

August NCAPPS Webinar Questions and Resources: "Exploring the Intersectionality of Peer Support and Person-Centered Planning Across Disability"

Questions

Q: I'm wondering about advocacy for people with disabilities in the Recovery sector. Many facilities are not accessible. Do any of you work in Recovery?

Ebony: Recovery, in general, means different things to different people. I think this is the same with "disabilities". I use this word because it is commonly used and frankly, can be helpful with identifying, understanding, and addressing certain challenges in oneself. Certain labels associated with disabilities also help with financial assistance and resources.

All that said, the word 'disability' itself, to me, is why so many facilities and opportunities are not accessible to those who identify as disabled(in any way) and in recovery(in any way). This is something I could go on and on about but in short, changing how we view those two words ourselves and then how we convey that in different settings, can be a helpful place to start with advocacy in that area, I think.

Q: What states are doing peer support specific to people who have experienced a brain injury?

Audience*: New Jersey Brain Injury Alliance provides Peer to peer support for both traumatic and non-traumatic brain injury.

Indiana Brain Injury Alliance (BIA) also has peer support available.

Thank you to those who shared your work and efforts in the Brain Injury Community to utilize peers, we have certified Peer Specialists in our public behavioral health system here in Maryland, not within our BI community in any formal way. As part of my work on our federal TBI grant, I have the opportunity to work with as well as train Peers about how to support those they worked with who may have a brain injury. I co-train with Peers, we would love to learn about how others have developed the Peer support model for people living with brain injuries.

Martha: My entry into the mental health system began with a mild TBI. I received no treatment for it at the time and instead received a psychiatric label. Looking back, peer support may have changed the course of my life then. The focus on how to support someone to realize there hopes and dreams is always important. Bill Anthony spread the concept of psychiatric rehabilitation that emphasized with the right skills and supports anyone can have success and satisfaction. I believe this can be applied to TBI as well.

Q: Our organization will be providing peer support to home and community-based services (HCBS) recipients with intellectual disabilities. We will be using technology and other creative strategies. Are there other experiences with resources and strategies to share?



Martha: There are several digital peer support APPS. I do not know the specific experiences of their use with intellectual disabilities. http://digitalpeersupport.org/ **Ebony**: I think maintaining creativity, especially during this time will be imperative. Thinking outside of the box and remembering the individual/families wants/ needs are most important. Partial participation is possible and empowering. Anyway someone with intellectual disabilities can do even a fraction of what they want to- it is worth investing time in. You all will figure out a way or an alternative to accomplish ANYTHING!!

Q: As a volunteer coordinator, how can I communicate to potential volunteers with disabilities that they are welcome and supported?

Ebony: So, my biggest secret is no matter what the situation, I always try to identify with the emotion- relate & connect. I would communicate the ability for them to feel welcome and support through the environment you are in and your conversations: Disclosing what helps you show up how you want to everyday as a coordinator, for example. Be genuinely curious about how they want to show up at work and in the world. Encourage that. You are doing it, they can too-but in the capacity that is right for them and chosen by them.

Martha: Focus on a person's abilities. Often people get accustomed to including their disability when they introduce themselves. This is fine, but encourage them to also include there abilities and strengths and what makes them a unique asset to the organization.

Q: Are there any states that use peers to train people in the system in how to codesign and build good relationships with the people they support so that they can move through providing services in the MOST person-centered, person DRIVEN way?

Martha: I have not seen this state-wide, but within certain organizations. Some examples are RI International based in Phoenix and Advocates in MA. These organizations incorporate those with lived experience throughout the organization and at orientation for all employees.

Q: How can peer support counter the medicalization of disability?

Martha: The inclusion of peer support throughout healthcare serves as proof of the unique abilities of those with disabilities. Peer supporters model a focus on strengths and choice. This needs to be expanded throughout our community so the views of the general public can be shifted as well, to a view that everyone has unique abilities. **Ebony**: I think peer support can counter the medicalization of disability by helping others see THEIR ABILITIES through or within their (said) disability. Help the individual find ways to grow within their limitations and support them push through negative self-talk that will, at best, distract them.



Q: I like the term "consumer control" over "person-centered." Do any panelists have thoughts on this?

Martha: I think we need to concentrate on the actions instead of the exact words. So often a word or phrase is used, but the actions do not follow. I have seen that happen with *recovery* and now even with *person-centered*. Personally, I don't like the word consumer for these reasons:

"Consumer" often refers to a buyer--someone who has a choice about where to shop and what to buy. This is often not the case, especially in the public system. The verb consume means:

- to destroy by using or to use up
- to absorb or take in, such as by eating or drinking up
- to destroy such as by burning
- to spend wastefully—this could refer to spending money or time

None of these meanings appeal to me.

Ebony: I think saying a person or individual served is ok. Even just saying someone I am working with. We are, hopefully, working with and alongside the people we are serving. Just because we may be providing a certain service doesn't mean they are no longer a person nor does receiving said service make them a certain kind of person.

Q: Could someone write out the quote that Martha shared?

Martha: "I haven't been in your shoes, but I've been in the shoe store." - Angelique Sobers, CPS (1972-2015)

Q: [During the live Q&A, there was some discussion on engaging in recreational activities.] What are people doing to navigate COVID while trying to engage in recreational activities?

Audience: we bring in unconventional opportunities too, we have brought in aerial dancing training and spoken word, all kinds of things. If the people we serve want it, we find a way to do it. A lot is about trying things on to see what we like and who we are now

*These answers were provided on the chat by various audience members during the live webinar.



Resources

NCAPPS National Environmental Scan of Definitions and Principles:

https://ncapps.acl.gov/docs/NCAPPS_Principles_NationalEnvironmentalScan%201912 02.pdf

National Practice Guidelines for Peer Supporters

https://inaps.memberclicks.net/assets/docs/nationalguidelines_updated.pdf

Tondora, J., Miller, R., & Davidson, L. (2012). The top ten concerns about person-centered care planning in mental health systems. *The International Journal of Person-Centered Medicine*, *2*(3), pp. 410-420.

https://pdfs.semanticscholar.org/bbc3/2bcd4e31b8289abad68af87b40087a18b952.pdf Smelley, J. (June 2020). 3 Tips for Working with Youth with Intellectual and

Developmental Disabilities and Trauma https://centerforadolescentstudies.com/3-tips-for-working-with-youth-with-intellectual-and-developmental-disabilities-and-trauma/

Southeast ADA Center Training and Events Calendar:

http://www.adasoutheast.org/eventscalendar.php

Rocky Mountain ADA Training: https://rockymountainada.talentlms.com/catalog/index

New England ADA Learning: http://learn.newenglandada.org/

Washington State Coalition Against Domestic Violence (WSCADV) https://wscadv.org/

Disability Advocacy Resource Unit: https://www.daru.org.au/courses-overview

Mobilize recovery: https://mobilizerecovery.org/

Getting in Touch with the Speakers and/or Their Organizations:

Martha Barbone: mbarbone57@gmail.com

National Association of Peer Supporters: https://inaps.memberclicks.net/

Ebony Flint: eflint@advocatesinc.org Advocates Inc. www.advocatesinc.org

Sassy Outwater-Wright – Massachusetts Association for the Blind and Visually Impaired

(MABVI): https://www.mabvi.org/