# Workshop Wednesday:

Peer Support Best Practices for Working with Individuals with Brain Injury

# Judy Dettmer

Director of Strategic Partnerships

**National Association of State Head Injury Administrators** 

February 22, 2023

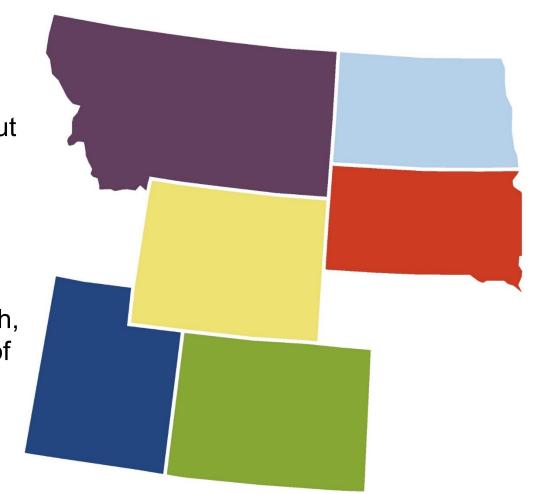




## The Mountain Plains Mental Health Technology Transfer Center

The Mountain Plains Mental Health Technology Transfer Center (Mountain Plains MHTTC) provides training and technical assistance to individuals who serve persons with mental health concerns throughout Region 8 (Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming).

We belong to the Technology Transfer Center (TTC) Network, a national network of training and technical assistance centers serving the needs of mental health, substance use, and prevention providers. The work of the TTC Network is under a cooperative agreement by the Substance Abuse and Mental Health Service Administration (SAMHSA).



# Land Acknowledgement Statement

Today, the University of North Dakota rests on the ancestral lands of the Pembina and Red Lake Bands of Ojibwe and the Dakota Oyate - presently existing as composite parts of the Red Lake, Turtle Mountain, White Earth Bands, and the Dakota Tribes of Minnesota and North Dakota. We acknowledge the people who resided here for generations and recognize that the spirit of the Ojibwe and Oyate people permeates this land. As a university community, we will continue to build upon our relations with the First Nations of the State of North Dakota - the Mandan, Hidatsa, and Arikara Nation, Sisseton-Wahpeton Oyate Nation, Spirit Lake Nation, Standing Rock Sioux Tribe, and Turtle Mountain Band of Chippewa Indians.



The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

STRENGTHS-BASED AND HOPEFUL

INCLUSIVE AND
ACCEPTING OF
DIVERSE CULTURES,
GENDERS,
PERSPECTIVES,
AND EXPERIENCES

HEALING-CENTERED AND TRAUMA-RESPONSIVE

Inviting to individuals PARTICIPATING IN THEIR OWN JOURNEYS

PERSON-FIRST AND FREE OF LABELS

NON-JUDGMENTAL AND AVOIDING ASSUMPTIONS

RESPECTFUL, CLEAR AND UNDERSTANDABLE

CONSISTENT WITH OUR ACTIONS, POLICIES, AND PRODUCTS

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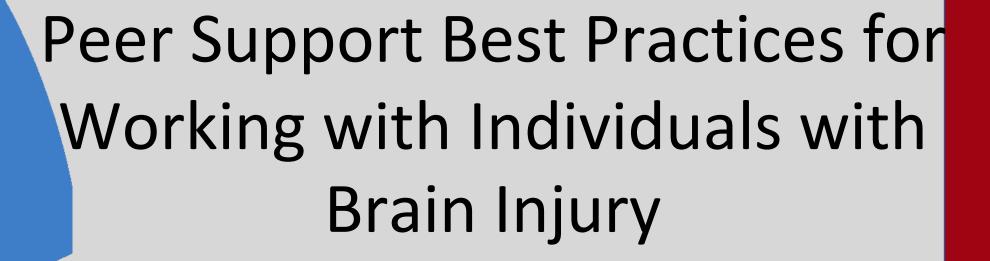
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idettmer@nashia.org

# National Association of State Head Injury Administrators

Nonprofit organization created to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families.



# Agenda

- . Background on the merits of brain injury peer support
- II. Overview of brain injury specific peer support models



### A Definition

"Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful."

When people find affiliation with others whom they feel are "like" them, they feel a connection, this connection, or affiliation, is a deep, holistic understanding based on mutual experience where people are able to "be" with each other without the constraints of traditional (expert/patient) relationships".

(<a href="https://mhepinc.org/defining-peer-support/">https://mhepinc.org/defining-peer-support/</a>)
(Adapted from Shery Mead)



### Another definition

Peer support is the process of offering support and assistance in order to improve wellbeing and adjustment. Peer supporters offer emotional support through listening and sharing knowledge/experience, teaching skills, and connecting people with resources, opportunities, communities of support.

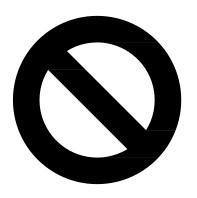
A peer has personal knowledge of what it is like to live and thrive with a brain injury.





### Peer Supporters are not:

- Therapists
- Advice Givers
- Legal Advisor
- A romantic partner
- Respite care giver
- Financial Supporters
- People that will do things for the Peer (help with moving, paperwork, etc.)





### Peer Support - Origins

In mental health services, the model is thought to have its origins in 18th century France, "As much as possible, all servants are chosen from the category of mental patients.

They are at any rate better suited to this demanding work because they are usually more gentle, honest, and humane".

Jean Baptiste Pussin
(in a 1793 letter to Philippe Pinel)





## Findings on Peer-to-Peer Relationships

- Hope through positive self-disclosure, "it is possible to go from being controlled by the illness to gaining some control over the illness, from being a victim to being the hero of one's own life journey".
- Modeling function to include self-care of ones' illness and exploring new ways of using experiential knowledge.
- The "relationship is characterized by trust, acceptance, understanding, and the use of empathy; empathy which is in this case is paired with "conditional regard"-otherwise described as a peer provider's ability to "read" a client based on having been in the same shoes he or she is in now".

### Peer - Definitions

- Peer Support
- Peer-to-Peer Support
- Peer Supporter
- Peer Mentor
- Mentees
- Support Groups



- 29% indicated the most beneficial part of the program was just having someone to talk to.
- 12% indicated that having someone to rely on who had experience with brain injury was most helpful.
- 12% indicated that the mentor's advice was most beneficial.
- 7% reported that the self-discovery process involved in mentoring was most helpful.

Hanks, Rapport, Wertheimer, and Koviak (2012) utilized a randomized controlled trial of 92 persons with TBI's and their family members.



Results of a Quasi-experimental design by Hibbard and Cantor involving 64 individuals with TBI divided between the control group and experimental group demonstrated:

- Decreased depression
- Improvement in empowerment
- Improvement in life satisfaction
- Improvement in coping
- Increased communication with the rehabilitation team.

Hibbard and Cantor (2005)



Research using a retrospective questionnaire and measures related to empowerment, coping, perceived control over life, and quality of life found the following:

- Increased knowledge of TBI
- Improved Quality and outlook on life
- Increased coping abilities
- Improved self-efficacy.

Hibbard, Cantor, Charatz, Rosenthal, Ashman, Gunderson, et al. (2002)



A meta-analysis of six research studies of peer mentorship for people with TBI found:

#### Social/community benefits

- Decreased isolation/increased community reintegration
- Increased independence in the community
- Increased social support

#### **Emotional benefits**

- Improvement with mood
- Quality of life
- Life satisfaction and general outlook

#### **Behavioral benefits**

- Decreased chaos in the living environment
- Decreased alcohol use
- Increased physical quality of life



# Models of Peer Support





### Volunteer / Paid

#### **PAID**

- It is possible to require more investment and training and program fidelity (getting paperwork in on time and duration of engagement)
- Less oversight (fewer peer supports matched to multiple peers).
- Easier to match if you have a peer supporter that has a greater breadth of awareness to the multiple aspects of disability.
- Qualifications, skills set, training are heightened considerations

#### **VOLUNTEER**

Heart of volunteerism and passion to be of service



### Formal / Informal

- Longer -term (One year recommended for adults; longer for youth)
- Potentially fuller impact on confidence, self-esteem, attitudinal shifts, and behavioral shifts
- Heightened:
  - Screening
  - Training
  - Administrative oversight
  - Program expectations
  - Supervision





## Formal / Informal

- Less time, money, and organizational requirements
- Short-term, low administrative oversight
- Training still required
- Matching could be done online or through staff experience with potential peer supporter
- Ideal setting inpatient or transition from hospital to home





### Family-to-Family

- Families receive education, information, and the support of others who have similar experiences
- Hope, guidance, advocacy, and camaraderie
- Coping skills and resources



### Hospital to Home

- Typically, patients are matched prior to discharge
- Support with answering questions, building confidence, and supporting in the community and/or at home
- These programs tend to be informal, so little data is collected as to the number of contacts or the duration of the match





### Special Considerations for Brain Injury

#### Mentor/Supporter:

- Have they mastered compensatory strategies
- Do they have the ability to follow through
- Are they able to inhibit
- Are they able to adhere to boundaries



### Special Considerations for Brain Injury

#### Mentee:

- May require reminders to ensure they make meetings etc.
- Structure will be important
- Clear roles are critical
- Clear expectations will ensure a successful interaction



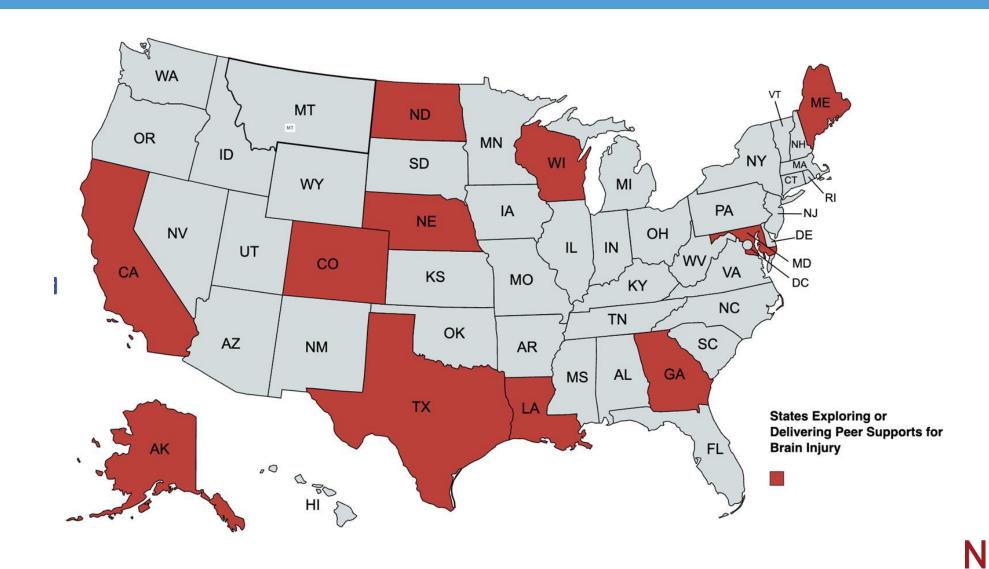
### Special Considerations for Brain Injury

#### Training:

- Ensure roles are clear
- Provide training on trauma To reduce chances for triggering trauma
- Provide training to help recognize suicidal ideation and resources for supporting someone who may be experiencing this
- Clear expectations for both the mentee and mentor will ensure a successful interaction



# A National Look at Peer Programming



# A Closer Look at Programs by State

State	Provider	Funding	Paid/Volunteer	Of Note
Alaska	Traumatic and Acquired Brain Injury (TABI) program	Grant (ARPA*)	Volunteer	Native Alaskan communities
California	Rancho Los Amigos, Downey (Los Angeles County) KnowBarriers	Contract with the LA County Board of Supervisors and Charitable gifts/donations	Volunteer/Paid	Rehabilitation Facility
Colorado	Brain Injury Alliance of Colorado	Local grant, shifting to State General Fund and Trust Fund	Volunteer	Youth and adults
Colorado	Craig Hospital	Hospital/ Foundation	Volunteer	Hospital to Home

# Programs by State, continued

State	Provider	Funding	Paid/Volunteer	Of Note
Colorado	Health Care Policy and Financing (Medicaid)	Federal/State Match	Paid	Brain Injury Waiver participants (16 & older
Louisiana	Brain Injury Association of Louisiana	None known	Volunteer	Development/ Launching
Georgia	Brain Injury Association of GA	Grants, Charitable Gifts & Donations	Volunteer	
Maine	Brain Injury Voices	State Funds, Charitable Gifts & Donations	Volunteer	

# Programs by State, continued

State	Provider	Funding	Paid/Volunteer	Of Note
Maryland	Training initiative with Maryland Addiction and Behavioral Health Professionals Certification Board	Grants & Medicaid Reimbursement	Paid	Individuals with brain injury and co-occurring behavioral health conditions
Nebraska	Nebraska Injured Brain Network (NIBN)  Brain Injury Alliance of NE	Grant (ACL**)  State Funds and Medicaid administrative claiming	Paid Volunteer	Post-pilot stage  Launching
		reimbursements		
North Dakota	North Dakota Brain Injury Network	Grant (ACL**) and Medicaid Reimbursement	Paid	1915 (i) State Plan Amendment - can serve Bl as a stand-alone condition



# Programs by State, continued

State	Provider	Funding	Paid/Volunteer	Of Note
Texas	Baylor Scott and White Institute for Rehabilitation	Foundation	Volunteer	Hospital to Home
Texas	Hope After Brain Injury	Charitable Gifts & Donations	Volunteer	Faith-Based
Wisconsin	SOAR Fox Cities	n/a	Volunteer	Paused

<sup>\*</sup>ARPA – American Rescue Plan Act



<sup>\*\*</sup>ACL – Administration for Community Living

# Peer Support Considerations





### Funding Strategies

- Hospital Foundation Funding
- Local Philanthropy Community/Foundation Grants\*
- Federal Grants, e.g. Administration for Community Living
- Private Donations
- Substance Abuse and Mental Health Services Administration (SAMHSA)/Mental Health Centers
- Home and Community-Based Services Waivers



### Establishing Program Purpose

- What is the goal of the program?
- Anticipated outcomes: increased knowledge and use of resources, increased connection, increased structure, increased support, decreased isolation
- What is the message of empowerment/hope one survivor can offer another?



#### Policies/Procedures

Confidentiality/HIPAA

Timeliness (e.g., program inquiries)

Mandatory reporting

Reasonable Accommodations

Medical and health protocols

Position responsibilities and expectations

Screening procedures

Matching

Eligibility requirements and processes

**Evaluation/Assessment Procedures** 

Training

Background checks

Supervision

Problem resolution

Record keeping

Transportation

Recognition

Safety/Alcohol, Drugs, Tobacco, and

Firearms

Closure

#### Personnel (Coordination)



- General coordination and program management
- Matching
- Supervision
- Training
- Recruitment
- Support with concerns/red flag issues
- Some programs start with part-time



#### Population - Targeted or General

- Traumatic Brain Injury (TBI)
- TBI/Non-Traumatic Brain Injury (NTBI)
- TBI/NTBI newly injured
- Youth with TBI/NTBI
- Veterans
- Criminal justice
- Brain injury and co-occurring behavior health



#### Age

- Adults
- Adults/youth
  - Colorado runs a youth peer program
- Family members/caregivers



#### Population - Considerations

- Will the program screen individuals out for safety reasons?
- Will you do background checks for peer supporters or all participants?
- To what extent do you identify the participants at risk in a program that will take place beyond direct oversight/supervision – or will the program take place on site and have supervision?
- Will peer support take place in person or will it be limited to remote methods?

#### Liability

- In-person and transportation activities may heighten liability requirements
- Participation contracts
- Volunteer liability and release of information
- Waivers



#### Training

- Traditional peer support/active listening model
- Motivational/role-model design that highlights a coaching role and active engagement
- Common training topics:
  - Healthy communication
  - ■Education related to Brain Injuries
  - ■Safety
  - ■Program expectations, policies/procedures
  - ■Boundaries
  - **■**Resources
  - ■The roadmap to a successful outcome



#### Training Considerations

- Hospital Volunteer Training
- Train-the-Trainer Model
- Online training (scenarios vs. role plays)
- Recording the training in modules for easy access



### Matching

#### Matching points may include:

- Race, ethnicity, sexual orientation, gender
- Substance use or abstinence
- Justice involvement history
- Age
- Type of injury, time post injury
- Severity of injury, interests, spirituality, goals, and education





#### Advocacy / Self-Advocacy

- Representing another or speaking on behalf of another
- Person speaks for himself, or selfrepresents

Finding your own voice and supporting others to find their own.





#### Recovery vs. Resilience

Recovery is a process of change through which individuals improve their health and wellness, live self-directed lives, and strive to reach their full potential.

(SAMHSA)

Resilience is the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands.

(American Psychological Association)



#### **Best Practices**

- Consistency is important! Invest in the process of developing and implementing a program.
- Create support positions for survivors that work within their strengths/inspirations.
- If possible, secure a point person/organization that takes leadership role (program manager or coordinator). May be part-time.
- Plan for the financial sustainability of the program.



### Why Peer Supports?



- Satisfaction in assisting others
- Increased self-confidence
- Decreased isolation
- Increased self-advocacy skills
- Increased insight

"I can walk beside you and be a support to you along the way."



## Questions?



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## Thank You!

# Judy Dettmer

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