Keeping the Passion: Getting and Staying Involved in the Brain Injury Community

August 31, 2022



TBI TARC is supported by contract number HHSP233201500119I from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201

Welcome to Today's Webinar



Terry Camacho-Gonsalves, PhD

Director

Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC) and HSRI Thank you for joining us to learn about **Keeping the Passion Alive: Getting and Staying Involved in the Brain Injury Community.**

This webinar is sponsored by the Traumatic Brain Injury Technical Assistance and Resource Center. TBI TARC is funded by the Administration for Community Living.

The TBI TARC is administered by the Human Services Research Institute (HSRI) with the assistance of the National Association of State Head Injury Administrators (NASHIA).

This webinar is free and open to the public.



Webinar Logistics

- Participants will be in listen-only mode during the webinar. Please use thechat feature in Zoom to post questions and communicate with the hosts.
- Towards the end of each section 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 live interpreted in Spanish.
- Live English captions can be accessed by clicking the "**CC**" button at the bottom of your Zoom screen.
- Live Spanish interpretation can be accessed by clicking the "**interpretation**" button at the bottom of your Zoom screen (world icon).To access the Spanish captions, please use the link provided in the chat.
- Se puede acceder a la interpretación en español en vivo haciendo clic en el botón "interpretation" en la parte inferior de la pantalla de Zoom (icono del mundo). Para acceder a los subtítulos en español, utilice el enlace proporcionado en el chat.
- 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 to <u>tbitarc@hsri.org</u>

(Please note: This email address will not be monitored during the webinar.)

 A recording, including a pdf version of the slides, will be available on the ACL website (<u>acl.gov</u>)





"In what role(s) do you self-identify? Select all that apply."

- Person with a traumatic brain injury (TBI) or other disability
- 2. Family member or friend of a person with a TBI or other disability
- 3. Self-advocate / advocate
- 4. Peer-specialist / peer-mentor

- 5. Social worker, counselor, or care manager
- 6. Researcher / analyst
- 7. Service provider organization employee
- 8. Government employee (federal, state, tribal, or municipal)

Speakers & Moderators



Maria Crowley, MA, CRC

Technical Assistance (TA) Lead

TBI TARC & NASHIA



Judy Dettmer, BSW

TA Lead

TBI TARC & NASHIA

Speakers



Carole Starr

TBI Survivor, Speaker, Author and Advocate

Traumatic Brain Injury Advisory and Leadership Group (TAL-Group)

Cheryl Kempf

Brain Trauma and PTSD Survivor, Advocate and Speaker

TAL-Group

Clifford Hymowitz

Brain Injury Survivor and Mental Health PEER Specialist

TAL-Group



Kelly Lang

Survivor, Caregiver and Former Board Member

TAL-Group

SECTION 1: INTRODUCTION AND PURPOSE

Maria Crowley Judy Dettmer

Introductions & Purpose

- Brief Introductions to:
 - Administration for Community Living
 - TBI State Partnership Program
 - Advisory Boards
 - Today's Webinar

Administration for Community Living

Mission

Maximize the independence, well -being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

Vision

For all people, regardless of age and disability, to live with dignity, make their own choices, and participate fully in society.

TBI State Partnership Program



Purpose: Create and strengthen person-centered, culturally **competent systems** of services and supports that maximize the independence and overall health and well-being of people with TBI across the lifespan and the people who support them.

TBI SPP GOALS

- Better coordinated public investment in effective, high-quality, equitable, evidence-based services & supports, resulting in...fewer people with TBI encountering barriers to needed services and supports
- Better collaboration and coordination across state systems and agencies
- Ample opportunities for *all* people with TBI to participate meaningfully in state efforts and plans to improve services & supports
- Enhanced data collection to show level of need for (and barriers to) various types of services and supports across systems
- Greater understanding of state demographics, resources, and program impact as well as effectiveness of services or supports

TBI SPP Grantees

- Alaska
- Alabama
- Arkansas
- California
- Colorado
- Georgia
- Iowa
- Idaho
- Indiana
- Kansas
- Kentucky
- Maine
- Massachusetts
- Maryland
- Minnesota

- Missouri
- Nebraska
- New Jersey
- North Carolina
- North Dakota
- Ohio
- Oregon
- Pennsylvania
- Rhode Island
- Tennessee
- Utah
- Virginia
- West Virginia



TBI SPP Grantee Responsibilities



State TBI Advisory Board Requirement

Description



The advisory board or council provides an opportunity to ensure a variety of stakeholders participate in determining the needs of individuals with TBI, their families, and support systems. It creates structure for statewide cross-systems collaboration, which is essential for systems change work. All grantees are required to establish and/or maintain an advisory board within the lead state agency

Clarifying points

TBI advisory boards or advisory councils should include the following in accordance with and in addition to the mandates of 42 U.S.C, § 300d–52, and in alignment with ACL's commitment to independent living and person-centered planning:

- Membership that is at least 50% comprised of people with TBI (i.e., survivors)
- Family member(s) of people with TBI
- Center for Independent Living/State Independent Living Council representation
- Aging and Disability Resource Center representation if one exists in the state
- Protection & Advocacy agency representation
- Long-term care ombudsman representation
- NIDILRR-funded TBI Model System Center representation if one exists in the state
- Is representative of the state and includes individuals from culturally and linguistically diverse populations from both rural and urban areas.

Other State Boards and Involvement

- Advocacy Organizations
- Coalitions
- Trust Funds
- Support Groups
- Peer Supports Advisories

Today's Webinar

- Readiness to engage and engagement
- Opportunities to engage
- Places/Events to engage
- Graduate to leading others
- How to find opportunities
- How to stay engaged

SECTION 2: READINESS TO ENGAGE AND ENGAGE AND Carole Starr Cheryl Kempf

Readiness to Engage

Carole Starr



Gauging Readiness

Questions for Brain Injury Survivors TBI Program Staff & State/Community Providers (1 of 5)

Where is the person in their brain injury journey—learning to cope vs. ready to pay it forward?



Gauging Readiness

Questions for Brain Injury Survivors TBI Program Staff & State/Community Providers (2 of 5)

Have they regularly attended meetings such as a support group?



Can they tell their brain injury story briefly, without excess emotion? Are they telling their story to help themselves or to help others?



manage brain injury symptoms?



Gauging Readiness

Questions for Brain Injury Survivors TBI Program Staff & State/Community Providers (5 of 5)

Do they know what accommodations they need to be successful?

What is Engagement?

Cheryl Kempf

What is Engagement? (1 of 3)

- Engaged is to be involved in an activity.
- If you have experienced a brain injury and the life changes it brings, being active in areas we did not choose is a decision that is hard.
- In the summer of 2012, an event happened to me that resulted in my deciding to work for a law to prevent what happened to me as a brain injury survivor on a road at night. The success along the way led me to the advanced levels of engagement; the passing of a federal law protecting brain injury and PTSD survivors by educating law enforcement about our needs.
- These points are drawn from my advocacy for the TBI and PTSD Law Enforcement Training Act, which I advocated for and saw become both a Texas state law, HB 1338, 84(R)), Naishtat, and at the US Congressional level as HR 2992 – 117th, signed into law by the President on August 16, 2022.

What is Engagement? (2 of 3)

- Engagement can be lowkey or complex as you participate in a goal or effort.
- Good engagement takes planning and preparation, to evaluate if you are ready, here are some questions and considerations.

What is Engagement? (3 of 3)

Points to consider

- **1. What is your comfort level?** As a brain injury survivor, I didn't talk much about it for many years. Not until I met other survivors. Never publicly.
- 2. What will it take to achieve your goal? I had to find the starting point and then the path for this law.
- **3. Where do you start?** With an interested person, learn what they know, who they know. The national level was more learning. I was invited to Washington for the first time in June of 2017.
- 4. Who are you speaking to? What is the environment? A few moments, loud, rushed, quiet?
- 5. How can you best present it so it is heard?
- 6. What do you want them to do with your message? State your ask.

7. Do they have a card for how you can reach them? Leave the impression that you will follow up. Then do.

- 8. Did it work? Watch for results.
- 9. Leave them a takeaway, a reminder of your work.
- 10. Say thank you for hearing me today and reiterate your purpose one more time.

Links to State and National Level Legislation

• H.B. 1338, 84(R), Naishtat

Acquired and Traumatic Brain Injury Training https://capitol.texas.gov/tlodocs/84R/billtext/pdf/HB01338F.pdf

House Bill 1338 amends the Occupations Code to require the Texas Commission on Law Enforcement (TCOLE), in collaboration with the office of acquired brain injury of the Health and Human Services Commission and the Texas Traumatic Brain Injury Advisory Council, to establish and maintain a training program for peace officers and first responders that provides information on the effects of an acquired brain injury and of a traumatic brain injury and techniques to interact with persons who have such a brain injury. The bill requires TCOLE, in collaboration with the Texas Veterans Commission, to establish and maintain a training program for peace officers that provides information on veterans with certain specified trauma-related injuries.

• H.R. 2992, 117th Congressional Session, Pascrell and Bacon

Traumatic Brain Injury and Post-Traumatic Stress Disorder Law Enforcement Training Act or the TBI and PTSD Law Enforcement Training Act <a href="https://www.congress.gov/bill/117th-congress/house-bill/2992#:~:text=H.R.2992%20-%20TBI%20and%20PTSD%20Law%20Enforcement%20Training,%282021-2022%29%20Bill%20Hide%20Overview%20More%20on%20This%20Bill

This bill requires the Bureau of Justice Assistance (BJA) to consult with relevant agencies to establish crisis intervention training tools for first responders to address individuals with traumatic brain injuries, acquired brain injuries, and post-traumatic stress disorder. The BJA must ensure that at least one police department designated as a Law Enforcement Mental Health Learning Site utilizes the tools and that such tools are part of the Police-Mental Health Collaboration Toolkit. Additionally, the bill requires the Centers for Disease Control and Prevention to study and report about the prevalence and incidence of concussions among first responders.

SECTION 3: OPPORTUNITIES TO ENGAGE Clifford Hymowitz Carole Starr Cheryl Kempf Engaging in Community/ Grassroots Efforts

Clifford Hymowitz

- Who is part of the TBI community where I live?
- Where do I find people in the TBI community to connect with them?
- How did I begin a grassroots effort?
- Asset-Based Community Development

The ABCD approach was developed by John L. McKnight and John P. Kretzmann at the Institute for Policy Research at Northwestern University in Evanston, Illinois. They co-authored a book in 1993, *Building Communities from the Inside Out: A Path Toward Finding and Mobilizing A Community's Assets*,¹ which outlined their asset-based approach to community development.² The Community Development Program at Northwestern University's Institute for Policy Research established the Asset-Based Community Development Institute based on three decades of research and community work by John P. Kretzmann and John L. McKnight.

¹ <u>https://en.wikipedia.org/wiki/Asset-based_community_development#cite_note-</u> <u>Building_Communities_from_the_Inside_Out-3</u>

² https://en.wikipedia.org/wiki/Asset-based_community_development#cite_note-ABCD_Institute_Website-4______31 Engaging in Brain Injury Support Groups

Carole Starr

 Brain injury support groups provide opportunities for survivors to practice skills and get involved

 Support groups are also a good place for TBI program staff & state/community providers to find brain injury survivors who are ready for the next level of engagement

Engaging in State Advisory Boards

Cheryl Kempf

- I have been an acquired brain injury, ABI, survivor since 1994.
- In that time, I have worked at many levels, from attending committee meetings to learn about brain injury needs and services to being the chair of the advisory council to the Health and Human Service Commission for the state of Texas.
- Most states have a brain injury advisory council, their meeting schedule and structure differ from state to state. The required make-up was presented earlier.
- These councils advise the state agencies about brain injury. They are usually supported by a program office that connects the council to the agency they work with.
- The councils are composed of both brain injury survivors with lived experience, family members, caregivers and program or agency employees.
- Membership qualifications are often by a specific background so that a balance of perspectives is maintained.
- There are opportunities to engage for survivors, program or agency staff, family members and caregivers. Nominations are made and members are appointed to the council.

Engaging in Committees

Cheryl Kempf

- The Advisory Boards are supported by committees whose job it is to research and do work between meetings on the aspects of the council's business.
 - They are a good way to learn the work of the council without the formal appointment or responsibility of the council.
- An example board might meet quarterly and has standing committees such as:
 - Legislative, Policy
 - Nominations
 - Education
 - Awareness, Outreach,
 - Services and Supports
 - Administrative items, such as database development or rules
- The committees provide an update to the advisory council at the official council meetings.

What have I learned as a board chair?

- Creating an open, welcoming environment helped survivors, ٠ family members and professionals to contribute to our effort for brain injury. Survivors and program people are our front line and can often give effective suggestions or solutions. Some suggestions:
 - \checkmark Be ready
 - ✓ Be organized
 - \checkmark Be flexible
 - ✓ Be fair
 - ✓ Be empathetic
 - ✓ Be mindful of time
 - \checkmark Be engaged
 - ✓ Do follow-up
 - ✓ Do work between meetings
 - \checkmark Work in writing or documentation
 - ✓ Keep your language and pages simple
- I resigned as Chair of TBIAC so I could advocate for the law, • the TBI and PTSD Law Enforcement Training Act, HR 2992 -117th (formerly Texas HB 1338, 84(R), which was signed into law on August 16, 2022.

BREAK

Up Next:

- Places and Events to Engage
- Graduating to Leading Others
- Finding Opportunities to Engage
- Staying Engaged
- Questions & Answers


SECTION 4: STATE & NATIONAL EVENTS FOR ENGAGEMENT

Kelly Lang

What are some of the places and events to engage in?

- State events
- Brain Injury Awareness Day
- Administration for Community Living Brain Injury Stakeholder Day

SECTION 5: GRADUATING TO LEADING OTHERS & PEER TO PEER SUPPORT

Clifford Hymowitz

Leadership Strategies (1 of 2)

• Building trust is the foundation for leading others (https://www.gallup.com/cliftonstrengths/en/250979/strengths-

based-leadership-building-trust-followers.aspx)

- Bring positive energy and a willingness to listen (<u>https://www.gallup.com/cliftonstrengths/en/250931/strengths-</u> based-leadership-building-compassion-followers.aspx)
- Ensure people can count on you (<u>https://www.gallup.com/cliftonstrengths/en/250817/strengths-based-leadership-building-stability-followers.aspx</u>)
- Encourage people to believe in a better future (<u>https://www.gallup.com/cliftonstrengths/en/250571/strengths-based-leadership-building-hope-followers.aspx</u>)
- Having a common bond of lived experience with those who are using services

Leadership Strategies (2 of 2)

- Speak from EXPERIENCE
- Educate other disability groups about TBI
- Show up when action is required
- Keep aware so that you can educate others
- Refer people to resources such as:
 - Administration for Community Living (<u>https://acl.gov/programs/post-injury-support/traumatic-brain-injury-tbi</u>)
 - NASHIA (<u>https://www.nashia.org/state-program-directory</u>) so that they can identify their local State Resources
 - Brainline <u>https://www.brainline.org/resource/national-resource-center-</u> <u>traumatic-brain-injury</u>
 - o Brain Injury Association of America https://www.biausa.org/find-bia
 - United States Brain Injury Alliance- <u>https://usbia.org/about/</u>

What is the Peer Mentorship Program?

Mentoring is a process of semi-structured guidance thereby the mentor shares their knowledge, skills, and experience to assist the peer. Mentorship is peer-centered.

Zach Hudson, Program Manager – Peer Mentorship, Brain Injury Alliance of Colorado

Benefits of Peers

- Increased community integration and independence
- Increased confidence with communication and interpersonal skills and perceived social support
- Increased satisfaction with life and selfempowerment
- Decreased isolation

Texas: Peer Support

- Brain Injury Network of Dallas (BIND) (<u>https://www.thebind.org/</u>):
 - Serves as the Dallas-Fort Worth areas only provider of peer-to-peer mentoring – a program called Peer Partners.
 - Launched in 2012, trained mentors are brain injury survivors and caregivers who offer support and resource facilitation to others who are experiencing adjustment challenges following acquired brain injury.
 - Also have a Clubhouse program that is based on the operating standards established by the International Brain Injury Clubhouse Alliance (<u>https://braininjuryclubhouses.net/</u>).
- Behavioral Health State Contact: Noah Abdenour (<u>Noah.Abdenour@hhs.Texas.gov</u>) a Certified Peer Specialist is the Director of Peer and Recovery Services Programs, Planning and Policy at Texas Health and Human Services Commission.

Georgia: Peer Support

• TBI Peer Support:

- Kathy H. O'Brien and Tracy Wallace (her collaborator at Shepherd Center) currently have a training program for people with mild TBI.
- The training is built off Sheperd's spinal cord injury peer program¹, which was developed by Pete Anziano and supported by a Patient-Centered Outcomes Research Institute (PCORI) grant.
- In developing their peer support program, they visited 8 different sites, including the most developed program through the Ontario Brain Injury Association (OBIA)

 Behavioral Health State Contact: Dana McCrary (<u>Dana.McCrary@dbhdd.ga.gov</u>) a Certified Peer Specialist-Parent and Certified Peer Specialist - Addictive Diseases is the Director of the Office of Recovery Transformation, Georgia Department of Behavioral Health and Developmental Disabilities, Division of Behavioral Health

¹ <u>https://www.shepherd.org/resources/peer-support</u>

SECTION 6: FINDING OPPORTUNITIES TO ENGAGE

Carole Starr

Start Small, Find Success & Build on It A Few Ideas for Brain Injury Survivors (1 of 5)

Join Brain Injury Email Lists

- Local brain injury organization
- Brain Injury Association of America https://www.biausa.org
- United States Brain Injury Alliance https://usbia.org
- Model Systems Knowledge Translation Center https://msktc.org/tbi

Start Small, Find Success & Build on It

A Few Ideas for Brain Injury Survivors (2 of 5)

Attend Events (or parts of events) & Meet People

- Brain injury support group
- State brain injury conference
- Resource fair
- Fundraisers

Start Small, Find Success & Build on It

A Few Ideas for Brain Injury Survivors (3 of 5)

Talk to Other Brain Injury Survivors

- Ask how they got involved
- Learn from their experience

Start Small, Find Success & Build on It A Few Ideas for Brain Injury Survivors (4 of 5)

Get Involved in Brain Injury Groups on Social Media

Start Small, Find Success & Build on It A Few Ideas for Brain Injury Survivors (5 of 5)

Raise your Hand & Get Involved

- Ask a question
- Volunteer

Start Small, Find Success & Build on It

General Advice

- Be Open to Trying Something New
- Push a Little Past your Comfort Zone
- Recognize that Strategies will be Needed for Success
- Keep Trying

Start Small, Find Success & Build on It

Advice for TBI Program Staff, State/Community Providers

- Break tasks down. Be specific about the commitment required from a brain injury survivor
- Use mentors to help turn challenging situations into successes
- Think about how to make an experience into a success for a brain injury survivor
- Know what the survivor needs, not just what your board/committee needs

SECTION 7: STAYING ENGAGED

Kelly Lang

Engagement for Survivors

- Prepare
- Know Yourself
- Accommodations
- Reflect



Engagement for TBI State Program Staff and State Community Providers

- Application
- Orientation
- Mentor Program
- Feedback







Real-Time Evaluation Questions (1 of 2)

- Please take a moment to respond to these six evaluation questions to help us deliver high-quality TBI TARC webinars
- If you have suggestions on how we might improve TBI TARC webinars, or if you have ideas or requests for future webinar topics, please send us a note at <u>TBITARC@hsri.org</u>

Real-Time Evaluation Questions (2 of 2)

- **1.** Overall, how would you rate the quality of this webinar?
- 2. How well did the webinar meet your expectations?
- 3. Do you think the webinar was too long, too short, or about right?
- 4. How likely are you to use this information in your work or day-to-day activities?
- 5. How likely are you to share the recording of this webinar or the PDF slides with colleagues, people you provide services to, or friends?
- 6. How could future webinars be improved?

MEET THE PRESENTERS



Clifford Hymowitz

Brain Injury Survivor and Mental Health PEER Specialist TAL-Group

Clifford Hymowitz is a member of the TBI Community in New York State, where he is employed as a Peer Specialist for Federation of Organizations in Suffolk County New York. He is presently enrolled in the Academy of Peer Specialist In for certification; as well as the PEER Specialist Training Group with the Mental Health and Wellness Association of Suffolk County He is currently serving as an appointed member to the New York State Traumatic Brain Injury Services Coordinating Council. He previously served as a member of East Seal's National Steering Committee of Project Action, where he was the first participant with a hidden disability.

Cheryl Kempf

Brain Trauma and PTSD Survivor, Advocate and Speaker TAL-Group

Cheryl Kempf is a survivor of an Acquired Brain Injury (ABI) event which occurred in 1994. She works and speaks on brain injury recovery, rehabilitation and adjusting to life changes, in topics such as "What Do You See When You" Look At Me?". In 2012, a negative law enforcement incident added PTSD to her life experience, and she became the catalyst for a Texas state law, HB 1338, 84th R Legislative Session, Naishtat, through her work summarized as "To Be Different Is Not To Be Guilty." In 2016 she was invited to Washington, D.C. and first presented this Texas law on a national level. On March 4, 2020 she was a panelist for the Congressional Briefing discussing this law as part of Brain Injury Awareness Day on the Hill. Her primary website, ever evolving is https://cherylswords.com/ .

Kelly Lang

Survivor, Caregiver and Former Board Member TAL-Group

Kelly Lang is a brain injury survivor and caregiver to her daughter who sustained a traumatic brain injury in 2001 at the age of 3. Kelly is a member of the Brain Injury Association of America's Brain Injury Advisory Council, a co-leader of The TBI Advisory and Leadership Group, and a former faculty member of the National Center for Advancing Person-Centered Practices and Systems (NCAPPS) Brain Injury Learning Collaborative. Kelly also serves on the Virginia Brain Injury Advisory Council. Kelly has spoken to many groups including speech, occupational and physical therapists, neuroscience students, attorney groups, and support groups. Kelly has presented at the TBI Interagency Conference on Traumatic Brain Injury and spoke at the NIH Conference for Rehabilitation. Kelly and her husband created a website <u>https://www.themiraclechild.org/</u> to educate others about brain injury and published a book *The Miracle Child: Traumatic Brain Injury and Me*.

Carole Starr

TBI Survivor, Speaker, Author, Advocate TAL-Group

Carole Starr sustained a brain injury in a car accident in 1999. The ongoing symptoms left Carole unable to return to her life as a teacher and classical musician. One small step at a time, she's reinvented herself. Carole is now a national keynote speaker, the author of the award-winning book To Root & To Rise: Accepting Brain Injury and the founder/facilitator of Brain Injury Voices, a survivor volunteer group in Maine. Carole serves on the Brain Injury Association of America (BIAA)—Maine Chapter Advisory Board, co-chairs the BIAA Brain Injury Advisory Council and was a faculty member for NCAPPS Brain Injury Learning Collaborative. Carole is passionate about using her brain injury experience to make a difference for others. She serves as TAL Group Co-Lead.

Thank You

The Traumatic Brain Injury Technical Assistance and Resources Center (TBI TARC) is an initiative from the Administration for Community Living that helps TBI State Partnership Program grantees promote access to integrated, coordinated services and supports for people who have sustained a TBI, their families, and their caregivers. The Center also provides a variety of resources to non-grantee states, people affected by brain injury, policymakers, and providers.





TBI TARC

Traumatic Brain Injury Technical Assistance and Resource Center