

# Better Together: Brain Injury Survivors Building Community & Making a Difference

*October 5, 2021*



NCAPPS



**TBI TARC**

Traumatic Brain Injury  
Technical Assistance and  
Resource Center



# Welcome to Today's Webinar



**Alixe Bonardi**

*abonardi@hsri.org*

NCAPPS Co-Director  
at HSRI



**Bevin Croft**

*bcroft@hsri.org*

NCAPPS Co-Director  
at HSRI

Thank you for joining us to learn about brain injury survivors' experiences in the NCAPPS Brain Injury Learning Collaborative.

This webinar is co-sponsored by the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) and the Traumatic Brain Injury Technical Assistance and Resource Center (TBI TARC).

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.wordshare.com/player/HSRI>
- El seminario de web estará subtulado en vivo en Inglés y Español. Para tener acceso a los subtítulos en Español, utilice este enlace: <https://www.wordshare.com/player/HSRI>
- 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@hsri.org](mailto:NCAPPS@hsri.org).

(Please note that this email address is not monitored during the webinar.)

- The recorded webinar, along with a pdf version of the slides and a Plain Language summary, will be available within two weeks at [NCAPPS.acl.gov](http://NCAPPS.acl.gov). We will also include questions and responses in the materials that are posted following the webinar.

# Who's Here?

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

1. Person with a disability/survivor/person who uses long-term services and supports
2. Family member/loved one of a person who uses long-term services and supports
3. Self-advocate/advocate
4. Peer specialist/peer mentor
5. Social worker, counselor, or care manager
6. Researcher/analyst
7. Community or faith-based service provider organization employee
8. Government employee (federal, state, tribal, or municipal)

# What is a Learning Collaborative?

- Teams from around the country came together with experts to share insights
- We used a modified version of the model that the Institute of Healthcare Improvement has pioneered
- This model has been used successfully in many different health and human service systems
- It's based on the Model for Improvement (Plan-Do-Study-Act)

# How did the Learning Collaborative work?

- Teams developed **local aims** based on a **global aim** for the whole collaborative
- Teams selected strategies to implement based on their local aims

Our global aim: **Expand and enhance person-centered, community-based supports for people with brain injury through:**

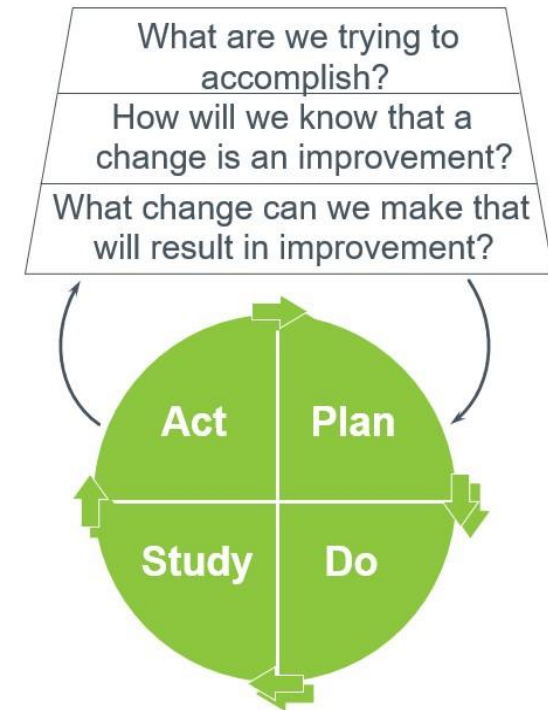
- **Engaging people with lived experience in self-advocacy and systems change**
- **Incorporating and improving person-centered needs identification**
- **Establishing person-centered planning best practice**
- **Improving and expanding person-centered services and supports**



# How did the Learning Collaborative work? (cont.)

- Teams worked together on the **strategies** they identified.
- Teams participated in monthly **coaching calls** to learn from each other. Expert faculty supported these calls
- Teams gathered for three extended **Learning Sessions** to share challenges and successes and learn from experts and one another
- We wrapped up the Learning Collaborative with a **Summit** to reflect on and share what we've learned through storyboards

## Model for Improvement



**BETTER TOGETHER:  
BRAIN INJURY SURVIVORS BUILDING COMMUNITY &  
MAKING A DIFFERENCE**

**WHO WE ARE**

**CAROLE STARR, NCAPPS FACULTY, ME**

**KELLY LANG, NCAPPS FACULTY, VA**

**ERIC WASHINGTON, NCAPPS FACULTY, MO**

**AMY BROSSART ROBINSON, ND**

**MARIA MARTINEZ, CO**

**RODNEY SMITH, WV**

**AUSTIN WILEY DUNCAN, AZ**

# WEBINAR AGENDA



Storyboard Presentation—Finding Our Success:  
From Sinking to Swimming



Break



Panel Discussion—Applying What We've  
Learned



Question & Answer Time



**DROWNING**



# WORD CLOUD PHRASES—DROWNING

Where do I fit in?  
What's my purpose?

Exciting to be part of a big, important project

So. Many. Emails.

Basecamp—chaos, overwhelming

Can I handle this?

Meeting new people

What have I gotten myself into?

Too much information

Extra brain injury grief

New awareness of brain injury issues in other states.

How do we navigate, which direction are we going?

What is the Collaborative?  
Can't get my head around the scope

New terminology

Lots of acronyms

Felt ignored & like a token at times

Can't keep track of the teams & aims

Territorial within team

Don't know what to expect

# AUSTIN

**Where do I fit in?  
What's my purpose?**

**So. Many. Emails.**

**Basecamp—chaos,  
overwhelming**

# AMY

**Exciting to be part of a  
big, important project**

**What have I gotten  
myself into?**

**Lots of acronyms**

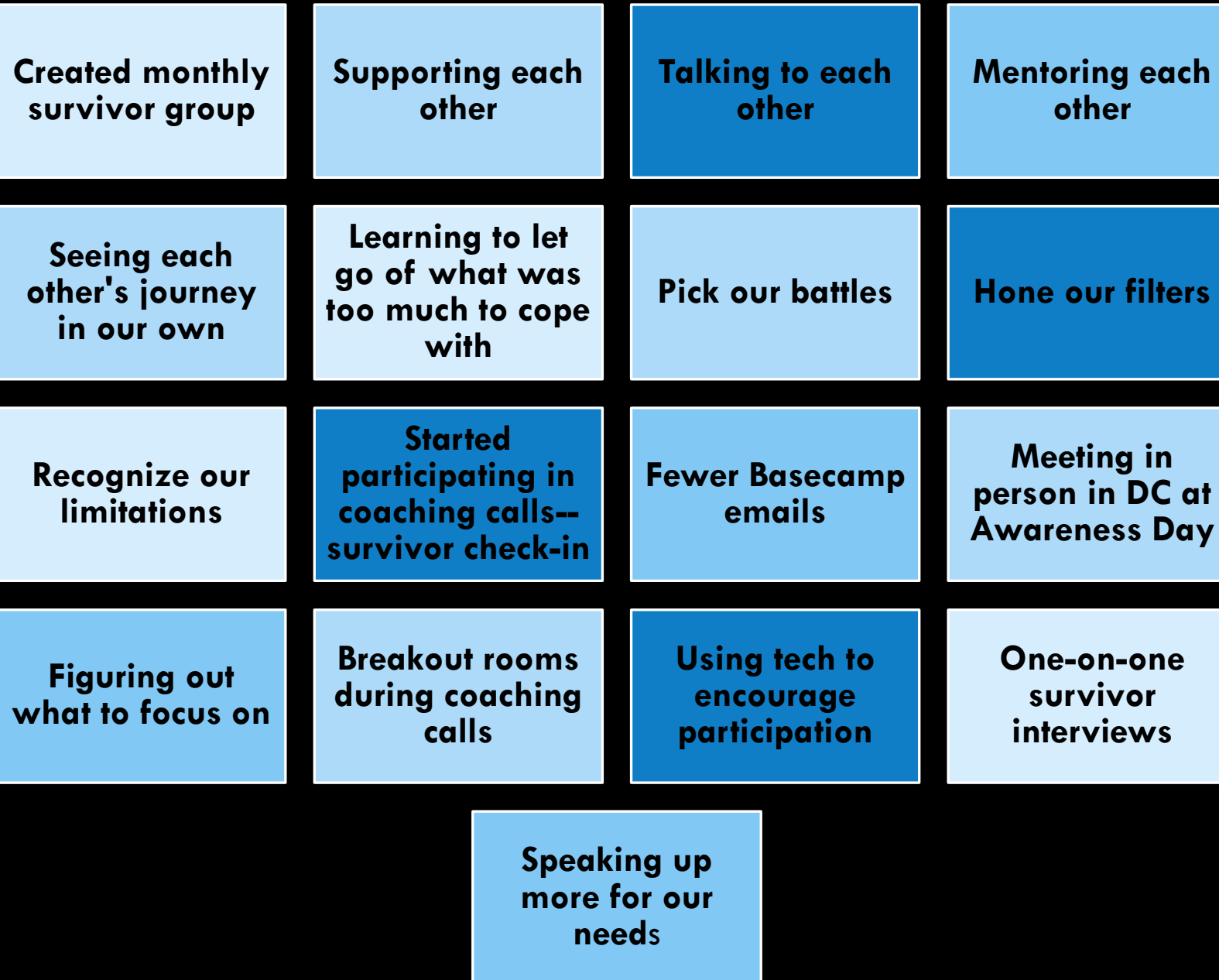




COMING UP FOR AIR



# WORD CLOUD PHRASES—COMING UP FOR AIR



# CAROLE

**Created monthly  
survivor group**

**Mentoring each other**

**Seeing each other's  
journey in our own**

# MARIA

**Learning to let go of  
what was too much to  
cope with**

**Pick our battles**

**Speaking up more for  
our needs**



SWIMMING



# WORD CLOUD PHRASES—SWIMMING

**New skills**

**Speaking more**

**Believing in  
ourselves**

**Increase in  
volunteering for  
other activities**

**Better advocates**

**Increased  
advocacy**

**Know what we  
can do**

**Know what  
works for us**

**Unwilling to be a  
token**

**Know when to  
fight obstacles vs  
let go or swim  
around them**

**Knowing our  
team well**

**Recognition that  
obstacles have  
helped us grow**

**Getting more &  
more involved**

**More interest in  
what we have to  
say**

**More self-  
confidence to  
speak up about  
needs**

**Continuing to  
participate in  
coaching call-  
survivor check-in**

**Having clear  
goals--something  
to swim toward**

**Monthly check-in  
reinforces we're  
not alone**

**Knowing the  
supports that we  
need**

**Knowing that  
our voices are  
important**



# RODNEY

**Speaking more**

**Knowing our team well**

**Knowing that our  
voices are important**

# KELLY

**New skills**

**Better advocates**

**Increased advocacy**

# **LESSONS LEARNED FROM OUR EXPERIENCE**

## **FOR BRAIN INJURY SURVIVORS**

**Don't be surprised if you feel overwhelmed, especially at the beginning. Don't give up. Take small steps.**

**Know when you need to reach out for help. Advocate for yourself—early & often**

**Connect with other survivors--community is key**

# **LESSONS LEARNED FROM OUR EXPERIENCE**

## **FOR PROJECT ORGANIZERS**

**Realize that survivors may be more overwhelmed than you know**

**Ask about the survivor's experience in the project & listen to what they tell you they need**

**Offer multiple ways for survivors to feel included. Check in regularly to find out if it's working and change course if necessary**



**BREAK**

---



# Panel Discussion



**Kelly  
Lang**



**Carole  
Starr**



**Eric  
Washington**



**Austin  
Duncan**



**Maria  
Martinez**



**Amy  
Robinson**



**Rodney  
Smith**



Questions?

# Real-Time Evaluation Questions

- Please take a moment to respond to these six evaluation questions to help us deliver high-quality NCAPPS webinars.
- If you have suggestions on how we might improve NCAPPS webinars, or if you have ideas or requests for future webinar topics, please send us a note at [NCAPPS@hsri.org](mailto:NCAPPS@hsri.org)



# Real-Time Evaluation Questions (cont.)

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?

# Thank You.

Register for upcoming webinars at

[ncapps.acl.gov](https://ncapps.acl.gov)

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

The content and views expressed in this webinar are those of the presenters and do not necessarily reflect that of Centers for Medicare and Medicaid Services (CMS) or the Administration for Community Living (ACL) .

