Considering Brain Injury

Why being brain injury-informed is critical for person-centered planning

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NCAPPS

Welcome to Today's Webinar

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Thank you for joining us to learn about person-centered supports for people with brain injury. We'll also cover the need for brain injury-specific information and understanding to guide person-centered practices.

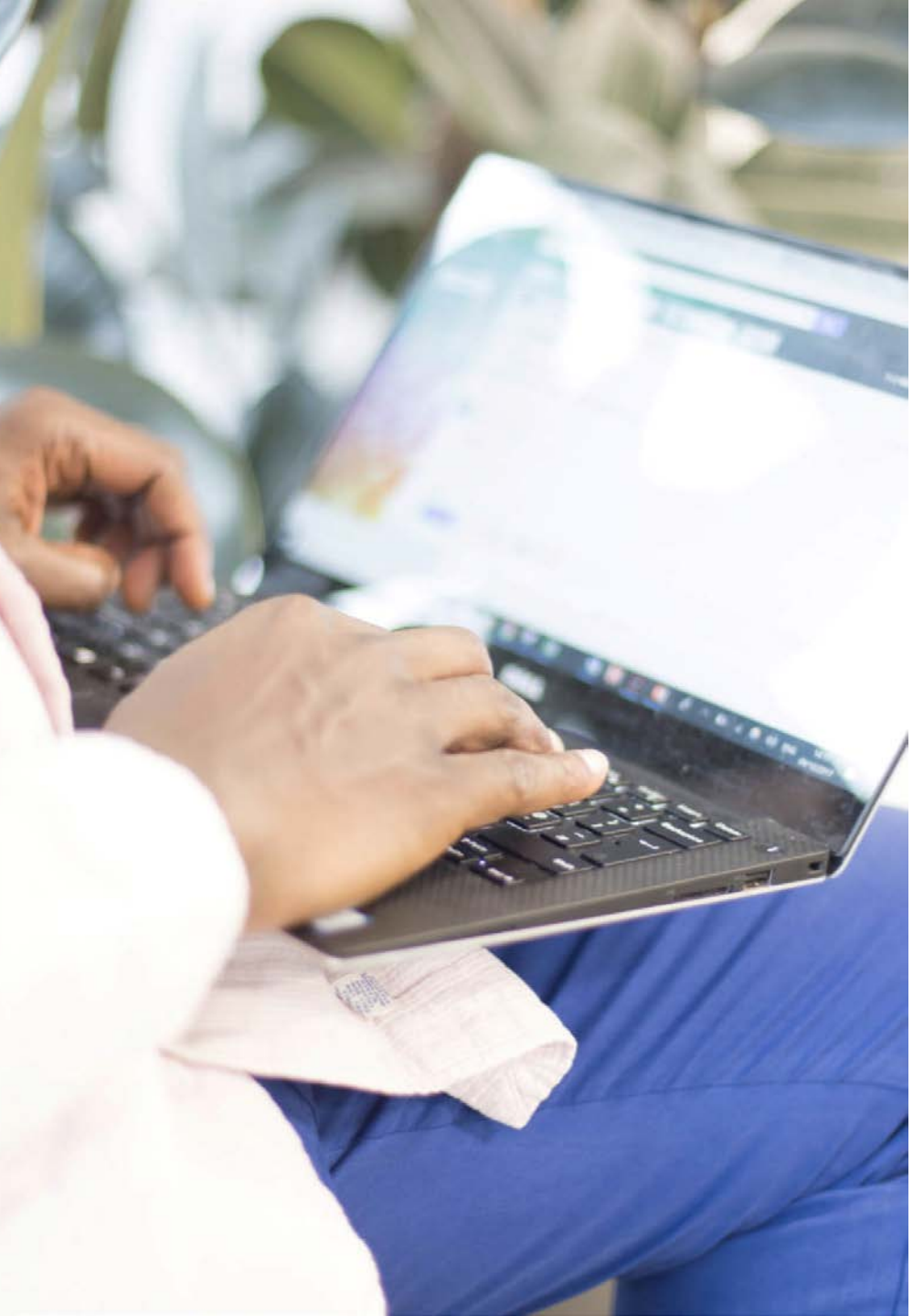
This webinar series is sponsored by the National Center on Advancing Person-Centered Practices and Systems. NCAPPS is funded by the Administration for Community Living and Centers for Medicare & Medicaid Services.

NCAPPS webinars are free and open to the public.

The goal of NCAPPS is to promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan.

Webinar Logistics

- Participants will be muted during this webinar. You can use the **chat** feature in Zoom to post questions and communicate with the hosts.
- Toward the end of the webinar, our speakers will have an opportunity to **respond to questions** that have been entered into **chat**.
- The webinar will be live captioned in English and Spanish. To access the Spanish captions, please use this link: https://www.streamtext.net/player?event=HSRI-SPANISH
- This live webinar includes polls and evaluation questions. Please be prepared to interact during polling times.



Feedback and Follow-Up

- After the webinar, you can send follow-up questions and feedback about the webinar to NCAPPS@acl.hhs.gov (Please note that this email address is not monitored during the webinar.)
- A recording, including a pdf version of the slides and a Plain Language summary, will be available within two weeks at NCAPPS.acl.gov. We will also include questions and responses in the materials that are posted following the webinar.

Meet Our Speakers

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Traumatic Brain Injury In America: The Big Picture

- The Center for Disease Control and Prevention (CDC) defines a traumatic brain injury (TBI) as a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury.
- Everyone is at risk for a TBI, especially children and older adults.

Source: https://www.cdc.gov/traumaticbraininjury/index.html retrieved 7.14.2019

CENTERS FOR DISEASE CONTROL AND PREVENTION

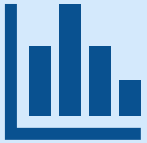
Poll question: Who is participating?

What brings you to this webinar? (can choose more than one)

I am…

- A person living with brain injury
- A family member or unpaid care provider for a person with brain injury
- Employed by a community service agency that supports people living with brain injury
- An administrator of local, state, tribal, or federal programs for people with brain injury
- A professional working in Aging and Disability Services
- A clinician working with people with brain injury
- A researcher
- Other

Poll questions: Service Access?



In your experience...

1. Services for people with brain injury in the community are person-centered

2. Services for people with brain injury in the community are adequate for people's needs

3. Accessing services for people with brain injury is

Traumatic Brain Injury in America:
Facts and Figures

- In 2014, falls were the leading cause of TBI. Falls accounted for almost half (48%) of all TBI-related emergency department visits.
- Falls disproportionately affect children and older adults:
  - Almost half (49%) of TBI-related ED visits among children 0 to 17 years were caused by falls.
  - Four in five (81%) TBI-related ED visits in older adults aged 65 years and older were caused by falls.
- Being struck by or against an object was the second leading cause of TBI-related ED visits, accounting for about 17% of all TBI-related ED visits in the US in 2014.

Source: https://www.cdc.gov/traumaticbraininjury/get_the_facts.html retrieved 7/14/2019

Traumatic Brain Injury in America:
Facts and Figures

- Over 1 in 4 (28%) TBI-related ED visits in children age 17 and under were caused by being struck by or against an object.
- Falls and motor vehicle crashes were the first and second leading causes of all TBI-related hospitalizations (52% and 20%, respectively).
- Intentional self-harm was the first leading cause of TBI-related deaths (33%) in 2014.

Source: https://www.cdc.gov/traumaticbraininjury/get_the_facts.html retrieved 7/14/2019

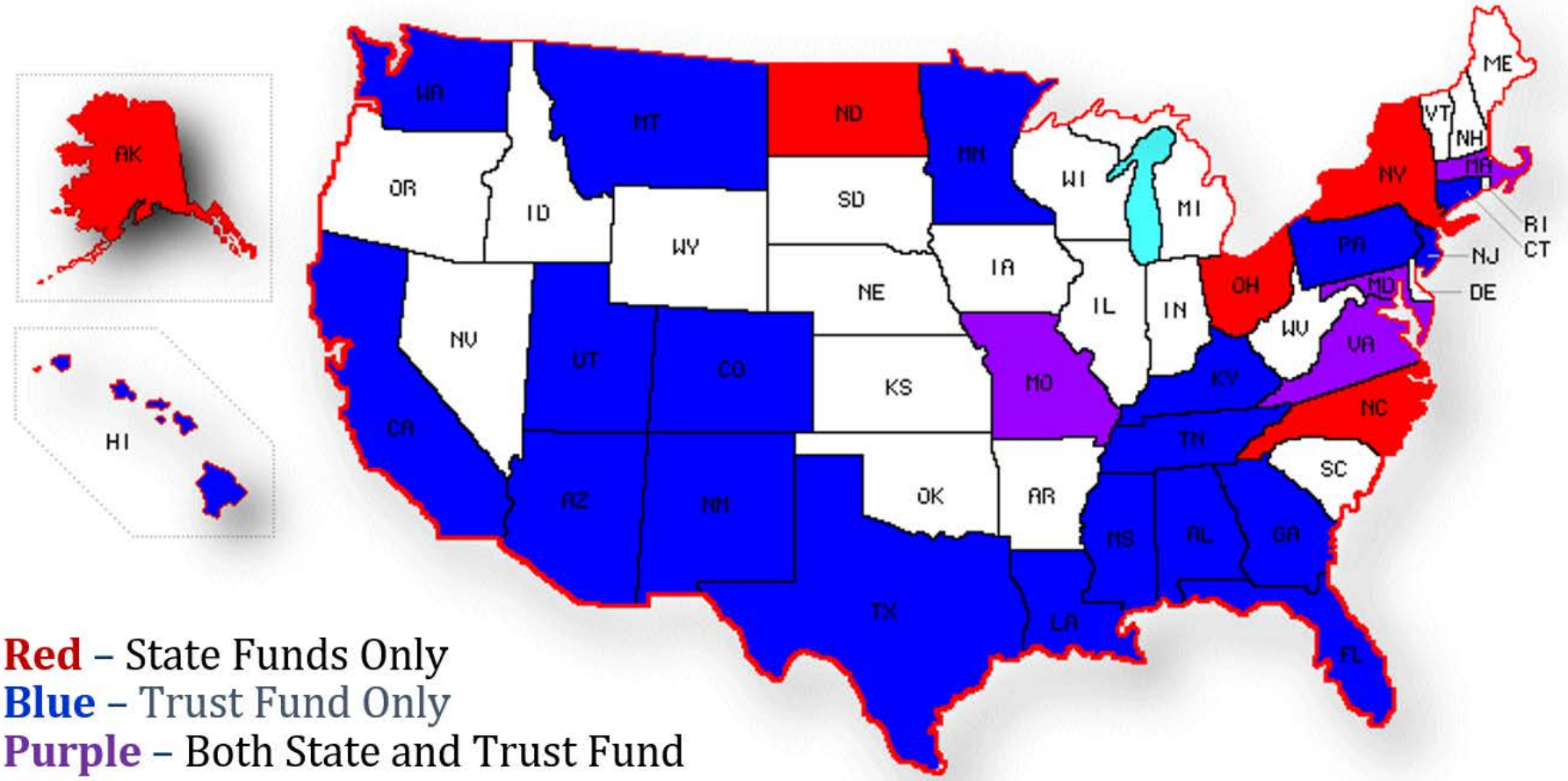
There is no defined “system” for brain injury

However, due to the advocacy of those affected by brain injury and their allies since the 1980s, movement toward funding, services and systems change is steadily increasing awareness and the need for **available, appropriate, timely services and supports for individuals living with brain injury** and their families.

Beginning in the 1980s . . .

- Registries
  - Data/surveillance, linkage to services
- State TBI programs and services
  - State appropriations
  - Trust fund programs
  - Medicaid
  - Multiple funding sources
  - Advisory Councils/Boards
  - State and National Brain Injury Advocacy organizations

BI Dedicated Funding / State Funding: Trust Fund and State Appropriations



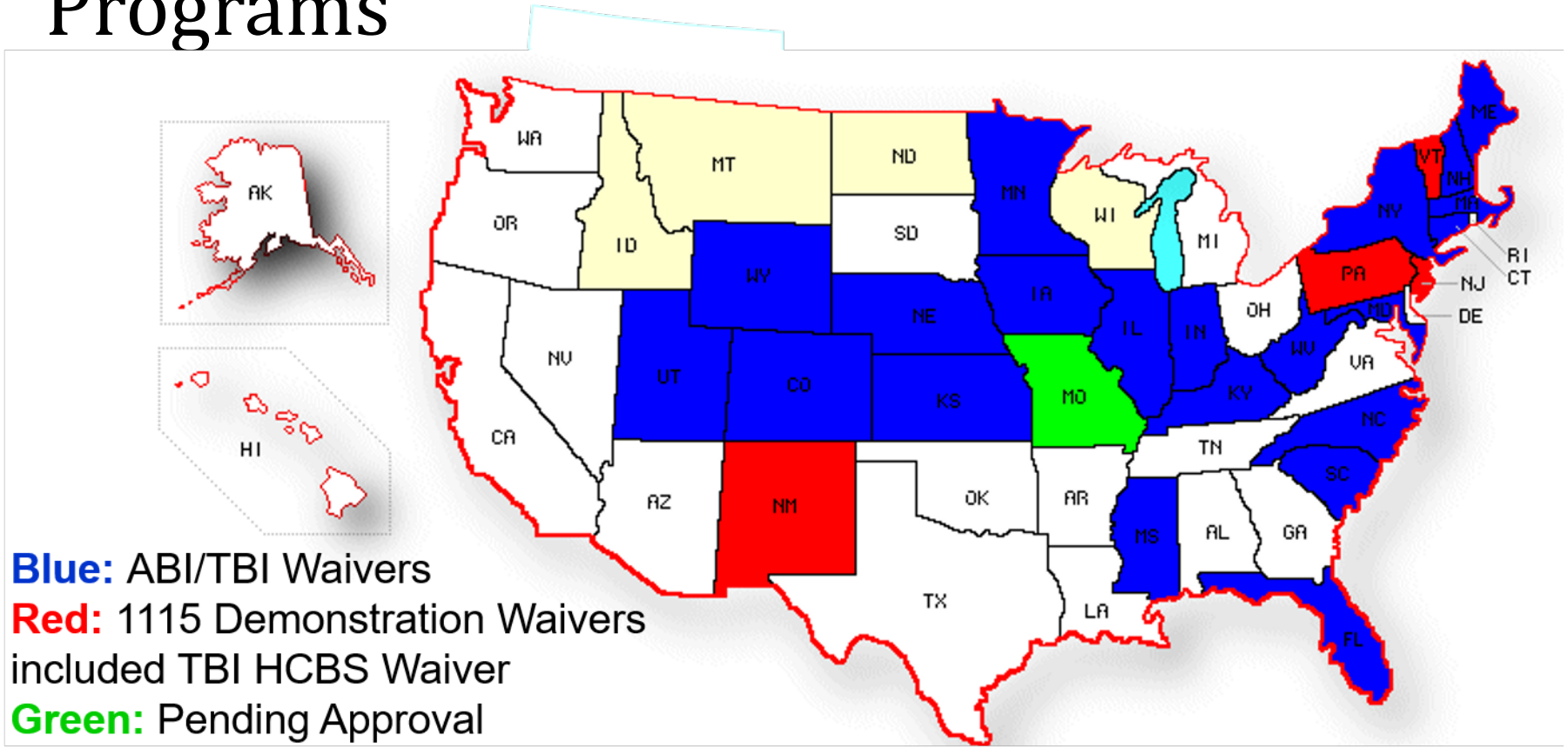
Source: Susan Vaughn, NASHIA

Trust Fund/State Programs

- Revenue generator, usually traffic fines
- Advisory boards/councils or task forces
- Purposes vary:
  - Research, public information, prevention administration, services and supports
  - Thru contracts, grants, provider agreements or direct program staff

Source: Susan Vaughn, NASHIA

Acquired Brain Injury/TBI Home and Community Based Services (HCBS) Programs



Source: Susan Vaughn, NASHIA

State Agencies for TBI Programs

- Vocational Rehabilitation
- Health
- Education
- Developmental Disabilities
- Mental Health
- Social Services/Human Services
- Medicaid

Source: Susan Vaughn, NASHIA

Common experiences after brain injury that can be supported and accommodated through person-centered approaches

- Memory, especially new learning
- Attention and concentration may be shallow, difficult to maintain
- Organizational issues
- Impulsivity and dysregulation of words and actions (can lead to misunderstandings, conflict)
- Auditory comprehension
- Word retrieval difficulties (tip of the tongue)

Common experiences after brain injury that can be supported and accommodated through person-centered approaches

- Coordination and motor control issues
- Sleep disorders
- Seizure disorder
- Fatigue
- Visual impairment
- Depression
- Anxiety
- Little to no awareness of injury imposed challenges and their application to day-to-day functioning

Individuals living with recognized AND unrecognized and unsupported brain injury history are highly represented among these populations

- Athletes – professional and amateur
- Incarcerated individuals
- Children & Youth
- Older adults
- Individuals served by the public behavioral health system (mental health and substance use disorder treatment services)
- Victims of intimate partner violence
- Victims of assault
- Service members/veterans
- Individuals who survive opioid overdoses/multiple overdoses
- Homeless and formerly homeless

Definitions

- **Person-centered thinking** is a foundational principle—requiring consistency in language, values and actions—that reveals respect, views the person and their loved ones as experts in their own lives, and equally emphasizes quality of life, wellbeing, and informed choice.
- **Person-centered planning** is a methodology that identifies and addresses the preferences and interests that make up a desired life and the supports (paid and unpaid) needed to achieve it. It is directed by the person, and it is supported by others selected by the person.
- **Person-centered practices** are the alignment of services and systems to ensure the person has access to the full benefits of community living and to deliver services in a way that facilitates the achievement of the person's desired outcomes.

Retrieved on 6/5/19 from https://ncapps.acl.gov/about-ncapps.html

Examples:
Non Person-Centered Approaches

- Narrow and presumptive assessments and evaluations at intake
  - e.g., an individual seeking services from a mental health provider is not screened/asked about history of brain injury, or addiction, or trauma...
- Treatment plans that consist of a checklist, use medical jargon, and are not accessible to the individual
- Treatment plans that are embedded in the electronic medical record and not easily available to the individual
- Treatment not individualized to the person

An attorney living with a brain injury working with a speech therapist for language and memory problems post TBI is given generic worksheets to address post-injury

A treatment team tells a young woman with severe cognitive, behavioral and physical barriers post brain injury that returning to graduate school (her goal) is "unrealistic"

Examples:
Person-Centered Approaches

- Holistic and flexible intake process; relationship-building facilitated through informal and formal tools (more time-intensive on the front end)
- Treatment plan is the culmination of the assessment processes and conversations and consultations with the individual, the treatment team, and any supporters the individual wishes to include in the process
- Treatment plan is written in a personal, jargon-free manner and the individual is given a copy, either electronically or a hard copy depending on their choice

The attorney's speech therapist, uses text from the LSAT and law journals to address language and memory issues during their therapy sessions

The treatment team, having taken the time to know the young woman and realizing that what she really misses is the social environment of a college campus and being around smart people, arrange for her, accompanied by her support staff, to audit a class at the local university

Barriers to delivery

- For those who have been diagnosed with and treated for a brain injury, whether mild (aka a concussion) or moderate to severe, care is delivered within the context of the medical model and can be fragmented and poorly coordinated.
- Long-term, brain injury-informed supports are **inconsistently** available for those whose brain injury is moderate to severe and/or the sequela of their brain injury is complex as well as for those with co-occurring behavioral health issues.

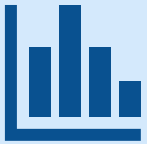
Barriers to delivery

- Over time, individuals and their families may find themselves seeking services from systems that are not brain injury-informed, resulting in: misdiagnosis, little or no appreciation of the functional implications of brain injury, difficulty establishing therapeutic alliances, and “treatment failure.”
- Individuals with a history of brain injury are served by State Aging and Disability Services as well as by programs that serve individuals with intellectual and developmental disabilities.
- Over the past 20 years or so, evidence is accumulating regarding the prevalence of individuals whose undiagnosed/undertreated brain injuries are the root of their entry into a variety of systems and programs.

Physical, Cognitive and Behavioral Signs & Symptoms can be Misunderstood Within Home and Community Based Services Settings

- Underscores the need for staff training
- More frequent planning meetings than is typical in HCBS settings
- Appreciation that for individuals living with a brain injury, there is usually a memory of life BEFORE the brain injury
- Improvements do and can occur, especially with appropriate supports, for years post injury; this underscores the need for referrals when indicated for rehabilitation services such as speech, occupational and physical therapy

Poll Question: Services that are hardest to access.



Please indicate the services that are MOST difficult to access for a person or people you support who are living with a brain injury. You can select up to 4.

- Brain injury rehabilitation services
- Psychiatry and mental health services & supports
- Substance use treatment
- Brain injury support groups
- Employment services
- Housing
- Transportation
- Resource coordination/case management

Foundations of **Brain Injury-Informed Services**

- **Screen, Screen, Screen** for a history of brain injury as part of intake and assessment as individuals enter services. There are several good tools that can help providers determine if a brain injury or brain injuries is part of someone's medical history (recognized gold standard is the Ohio State University TBI Identification Tool; the HELPS Screening is a good tool to begin the discussion).
- **Support and Accommodate.** Again simple tools and strategies can be tailored for individuals by collaborating with them and their natural supporters to see what works for them.
- Do not take "uncooperative" or "manipulative" behavior at face value.
- Ask open-ended questions, not "yes" or "no" questions.

Foundations of **Brain Injury-Informed Services** (cont.)

- Use person-centered language at all times.
- Trauma-informed strategies do double duty as supports for individuals with brain injury-related cognitive barriers (e.g., clear signage and quiet spaces within agencies, programs, facilities).
- We do not have to reinvent the wheel in terms of person thinking and person-centered care planning. We can borrow and adapt from our colleagues doing this work in the developmental/cognitive disabilities and behavioral health arenas.

Questions?

Real-Time Evaluation:

We want to hear from you!

Resources

- Brain Injury Association of America www.bia.usa
- Centers for Disease Control and Prevention https://www.cdc.gov/traumaticbraininjury/index.html
- NASHIA https://www.nashia.org/
- Administration for Community Living, Federal TBI Program https://acl.gov/programs/post-injury-support/traumatic-brain-injury-tbi
- TBI Model Systems https://msktc.org/tbi/model-system-centers
- BrainLine https://www.brainline.org/
- Ohio Valley Center for Brain Injury Prevention and Rehabilitation online resources and tools https://tbi.osu.edu/modules

Thank You.

Register for upcoming webinars at
https://ncapps.acl.gov/

Coming Soon: Learning Collaborative: Person Centered Practices for people living with Brain Injury

NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by HSRI.

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