughter would not receive services

especially after being on the waiting list for 8 years, but when we completed the functional assessment, she qualified.

Question: What are some resources family members can use so that their family members (e.g., siblings, teenage son, etc.) can receive services?

Susan Vaughn: Depending on the state, there may be a state Brain Injury Association, state Brain Injury Alliance, state brain injury advisory council and/or state program that can help with resources. Each state also has a protection and advocacy services agency, sometimes referred to as a state disability rights organization that also receives federal funding to assist individuals with TBI in advocating for services. You may contact NASHIA at execdirector@nashia.org and they may point you in the right direction.

Most states organize their services and systems based on diagnosis such asHi all, mental health/behavioral health; substance use; TBI/ABI; or by a combination of diagnosis and age. Some states do try to collaborate/coordinate across systems to accommodate people with more than one issue—such as TBI/opioids/substance use and substance use providers may screen for a TBI-related disability. Similarly, if seeking TBI funded services, the TBI program may ask about drug use in order to help determine appropriate services. A point of contact may be the state brain injury program, if they have one—regardless of how it is funded; and state brain injury association/alliance to direct you to the services in your state.

I think families/parents often have to fill in information that doctors and other professionals may not know or overlook or may not view as their primary focus. At age 15, a student may be eligible for accommodations with regard to academics—but the school needs to know— may be eligible for transitional services with regard to post school activities, which may involve vocational rehabilitation—which provides job training and assistance to anyone who meets physical/mental disability requirements. Having all the student's history may help determine how best to address his/her needs.

Kelly Lang: If you are looking for resources, I suggest contacting your state brain injury association or alliance. They are a great source of referral information. Your state may also have organizations who can provide case management services. If you need help finding your state organization contact The Brain Injury Association of America https://www.biausa.org. They will be able to direct you to your state resources.

If you suspect someone has suffered a traumatic brain injury (TBI) from an overdose or any other incident you can contact your primary doctor or a local hospital for a referral. Many also have concussion clinics who can direct you to either a program run by their organization or another resource. A neuropsychologist can conduct testing to determine if there has been a cognitive decline based on previous baseline such as education, job, etc. If the testing determines an injury occurred, you can be referred to other specialties.

Is there additional info on geriatric brain injuries?

Susan Vaughn: The Centers for Disease Control and Prevention (CDC) supports activities and initiatives relating to older adult falls, including questions for physicians to ask patients with regard to falls. CDC's Stopping Elderly Accidents Deaths and Injuries (STEADI) initiative is an evidence-based older adult fall prevention strategy, which consists of three core elements: screen patients for fall risk, assess a patient's risk factors, and intervene to reduce risk by giving older adults tailored interventions. To help healthcare providers screen, assess, and intervene materials are available on the CDC website: https://www.cdc.gov/steadi/pdf/steadi_tool_kit_materials_handout-a.pdf

Anastasia Edmonston: In addition to the Centers for Disease Control and Prevention's wealth of online resources https://www.cdc.gov/steadi/patient.html, as Susan mentioned, BrainLine has information on older adults and brain injury, go to: https://www.brainline.org/topic/seniors-brain-injury

Kelly Lang: BrainLine (https://www.brainline.org/topic/seniors-brain-injury) is an excellent source of information on brain injury. The site has a wide range of resources, blogs, and articles on different types of injuries. Another good source is https://www.psychiatrictimes.com/special-reports/tbi-older-adults-growing-epidemic.

The National Institutes of Health is another great resource for articles pertaining to the diagnosis and treatment of brain injuries https://www.nichd.nih.gov/health/topics/tbi/conditioninfo/diagnose.

Question: Can you recommend a screening tool that will work to be able to recognize a brain injury in a person who does not use words to talk?

Anastasia Edmonston: I cannot recommend a specific tool as I am not qualified to make recommendations in this area. However, I do know from working with individuals who were nonverbal following a brain injury, that the staff neuropsychologists, occupational and speech and language pathologists were able to do some assessment of cognitive skills as long as individuals had a reliable yes/no response, often through eye blinks or hand squeezes. This article written by Italian researchers discusses assessment in nonverbal individuals, I apologize in advance for the highly non-person centered title of the article https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3814512/pdf/11_pg55_59.pdf

Question: When an infection, such as septicemia, leads to high fever, can this also cause Acquired BI, as I have witnessed these symptoms in clients? When an individual has a confirmed inter-cranial bleed on CT related to injury, but has only briefly lost consciousness, are they considered to have a mild or moderate brain injury? Is damage caused by stroke also considered TBI? Is a seizure disorder a TBI?

Susan Vaughn: An acquired brain injury is one which is not hereditary, congenital, degenerative, or induced by birth trauma and is an injury to the brain that has occurred after

birth. Examples of ABI include stroke; alcohol and drug abuse; anoxia (lack of oxygen) due to near drowning; brain infections; tumors, cancer and illnesses. A stroke can cause lasting brain damage—if oxygen is blocked to the brain or sudden bleeding.

One of the problems that can occur after a TBI is seizures. Some may occur months or years after the injury. According to the National Institutes of Health, about 70-80% of people who have seizures are helped by medications, and can return to usual activities.

Anastasia Edmonston: Susan gave a thorough response to these questions. The only thing I would add regarding acquired and traumatic brain injury is that specific diagnoses can be misleading. Yes, someone who has had a loss of consciousness and/or period of confusion for less than 30 minutes is considered to have sustained a "mild" traumatic brain injury. However, as was discussed during the webinar, the consequences of a mild TBI can be anything but mild for some people; this can hold true after one mild TBI as well as for those who sustain multiple mild TBIs. The key is, how is the person's functioning post the incident, and are they able to resume their normal activities after a period of recovery? I have worked with individuals who had a very complicated course of recovery post a "mild" TBI who required support for an extended period of time post injury, and those who had experienced a moderate or even severe traumatic brain injury with extended periods of unconsciousness who were able to resume their work, home and community lives fairly quickly.

Regarding seizures, it is not unheard of for someone who did not have a seizure at the time of the injury or at any time during their recovery and rehabilitation to have one even years later. In my experience, the seizure or seizures was related to an individual drinking alcohol. A brain injury can lower the seizure threshold, and alcohol can lower it even further. Some medications also can heighten seizure risk in those with or without a brain injury in their history. Almost every brain injury professional will educate those they work with about this risk. Each individual should consult their own doctor about their personal risk of seizure post a brain injury.

If someone's seizures are not well-controlled, there could be some risk of acquired brain injury.

Kelly Lang: The classification of brain injuries is evolving and most likely will continue for many years to come. A good source of information is www.Brainline.org, National Institutes of Health, and https://www.acnr.co.uk/2013/07/classification-of-traumatic-brain-injury/. A doctor determines the diagnosis and some may disagree. My daughter suffered a concussion a few years ago and the Emergency Room doctor did not diagnose a concussion. However, I knew she had one. I took her to the Children's Hospital Concussion Clinic, and she was diagnosed with a severe concussion.

The Centre for Neuro Skills (https://www.neuroskills.com/brain-injury/stroke/what-is-stroke/) has good information regarding strokes and brain injury as well as National Institutes of Health.

Seizures can occur following a brain injury and many patients are placed on seizure medications immediately to avoid them. This article explains the relationship between seizures and brain injuries. https://msktc.org/tbi/factsheets/seizures-after-traumatic-brain-injury

Question: Can you demonstrate the "red line" technique?

Anastasia Edmonston: The red line technique was introduced to me years ago by a speech and language pathologist.

Take a large index card, usually the larger the better. On one long edge of the card, take a red marker and color from the edge in about ¼ of an inch. The reason for the color red, is it is a color the eye is drawn to (hence our stop signs and traffic lights!). The red lined edge is then used as a guide for people who may have vision issues where they have difficulty tracking the written word on the page, or who have what is referred to as a "neglect" where they do not recognize, especially immediately post injury. part of their visual field. Some people do not see the left side of their visual field; some their right; some have essentially tunnel vision; some have neglect in all 4 quadrants of their visual field.

For some these issues will eventually resolve, but until they do, using this visual cue to track information on the page is a great way to learn how to move your head and your eyes to make sure you take in your environment, starting with reading is a very concrete activity and eventually the goal is the person internalizes the strategy to physically turn and look in the direction of the neglect so they are not at risk of making a misstep, bump into walls etc. To use when reading, see what works best for the person, if they have hard time focusing on the page, they can just place the card, with the red edge right under each line as they read down the page. For those with neglect, say on the left side, the strategy is to place the redline in a vertical position, go all the way to the end of the sentence on the right and then pull the card/red line all the way to the left side of the page, till you run out of text. Then you know where the beginning of the line of text is and start reading from that point across to the right. This is a good strategy that can support both visual issues and problems with attention and concentration.

Question: I work with people who have intellectual/developmental disabilities. I suspect a large number of them have unrecognized and unsupported brain injuries

Susan Vaughn: Yes, people who meet the definition of developmental disabilities often do not have medical documentation of a TBI, or the family may have not conveyed that the individual sustained a TBI or even know that a bump on the head—fall out of the high chair, etc. can have some lasting results. Yet, ascertaining whether TBI could be a factor will help to determine approaches with regard to working with someone who has TBI-related symptoms—such as cognitive and behavior. For example, a person with TBI may remember old learning, but have difficult with new learning. They may answer that he/she can make a sandwich, but not remember the order of making a sandwich, to remember to make one or even to eat one without some cueing/accommodations/reminders. They may have had personality and behavioral changes—often related to frontal lobe injury. Individuals with TBI generally do not transfer learning or behavior in one setting to other settings—rather, providers may need to structure their days, environment to accommodate cognitive and behavioral difficulties.

Understanding these types of issues will help to elicit information regarding their goals and the types of supports needed to work towards those goals—and also how staff should interact.

Anastasia Edmonston: I suspect you are correct, and Susan gave an excellent response. The only thing I would add, is if a person had a TBI before the age of 22, they may be eligible for services through their state agency that supports those with developmentally related intellectual and cognitive issues. On occasion, a person who is in services who had their brain injury 20 years ago, say at 20 and is now 40, their direct support staff and even managers of programs may not be aware of that person's TBI history. It's always good to make sure the history of all and any brain injury, either one that initiated the person into services, or a TBI(s) that occurred once entered into services, is known by those working with the individual, especially direct care staff. This is really important to keep in mind as we are just learning how aging with a long time history of brain injury can have implications for care as people living with brain injury are vulnerable to chronic illness, accidental overdose, and other conditions and circumstances related to their history of brain injury which makes long term follow up, through a brain injury informed lens that much more important.

Kelly Lang: If you suspect someone has a history of brain trauma encourage them to seek an evaluation. Brain injuries can be treated many years later.

The following list of resources were identified by webinar attendees in chat during the August webinar:

National Resources

National Association of State Head Injury Administrators (NASHIA): www.nashia.org

ACL's Traumatic Brain Injury State Partnership Program: https://tbi.acl.gov

United States Brain Injury Alliance: https://usbia.org

Brain Injury Association of America | BIAA: https://www.biausa.org

BrainLine: https://www.brainline.org/

State-Specific Resources:

Iowa

Brain Injury Alliance of Iowa: www.biaia.org

Minnesota

Minnesota Brain Injury Alliance: http://www.braininjurymn.org

Tennessee

Traumatic Brain Injury: https://www.tn.gov/health/health-program-areas/fhw/vipp/tbi.html

Texas

Comprehensive Rehabilitation Services (CRS) | Texas Health and Human Services: https://hhs.texas.gov/services/disability/comprehensive-rehabilitation-services-crs

Utah

Brain Injury Alliance of Utah: https://biau.org/

West Virginia

WV Traumatic Brain Injury Services | Center for Excellence in Disabilities: http://tbi.cedwvu.org/

Additional Resources

The Life Skills Manual: Strategies for Maintaining Residential Stability, developed by Christine Helfrich, PhD, OTR/L, FAOTA, under several grants from NIDILRR: https://naric.com/?q=en/content/order-life-skills-manual
Electronic delivery is free. There is a fee for print editions.

The Learning Community for Person Centered Thinking: www.tlcpcp.com

Charting the LifeCourse Infographic: http://www.lifecoursetools.com/planning/

Building Blocks of Brain Development "Great resource for school aged children and youth": https://cokidswithbraininjury.com/educators-and-professionals/brain-injury-matrix-guide/

Brain Injury in Youth – Supports for School Success: https://youthbraininjury.obaverse.net

The 411 on Disability Disclosure: A Workbook for Youth with Disabilities: http://www.ncwd-youth.info/publications/the-411-on-disability-disclosure-a-workbook-for-youth-with-disabilities/

Living with TBI Model Systems Knowledge Translation Center (MSKTC) https://msktc.org/tbi

Commission on the Accreditation of Rehabilitation Facilities (CARF): http://www.carf.org/home/