



NCAPPS Webinar Transcript: “Better Together: Brain Injury Survivors Building Community & Making a Difference”

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SPEAKERS

Eric Washington, Austin Wiley Duncan, Carole Starr, Amy Brossart-Robinson, Bevin Croft, Rodney Smith, Kelly Lang, Maria Martinez

Bevin Croft 00:00

All right, again, welcome to the NCAPPS, National Center on Advancing Person-Centered Practices and Systems and Traumatic Brain Injury Technical Assistance and Resource Center "Building Together Brain Injury Survivors Building Community and Making a Difference" webinar. Pardon me, "Better Together." My name is Bevin Croft. I am a white woman in my early 40s. I'm in a brightly colored room. I have blonde hair up in a bun. And I am one of the two co-directors of NCAPPS. We're pleased to bring you all webinars each month that are free, open to the public. And as I mentioned, this month, we're bringing this webinar in coordination with the Traumatic Brain Injury Technical Assistance and Resource Center. Next page, please. For those of you who are unfamiliar with NCAPPS, we are a federally-funded center that provides resources and technical assistance. And our goal is to make person centered principles not just an aspiration, but a reality in the lives of people who use long term services and supports across the lifespan. Next slide, please. A few logistics to run through for you. We are working on getting, making closed captions available to you. Hopefully, closed captioning will be available momentarily. This is a webinar format. So everyone is muted, but you are welcome to use the chat feature to communicate with the panelists and with each other. If you would like to make a comment that you'd like the whole community gathered here to see, be sure that you select everyone in the, in the drop down menu just before the chat box, just above the chat box, so that everyone can see your question or comment. And you can also send comments directly to the panelists or to individuals. You will be seeing a bunch of information going into chat, I recommend having chat open so that you can access the additional accessibility features for this webinar. We



have slides available to you to download as a PDF and you can access them at the link that Saska provided in chat. This webinar is also now successfully being transcribed, live within the Zoom platform in English, you can access that by clicking the CC button at the bottom of your Zoom screen. We also have live captioning available in Spanish. And the link to that can be found in chat. We will have a poll at the beginning coming up momentarily and at the end of this webinar. So please be prepared to interact with us there. Next slide please, Saska. Um, we are always open to feedback always open to communication, you can, you can get us at ncapps@hsri.org. You can send us follow up questions after the webinar at that address. But note that we will not be checking email during this webinar. If you need to get a hold of us, then please use chat. And this webinar is being recorded. And we will post the recording a PDF of the slides a plain language summary a Spanish language transcript and the answers to any questions that we don't get to today on our website: ncapps.acl.gov within a few weeks. Next slide please. So let's find out who's here today. There are over 200 folks logged on. Saska is going to pull up a poll and please go ahead and select all that apply as the the roles that you self-identify: a person with a disability, a survivor, someone who uses services, a loved one of someone who uses services, self advocate, advocate, peer specialist, preventer, social worker, counselor, care manager, researcher, analyst, service provider organization employee or government government employee, recognizing that these are absolutely not mutually exclusive types. So we'll give folks another five seconds to please check your roles Okay, and let's see who's here. Great. So we have pretty broad representation across the different roles with the plurality being government employees. So folks who are working within state, federal, tribal, or municipal governments, but lots of representation across the other groups as well, welcome. We're glad that you're here. We can go ahead and close that poll. And onto the next slide, please. I'm going to provide just a bit of background about why we're here and what we're talking about. This is the first of two webinars in October that are focused on learnings from the NCAPPS Brain Injury Learning Collaborative. This was a year and a half plus engagement with state teams from all over the country where we came together to share insights. We used a modified version of the Breakthrough Series Collaborative model that was pioneered by the Institute for Healthcare Improvement. It focused on principles of



quality improvement, specifically, the model for improvement that some of you may be familiar with that uses PDSA or Plan, Do, Study, Act cycles, we applied those principles to brain injury systems. Next slide, please. The overarching aim of the entire effort was how can we expand and enhance person-centered community-based supports with for people with brain injury through four different areas. First, and what we're going to talk about today, is how do we engage people with lived experience in self advocacy for six systems change? How do we incorporate an improved understanding what people's needs are it through person-centered processes? How do we establish best practice in person-centered planning within the brain injury space? And how do we improve and expand person-centered services and supports, especially those that really support a person to live a full and meaningful life in the community? Based on those individual aims, state teams develop their own specific aims based on where, you know, they saw the most opportunity for change, and then selected specific strategies. Next slide, please. Very briefly, we, we had monthly coaching calls with all of the teams and then the teams met individually without us. Throughout each of the months, we gathered for four different learning sessions in which we shared challenges successes, built community, and then wrapped up and, and created storyboards. And actually, if you tune into our webinar, later this month, on the 20th, you'll hear, you'll actually be able to see three of the storyboards that were created by three, by three states. This did happen in the midst of COVID. And we were able to pivot and to make the most of that situation. And I think, given that we were virtual to begin with, we learned a lot, but we're able to keep going, which is a credit to everyone who's been involved in this effort. Next slide, please. All right, so just the last thing for me to say, and then I will stop talking and hand things over to the very fantastic group of survivors, who will be speaking for the rest of the webinar, we really made it a priority, both for ourselves that NCAPPS and for the state teams, that lived experience perspectives be elevated, and, and prioritized in every aspect of this process. And that meant for us hiring three brain injury survivors to be part of the faculty for the Brain Injury Learning Collaborative, and urging each of the state teams to, to recruit and invite brain injury survivors to be a part of their working groups and a part of their teams. And this webinar is really those survivors, those folks sharing about how this went from their perspective. I will say personally, I



learned so much from these folks, I was so happy and excited to be a part of this process. And I think that the challenges, the struggles, and the rewards that you're going to hear about will hopefully be instructive for you and hopefully have you walk away inspired to prioritize and and lived experience in your work in your own work role. And see, you know how there are a lot of opportunities to think creatively about how we really live up to the "Nothing About Us Without Us" mantra of the disability rights movement, which is really what this is all about. So without further ado, I'd like to turn things over to the group to introduce themselves.

Kelly Lang 10:15

Hi, I'm Kelly Lang. And I wanted to start the introduction. I am a woman, middle age with darkish hair and wearing an electric blue blouse. We started this, this team work together, we've been working together probably for about close to two years. And we just wanted each of us to go around and introduce ourselves. I'm Kelly Lang. I'm from Virginia. I am both a survivor of brain injury and a caregiver to my daughter. We were injured in the same accident close to 20 years ago. And I've spent a lot of that time learning to be a better advocate. And this experience working with the NCAPPS team was just phenomenal and taught me so much. So next, I want to introduce Carole Starr.

Carole Starr 11:12

Hi everybody, I'm Carole Starr. I am a white middle-aged woman, wearing with blonde, brownish, blond blond hair and wearing a pink sweater. And I have been a brain injury survivor since 1999 from a car accident. I was 32 years old at the time of my brain injury. And like so many of us, it changed my life forever. I had been a teacher and a musician. And I was not able to go back to any of those things and had to reinvent myself, took many years to find out who the new Carole is. And I discovered that, that I really wanted to make a difference within this new community that I found myself within the brain injury community. So now I do that as an author, as a speaker. And it has been such a tremendous gift to be part of the learning collaborative, to use what I've learned as a survivor to help make a difference for others. I think next on the list is going to be Eric.

**Eric Washington 12:23**

Hello, my name is Eric Washington. I'm African American. I have some extremely large glasses on, sleek sweater from Walmart. And I am 37 years old. I'm from, I'm from Detroit, Michigan. I currently reside in Missouri, where I launched all my advocacy projects. I sustained a neck injury and spinal cord injury, as well as two or three concussions playing football throughout the years from six years old to 27. And now I just look forward to trying to help people and motivate people and help them focus more so on the positives instead of what they can't do. So that's me. And next is Amy.

Amy Brossart-Robinson 13:19

Thanks, Eric. I'm Amy Brossart-Robinson. I'm from North Dakota. I'm a white 50 year old woman with brown hair and glasses. And I am from North Dakota, I think I already said that. My lived experience is that I I'm a parent to a 12 year old boy that was born with congenital hydrocephalus and has epilepsy. So I work a lot with many different professionals and working on the many brain surgeries that he's had and developing with some of the Developmental Delay Specialists as well. That's my lived experience. And it was, as Kelly said, wonderful to be a part of this team and get to get to know everybody. The next person on my list is Maria Martinez from Colorado.

Maria Martinez 14:22

Is Maria Martinez. I'm from Pueblo, Colorado. I have long hair, glasses. My skin color is black. I'm Native American. And I'm a support group leader in Pueblo and an advocate and I recently lost my mom to who was a brain injury survivor and lived to be 100 years old. So I want to continue to move forward as an advocate in support group. And to be honest, I'm not sure who's next. Rodney, Rodney Smith from West Virginia, come on on.

Rodney Smith 15:15

Yes, I'm Rodney Smith. I am a 65 year old male from West Virginia. I am kind of balding with gray hair, got glasses, got a blue shirt on. And I'm a 13 year survivor of a motorcycle and truck accident that a guy pulled out in front of me and changed my life forever. Survived a traumatic brain injury diffuse, same thing like



that. But what I do in the state of West Virginia, I'm the chair of the TBI waiver QIA Council and a member of the brain injury advocacy or the Brain Injury Advisory Board in the state. And I got involved in this to help other people get a better outcome and a better outcome but a more smooth process of outcome as far as how they recover from their brain injuries and such. So I have to do as much as I can to help people live better. Austin Wiley is next, he's from Arizona.

Austin Wiley Duncan 16:23

Hello, everyone. My name is Austin Wiley Duncan. I'm a 40 year-old white man wearing a gray cap, glasses and a white button down shirt. And behind me is a background of the Sonoran desert in Arizona, where I am a medical anthropologist and postdoctoral scholar, and also a very severe traumatic brain injury survivor from an injury that I had in Luxor, Egypt in 2003, when I was hit by a bus, and I will pass it on back to Carole and Kelly to get things started.

Carole Starr 16:57

Wonderful. Thank you. Next slide, please. So we just wanted to review what our agenda is today. So we're gonna start with our storyboard. During her introduction, Bevin mentioned the storyboards that we're going to share a little bit about what our experience was in the Brain Injury Learning Collaborative. We call this finding our success from sinking, to swimming. And you're going to understand a little bit more about that very shortly, then we're gonna take a break. And then we're going to go into a panel discussion, that what we want to do is we want to take our specific experience of being part of a learning collaborative, and then how do we generalize that? What can all of you as the folks who are watching this webinar take from, from our experiences through this. For the panel discussion, we hope to to make that clear, then we'll, then there'll be some time for questions and answers. So where we'll begin is with our, our storyboard. So when we were, when we, as the collaboration was ending, and we were beginning to do the, think about the storyboards and think about what was our experience, like, particularly at the beginning of the collaborative, the first image that came to mind for many of us was, we felt like we were drowning, we felt like we were, it was so much information coming at us, so many emails, so many people to meet, so much new information, that that was just that was a



theme that that worked for us. And that over time, as we learned more as we came together as a group, it felt like we were coming up for air. And then eventually, we learned to swim. So that's the theme that we, that we used for, for our story board. And we're gonna go and as we go through, we're gonna go through each stage stage and talk about, well, how do we get from feeling like we were drowning, like, like, wondering, can we do this? Do we belong here to feeling like at the end, that yes, this is indeed a project that we do belong at. So Kelly is going to talk now about, about how we kind of brainstorm some words to go along with some of these images that we're going to show you.

Kelly Lang 19:10

So this group, for the most part, met, for the past two years, we had a monthly support group where we supported each other outside of our team and faculty meetings. And when we started to think about the storyboards, we decided to just have a meeting where we just threw out all the feelings and thoughts we had at the beginning of the collaborative. So right at the beginning when we all first started, and after we came up with all our words, we then developed a survey, we decided who, which words meant the most to everyone and we kind of rank them and as you can see, there's a lot and the words that are out more in bold are the ones that really resonated with every single one of us. And so those were the basis for this, the drowning portion, the beginning part of the collaborative. And I think Carole is going to now describe the next slide.

Carole Starr 20:12

Yes, if you go to the next slide. So this is a slide that shows some of those words on that, that word cloud, it's a little hard to read some of those words. These were some of the, the feelings that we had, as the collaborative began. When we felt like we were, we were drowning, like that was was this too much. And so Austin and Amy are going to talk in more detail about, we can't talk about all of these words. Well, we can talk about a few of them. So if we have the next slide, and Austin is now going to talk about three in specific.

Austin Wiley Duncan 20:45



Thanks, Carol, this is Austin. So when things first started, I know the feeling that I experienced, and most of the other members on this panel also experienced with us. Where do I fit in? What's my purpose? You know, what am I doing here? Both because TBI related impairments, we didn't know exactly what our purpose was. But also because how do we fit in with the rest of this team where individuals are not themselves survivors? What is our specific role to the team? Now on top of that, because we all experienced this, we were also receiving hundreds of emails, it was incredibly overwhelming, through the system that we use called Basecamp, which sent out emails every time someone updated, from one of their teams, updated something on their profile. In other words, we were just, we were wondering what we were doing there. And then we felt like we were, we didn't know what was going on. And there was so much happening around us. And it was impossible for us with our brain injury related impairments and senses of organization and executive functioning to know exactly what we were supposed to be doing, was very concerning, and also confusing. And so I know that was a situation, a lot of us, and this would be true for a lot of brain injury survivors, as part of teams around the nation will feel at the beginning. And in order to think about that, we also considered some things that Amy's going to share.

Amy Brossart-Robinson 22:34

Hello, so when I began this portion of the collaboration, I had very mixed emotions, we definitely have that sinking, drowning feeling. But also there was some excitement in being involved in such an important project and such a much needed project to better serve people. I also at the same time, was feeling that overwhelmed, thinking, what have I gotten myself into? Am I do I have the right abilities? Do I have the right amount of time? Just lots of, lots of emotions, as aAustin said there was many emails and I think sometimes that adds to the overwhelm more than, more than almost anything else. In addition to the emails, there was many, many acronyms, so just trying to become familiar with some of what the acronyms were, use them in a manner that was functional for making progress, and just getting to know everybody. So again, that was wonderful to get to know everybody. But definitely mixed emotions as as we were getting into the beginning parts of the project here. And I think I can't remember who I'm going back to, but I'm sure that that person knows.

**Kelly Lang 24:12**

It's Kelly. Yeah, so as you know, as with when kids, when you're learning to swim, you know, you feel like you're not going to be able to do it. And then you start to come up for air. And that's how we all feel that was at, once we got past the initial stages of the overwhelm, and the, you know, "what have I gotten myself into" phase, we started to feel like whoa, I can finally take a breath. I'm finally figuring this all out. So we came up with some more words to describe. And you can go to the next slide, please. And these are the words that kind of stuck out for all of us. What it felt like when we were coming up for air, we developed this support network for ourselves so we could talk about things with each other. Because we could understand what each of us was going through, because we were all dealing with our injuries, and how it affects us when working on a project such as this. So, again, the bold words are the ones that meant the most, and really helped describe for each of us what it felt like to come up for air. And you can go the next slide. And then these are all the words that were listed in the previous one where you can see them a little bit better. And I think Carole is going to start talking about the multi-survivor group and others that meant the most to her personally.

Carole Starr 25:45

And next slide, please. So, early on in the collaborative, there was the the first learning session, which was like three or four or five hours, it was it was many hours long and had breaks. But still, as a brain injury survivor, it was really, really long, it was really hard to to make it through the entire thing. I was on the couch for days afterwards, and I felt very overwhelmed. And that's when I was thinking, I was really surprised by that. Because I mean, I am 27 for, more than 20 years post injury. And I thought, well, geez, if I am struggling with this, then I bet that other survivors on teams are also struggling. So I know that when I'm struggling as a brain injury survivor, the people that I want most are other brain injury survivors, other people who, who get this, who are also experiencing the same thing. So as faculty members, Kelly, Eric and I talked together, I decided that you know what, let's we asked if we could do this, let's form a group within the within the collaborative. So we created the survivor group, which we met monthly. And



it was an opportunity to talk about the issues that we had, as brain injury survivors within the larger collaborative of what it meant to be on a team with people who didn't have brain injuries, any issues that were coming up, how do we know what to focus on, what not to focus on. And in the process of doing that, it was an opportunity to mentor one another. Because if one person was having an issue, then invariably somebody else had run across that could give each could give each other feedback. But what had worked for us, it was also an opportunity to see each other's journey in our own to know that, that our struggles were not just ours, because as brain injury survivors, it can be so isolating sometimes when you feel like you're struggling. And if nobody knows that you're struggling, that when you have this group that you can talk to. And you know that others see that too, that others are experiencing the same thing, that it was a place where we could share those things and know that we weren't alone, in in this experience. And it helped to move us from that feeling of drowning, to being to coming up for air. So Maria is going to talk now about some more things that that we did that helped us come up for air.

Maria Martinez 28:28

So I'm looking at these panels here, learning to let go of what was too much to cope with. I think the main thing was I because I was part of the Brain Injury Advisory Board in Colorado, it gave me an initial type of ideal of what may be occurring with the collaboration if it was helpful, to focus on tasks that I need to participate in. And it was helpful to understand that if I chose those areas that I could probably manage them a lot better. If I ran into issues with how to cope with them, then I would ask for assistance through the group or through other survivors, or individuals that were part of the collaborative, collaborative. Picking my battles was understanding what my own battle was, what was overwhelming for me, what was necessary for me to be able to stay and maintain a connection with the people and understanding how I can focus on person-centered practices for myself during this process, speaking up for, more for our needs, I think that's the advocating we had to understand, or at least for myself, understanding that each of us who was advocating for our needs, if there was, I think if we advocated for ourselves, it releases a lot of the unnecessary stress that we tend to pick up, work. And then on the outside of that, I was connecting with other



people outside the collaboration, and that would allow me to share what was, what I was going through with the collaboration. So I think in that sense, it was always important to self advocate for what I was trying to do with the, with the collab, collaboration. And I'm going to turn it back over to Kelly.

Carole Starr 30:34

I think actually, to me. I'm just gonna introduce the swimming portion. So by the end of the of the collaborative, as a group, we felt like we had we learned to swim, that we had learned how to, to work within this structure, to get things done, as survivors to work with our injuries to work with our with our teams. So we again, brainstorm words that well, how do we get to the swimming phase? What were some of the things that happened? So we can go to the next slide. That's our word cloud. Again, as Kelly has said on some of these, that the bigger things are the things we felt more strongly about, such as speaking more and having new skills and believing in ourselves. So now, Rodney, and Kelly are going to be talking more, I'm sorry, one more slide first. Here's the boxes, which lists all of those. Those words that we brainstormed by the swimming section of this. And now Kelly and Rodney are going to be talking more about some of those. So Rodney is up next.

Rodney Smith 31:45

This is Rodney from West Virginia. I'm decided just after we got over the overwhelming part of the process and everything, I decided to get really involved as much as I could, with with the group, started speaking more and voicing my opinion more. And we actually at one point, they decided they were going to do some training for the caregivers for people on the TBI waiver program. So they did an interview with me about my experience. When I went to rehab, I went to rehab at Shepherd Center in Atlanta, it took me two and a half months to get from point A to Shepherd Center. And that's actually when recovery started when I got to a place that knew exactly how to do rehab. So I shared with them, the person-centered practices that they use at Shepherd Center, that make life so much easier for a survivor of a brain injury. So we put that together and interviewed and they use that to train, went to at least four training sessions with case managers and such things as that for brain injury survivors. So I feel like



I've contributed pretty well with that. And the process, I got to know my team very well and got a lot of support from those that were on the team, we shared information, and actually listened to me. So that was very, made it feel like I was really making a difference. Kelly?

Kelly Lang 33:19

Thanks, Rodney. So I think the big thing for me was, I've spent, I'd spent most of my advocating career, if you want to call it that, advocating for my daughter, and I neglected myself in the process. And I learned that, you know, I started before, I never really talked about my own injury and realize that I needed to talk about it because I needed to set a good example for her. And in doing so I learned these new skills and how to become a better advocate and to speak up and to say what I need. And to get that self confidence that I can, what I need and what I want matters. And, you know, I should say what I need, I might not always get what I need, but I should at least say and try to get it and trying to get these accommodations, it also taught me how to be a better advocate about which things were worth advocating for and which things I would just let go. Because that is also part of the recovery, if you have to like Maria said before, you just have to learn which things to focus on. And it's also helped me to increase my advocacy at different levels. You know, I became a member of the Virginia Brain Injury Advisory Council. I had been in, was on the board of the Brain Injury Association of Virginia. So I have been taking these steps into other groups into other avenues to increase that advocacy about people to learn more about brain injury, what, how a family, because that's a big component for me is, how many entire family is affected. It's not just the individual, it affects the whole family. And that it's just been a great experience for me. And I think Carole's gonna introduce our next section.

Carole Starr 35:16

Yes. So from all of these, all of this experience comes some lessons that it's, it's time now to as, we reflect on this experience that we've had. So what kind of advice do we have for, for brain injury survivors, for for program organizers for the folks who are, we're running committees and running projects. And we really wanted to spend a little bit of time and talk about, about what we've learned, and



what we think that that others can benefit from that completely outside of, of the collaborative, kind of generalizing our experience. So we would want to spend a little time to share some of our learnings. So Amy's going to talk about the first first learning.

Amy Brossart-Robinson 36:05

So with any new learning experience, there is lots of overwhelm involved. So one of the key lessons, takeaways was, don't be surprised about that overwhelming feeling. And especially at the start of any new learning or any new project. Just remember to stay strong and don't give up. And one way that we talked about doing that is taking those baby steps, taking small steps, remembering to rest as you needed and honor yourself with, with the knowledge that this too shall pass given, you're not going to be overwhelmed the whole time, it's new. And I think Maria is next.

Maria Martinez 37:04

My name is Maria. So we're looking at, know when you need to reach out for help, advocate for yourself early and often. You know, I came from a family of disabilities, my mom was blind and had a stroke. And my dad had muscular dystrophy and then myself with stroke and brain injury from motorcycle accident. And I think we we have to look our past and understand that, I think we're advocates, and we just see need to fine tune that. And I think that's how we understand how to reach out. You know, if I, if I'm not clear about something, and I need clarification, I, I asked people, you know, I asked people that were on this, on this monthly group that we met, Kelly or Eric or whoever was on, and it helped me to understand more and more what I needed to work on, or perhaps what my strengths were, and where perhaps my weaknesses so our voice is so important. And I think that's something that we shouldn't shy away from. Now I'll turn it over to Kelly.

Kelly Lang 38:18

Thanks, Maria. For me, as all of you have heard a million times probably is that if you've seen one brain injury, you've seen one brain injury, no two are alike such, it's also true that none of our recoveries have been alike. We all have different



deficits after injury, we all have different strengths that we develop, and just connecting with other survivors and learning, they might have a technique that I could use, a compensation strategy, or how to do something different that I hadn't even thought about. And that community I feel is key of just learning that you're not alone, that you have support if you need it, you can be it's hugely satisfying to be able to support someone else through their journey especially, and knowing that, you know, you can be that mentor, you can be that peer that they come to, with, you know, when they're feeling overwhelmed when they're feeling like they're not making a difference. And you know, you can do more together rather than trying to do it alone and getting frustrated. So one of the things that was really important to me, it was the sense of community, which I think this group in particular really was able to do and hopefully we'll be able to continue it as we go along. So next I'm going to introduce the next slide. Um, so we, as we were talking about all this, we came up with tips for survivors, but we also have tips for Project organizers of how things can be done. A little differently or just to be more aware, whenever you're working with a person with lived experience a family member who's working on your projects, because you definitely need their input. But you might, things might have to be a little, you know, skewed a little differently for them. And so these are just some things to start thinking about. And Carole is going to start off with the first one.

Carole Starr 40:25

Our first tip was realizing that survivors might be more overwhelmed than you realize, that there is a big difference between in a group with a professional pace and what the survivor pace might be. And when there are a lot of emails going on with a lot of information, that it might not take somebody, take much to overwhelm us, especially if, if we've been out of the game for for quite a long time. And I found that there was a difference, like because I'm, I've been at the brain injury gig for more than 20 years. When I get overwhelmed, my instinct now is okay, I want to do something about it. When I was, you know, three, four or five years about it, it was just backup and disappear, because it was too much. And so I think knowing where the, where folks are in their journey, because it might, it might impact if they're, if they're very overwhelmed, they might just come to a meeting and then never come back because it's too much. So realizing that



that's, that they may or may not even tell you that they're overwhelmed, they may just not, come not come back. So I think recognizing that is an important piece of involving people with lived experience on in projects. So Austin is next.

Austin Wiley Duncan 41:51

Okay, so this is advice that is good for everyone, but especially for project organizers. Now, yes, survivors do need to learn how to explain their needs, but it's not all on the survivor. So in your role as a project organizer, you need to ask what the survivors experience in the project is like, and this is the important part, don't just ask, listen to what they say, it might not meet with your expectations. Remember, they have more personal experience with this than you do so ask and listen to what they're telling you about their needs and their experiences in the project. And for our final point, let me turn it over to Rodney.

Rodney Smith 42:49

It would help to unmute, I'm Rodney, it, one of the ways that you can get survivors involved is giving them multiple options of ways to do things within a, within a collaborative like this, or any kind of program that that you want us to participate in, you know, even offer ways like being a part of a work group, or part of, you know, small, you know, projects on the side, or doing little things like research and things like that to provide information. Of course, ask us questions about our experience. In the years that we've been, you know, I think like she said, every injury is so much different. So you're going to get a different set of experiences from everyone that you ask about this. So you know, get us involved and get us involved in multiple things. And, and then you want to check in regularly with the survivor, that you've got involved to make sure that they're doing the best they can and make sure that they're not overwhelmed. And if there's, they seem to be overwhelmed and seem like they're losing interest, or it seems like that we're not, feeling like we're part of something, you need to change directions and make a, make a little bit of change as far as a way to adjust so that we do feel like we're part of doing something and that we do feel like we are really contributing. So you've got to be flexible as a professional working with a, working with a brain injury survivor because we all have different levels of abilities and different, different ways of interpreting things. So patience

with us, ask us questions. And like Austin said, listen to what we say and apply what you see that we know works for us. Kelly, or Carole, Carole?

Carole Starr 44:46

All right. It is time for a short break. We're just going to take five minutes to give everybody time to get some water, stretch your legs. So take take a little bit of a break and we're going to come back at at 3:51 Eastern time, we will see you shortly.

Kelly Lang 45:49

Hi everyone, welcome back. From our break, I hope you all were able to get something to drink and otherwise. So now we're going to stop the screen sharing. And we are going to go into a panel discussion, which is going to be moderated by Eric Washington, who was also one of the brain injury faculty members on the NCAPPS project. So Eric, I'll let you take it away.

Eric Washington 46:20

Hello everyone, we have a great panel. Everyone's amazing at what they do. I'm just glad, I'm happy that I can actually be here to listen to them speak, listenening to all of them. So our first question, we're gonna have multiple questions directed at, you know, a couple people, two people to answer and then we'll just go forward from there. So the first question is to Amy and Carole. Was there, was there any point in time where you felt like you wanted to quit? And when you felt overwhelmed? Why didn't you give up? Carole, you can go first.

Carole Starr 46:59

Sure. There was no time when I wanted to quit. But I definitely felt overwhelmed at the very beginning and wondered, you know, what am I doing here? Am I going to be able to do this. And one of the reasons why I didn't give up was this feeling of, I really liked being part of something that is bigger than me, that, that I missed, I'm part of a project where, where I can make a difference. And also knowing that in the past, when I've gotten overwhelmed, it does get better. So I think somebody had had mentioned that as part of, that's part of one of our things that, that, yes, oftentimes, things do start out as very challenging. But with



strategies with help, with time, that I can make things, do things better, and that if I quit, you know, early on, then I don't get the opportunity to find a way to to make things work. How about for you, Amy?

Amy Brossart-Robinson 48:08

Similar, except for I, I didn't want to quit, initially. But I also came around as I, as I got to know more people within my group and listening to everybody's stories and learning. And making some of those connections as far as helping to provide resources and share resources really made a huge difference in my life over the last year and a half of being part of this. So those monthly meetings were really meaningful and helpful. And so those are reasons that I did not give up being them all. Felt like you're at times.

Eric Washington 48:55

Okay, Amy, I'm glad you didn't quit. And Carole, you're doing an amazing job. So the next question is devoted to everyone. So everyone gets a chance. There are many ways a person can feel otherness, you know, including culturally, racial, gender, sexuality, language, geographically, disability and age. How did any of these impact your participation? And how did you feel about the project in general? I go with the people on my screen how I see it in order so Carole, you're first.

Carole Starr 49:26

Lucky me, I get to go first again! I answered that question around disability. And what surprised me at the beginning was, that how, how it impacted me that by going to these these meetings, and seeing all these, these, a lot of women who are roughly the same age as me, and I lost my career when I was 32 years old, and seeing how far other people had gotten in their careers who didn't have brain injuries. And it, it brought back some of the brain injury, grief. And it did give me that feeling of otherness, that feeling of, of what could have been in my life, had I not had a brain injury, how far my career had had, could have gone. I mean, I am still enormously proud of everything that I have accomplished since my brain injury and it didn't take away any of those feelings. But it it did bring forth some of those, those "what if" kinds of feelings, that feeling, a little bit less than because I



had a disability. And no, I'm not saying that anybody said anything at all, that that led me to feel that way. This was all an internal, internal feelings that I had as as part of a group. I think it's just it's one example of some of those hidden feelings that you just never know that somebody might be having, when, when they're in a group. Seems like you guys are just bouncing around on my screen. So we'll just go, who just went to the left, Miss Kelly Lang. Do we just just to make it challenging for you there, Eric?

Eric Washington 51:10

Exactly.

Kelly Lang 51:12

I was getting a headache from you know watching everyone move around. You know, I have to piggy back on part of what Carole said. And that is that, you know, I agree that we'd sat in those faculty meetings, and with the exception of a couple people, one being Eric, it was mostly females and very accomplished females at that. And, you know, my plan had always been to return to, you know, work once my children were in school full-time. And that all changed very suddenly for me in 2001. And I had a severely injured daughter I had to take care of, and I had to take care of myself in some respect. But my other thing that I noticed was, I had wished that there was a little bit more diversity on some of the teams, especially some of the teams that really could have used some of that diversity. And they're talking about what they were doing for their own states, because those are their constituents. So I would have liked to see that a little bit more. And heard a little bit more from the other survivors in those states. When Carole and I started that, and Eric started this workgroup, we reached out to all the survivors, and we're really hoping that we would get all those representation and we didn't. So that was a shame.

Eric Washington 52:37

Okay, I like that answer. So Miss Maria Martinez?

Maria Martinez 52:44



Um, that's a big question. You know, this is, this covers a lot. So as a woman of color, and then a woman that is indigenous, and lives in a rural setting. And age, I'm 66. And I think I think it affected me quite a bit. I think. It impacted me, I wished the states had more representation, so that we could have more engagement of what's going on in those states. Because I think it's very important that, that that becomes something that other people can hear. And, and, and hopefully want to participate in. But I also think that part of the project was that it was a challenge, you know, and that challenge was a good challenge, because it allowed me to advocate for the things that I advocate for so much here in Pueblo, being in a rural setting, being a person of color, people that have difficulty finding jobs, finding apartments and things like that. So yeah, it was a very beneficial. Thanks, Eric.

Eric Washington 53:58

No, thank you. Alright, Miss Amy.

Amy Brossart-Robinson 54:07

My piece just being in very, very high. I'm in very rural Minnesota, actually, I'm right on the border here. So that was my piece. Again, we didn't have a ton of diversity. We do have some indigenous people on the team to start with, but I would, like Kelly said, like to have seen a little bit more diversity, but again, we're in rural North Dakota, Minnesota. So that was one piece of it, but it was good to get to know, just to delve into this question a little bit further, too. So thank you for including everybody in the answer.

Eric Washington 54:51

Mr. Austin.

Austin Wiley Duncan 54:54

Yeah, I can, I'm, I think the only one on the call aside from Eric, who is, I had my injury at age 22. I was eight months out of undergrad education at the time. And I can say that I'm used to feeling, you know, I never had a real strong sense of myself as a competent adult when I had my injury, and then all of a sudden to be knocked back to what was a very infantilizing experience of being stuck at home



and unable to walk and taking care of every moment of the day was difficult. And so when I meet other people who see me being high functioning and able to get a PhD, and be an academic, they don't understand that I have this experience. And so they automatically treat me like someone who's a brain injury survivor, but not quite, and maybe coming up with excuses, or what's the word, malingering for when I have problems that are brain injury related. And so they automatically cast me because of when I had my injury, as some sort of a deceitful, somebody who's trying to game the system. And that can be very upsetting. Also difficult to deal with, at the same time, as I recognize that everyone else, especially those who are not white, and male, have very different experiences than mine, and that most people don't seem to understand the ways that all of these factors age, geography, language, sexuality, gender, race culture, can interact with what TBI means, in each of our cases. So I will turn it back over to Eric.

Eric Washington 56:40

Right answer, right answer. And last but not least, Mr. Rodney?

Rodney Smith 56:45

Yeah, this is Rodney. In our state there, you know, West Virginia, there's not that much diversity unless you play football or something like that. So it wasn't very much of an issue. The rural illness is definitely an issue with us, because I'm in a very much rural community. So dealing with all of the Zoom meetings, we didn't have any face to face meetings during any of this time. So having to do everything over Zoom and stuff was was kind of overwhelming at times. But what I enjoyed most about this collaborative was hearing from people like Eric and Maria, about the diversity issues, and the different perspectives, I'm always interested in hearing these things. I did 30 years, 24 years in the Army. So I was around a lot of racial, different types of racism, such things as that. But as far as living where I live, I kind of been away from it for a while. So it was great and refreshing to hear the different things that you guys deal with and understanding that it's not the same for everybody. So, and I hope to help those around here that may have those kinds of issues. And, and I might even tag you and Eric or Maria for help at some point. Eric?

**Eric Washington 57:57**

That was actually, that meant a lot and Austin, you ought to you know, you're, you're probably the second smartest person I know, besides myself, but just joking. But actually, that means a lot from you know, both of you guys and that, trust me, the world would be a better place if we all thought like that. So now the next question is to both guys, who did you, who did you guys rely on? Who was your biggest allies in these groups?

Austin Wiley Duncan 58:30

Rodney, do you want to go first?

Eric Washington 58:32

We'll go, we'll go with Rodney first.

Rodney Smith 58:34

Okay, yeah, mine, my team was very supportive, especially the team lead Barbara Recknagel. She got me involved in everything she can get me involved in. Some of the things I didn't fully understand but gave everything I could with it. So it, it made me feel very much a part of something. And this, this group of survivors gave us something to to lean on, you know, when we were overwhelmed and such things, so it helped me a lot. And it gave us, you know, a place to compare notes and a place to vent especially early on didn't it, Eric?

Eric Washington 59:10

Yes, yes. Yes. Mr. Austin.

Austin Wiley Duncan 59:17

Okay, so my experience is very common with brain injury survivors and was a bit different from Rodney's as, if you've seen one TBI, you've seen one TBI. I didn't have anyone to rely on in this project until later. So at the beginning when I was feeling overwhelmed and confused and not sure what my role is, I didn't have anyone that understood me but that spoke to me on a regular basis. And it wasn't until I found Carole, Kelly and Carole, Kelly, Eric and the rest of the group that I



was able to start to gain my sense of self within this program, and actually do what I had initially intended to do when I started and it's, it's thanks to them that I am still here. And that's important for everyone to realize that as program managers or leaders, you need to help survivors who don't have anyone to rely on because that's the case for a lot of us to find a sense of community and people that they can talk to and rely on when they're feeling overwhelmed, or troubled or bothered or something like that.

Eric Washington 1:00:33

Two great answers from two great men. All right. Now on to the next question. Were there any disappointments of things that you feel like didn't go well? Or things that you would change or do differently? This question is for Kelly and Maria. So we'll start with Kelly first.

Kelly Lang 1:00:49

I'm with what Austin said, and one of my biggest disappointments would be that for any survivor to feel that they didn't have anyone to lean on, or they felt lost or alone, I would never want anyone to feel that way. So I'm glad Austin that you came and that you took our support because you are a valuable, extremely valuable member of this team. And so I wouldn't have I get that's my biggest disappointment is if anyone else felt that way and just didn't stick to it like Austin did, that they felt alone in this process. Because everyone knows that brain injury is very lonely keeps you away from others it, you feel that otherness, and that's always been one of my goals is to make sure that other people feel included that they feel part of the team, they feel part of a group, no matter what type of group or team it is. I just feel that we're all in this together. And we have to support one and meet one another.

Eric Washington 1:01:54

OK, Maria?

Bevin Croft 1:02:07

Maria, you're on mute.

**Maria Martinez** 1:02:11

I like that. I like that muteness. Oh, but I think what I was, what I was saying was that I think the discipline would be when the voices are heard. And but I think towards the end, I think the voices got louder, and, and I think ears will pop them. So I think that's a good thing. And I, would I change anything, I think it's just a, taking a risk to share what you feel, be as authentic as you can, and put it on the table. And, and just roll with it. You know, you got to take a risk. And I think that's part of this collaborative was, we took a risk, you know, and I'm very proud that we did and would I change anything differently, ah, I think I think just being able to participate and interact, and be more open with everybody from all states, because I think I learned so much from every state that it made me want to stay in longer. And I'll turn it back over to Eric.

Eric Washington 1:03:20

Thank you. Thank you. So the next question is, how did you organize yourself? Your time through this entire project? First, we're gonna go with Miss Amy.

Amy Brossart-Robinson 1:03:33

There's a certain amount of irony in me answering a question about being organized. But that said, I really leaned on the email information from Miso who sent out a lot of info, or the NCAPPS organization sent out a lot of information and reminders. So that was good. And then I often, I often connected with other team members from the lived experience teams to, if I had questions and was easily redirected as needed. Rodney was gonna comment too I believe.

Rodney Smith 1:04:13

Yeah, this is Rodney. My basically was just like, compensatory strategies that I've learned. But just Google, Google Calendar, and sticky notes all over the place, all over the fridge, all over my computer. And here's my calendar. It's got, you can't really see it, can you? It's got, every day has something in it, about three or four different notes for every day in my Google calendar. So it's dinging and dinging all the time to remind me that, hey, I got a meeting coming up. I need to study for the next meeting. I need to read these emails and such things. So just old fashioned compensatory strategies. Eric?

**Eric Washington** 1:04:50

I must admit, Rodney, you have the most impressive bookshelf behind you. I really liked that organization. I really think that's organization one-on-one right there. So now this, the question is for everyone. What do you think, makes survivors hesitant to participate in projects like this? So once again, we'll go from left to right, please don't move anymore, Kelly, Miss Kelly Lang.

Kelly Lang 1:05:18

What makes people hesitant is, they're not really sure what their role is going to be. And if, if they do have a voice, they're not sure it's going to be heard. So I think that's the number one reason a lot of people with lived experience will not participate or, or are hesitant to participate. And I think some of that also comes back to their history of maybe jumping in too early and participating in groups and, and having it not work out. And then they're afraid to get involved again, so but I would like, I would love to see everyone get involved in in whatever way they feel most comfortable.

Eric Washington 1:05:56

Miss Carrole.

Carole Starr 1:06:01

I think one reason that folks have a hard time participating is that fear of being the token survivor, of being alone in a group, when where nobody understands their, their issues, and having to, to constantly advocate for themselves that it did, it gets tiring, after a while, I mean, I get that that is something that we have to do as, as survivors. But this project where there were three of us on the faculty with brain, with brain injuries. I mean, that was a revelation. To me, that was the first time that I've been then, like on a committee where I'm like, I'm not the only one. That there there, we had a team that we could, that we could figure things out together. And it, what a difference that made. And I think that when when folks don't have that, then it's easy to feel, to feel that otherness, to feel that that isolation. So I think that's that's one reason why, why folks hesitate to participate in projects.



Eric Washington 1:06:58

Miss Maria?

Maria Martinez 1:06:59

Maria here, um, maybe it's not even knowing how to be invited, you know, or how to participate in who you're connected to, you know, in the community. Because it just, you just don't just join NCAPPS and say, "hey, I'm here," you know, it's, there's a map, and then I think a lot of people are left out of that method. And hopefully, it'll, it'll filter out. So there's more people involved. And, you know, I think the other part is, is what is the mission? You know, do they, or do they want to be part of that mission of what's being shared? And does it, is it gonna impact their communities and where they come from? I think that's really important. We'll take it back to Eric.

Eric Washington 1:07:57

Miss Amy.

Amy Brossart-Robinson 1:08:03

Sometimes goes back to that overwhelm piece. And just having another thing to learn, sometimes is, is enough to make people hesitant about joining, even though the benefit might be great. Luckily, all these wonderful people continue to join despite any thoughts to that effect. So.

Eric Washington 1:08:30

Oh, short and sweet, huh? Okay. Well, wasn't expecting that one. Mr. Austin.

Austin Wiley Duncan 1:08:37

Piggybacking off on what Kelly said earlier, I think a lot of it goes back to survivors' personal history. And so, this is a comment for everyone on the call. Every time you treat a survivor in a way that is discriminatory, or doesn't respond to their needs or interest, you build up that, that resistance in them to being part of projects in the future. And so because of their personal history, with things that didn't work out, where they didn't feel like they were included or welcomed, that



makes them more hesitant to participate in projects like this great NCAPPS project in the future. So everyone in disability, studies principles of universal design, just treat everyone with more of that sense of understanding and acceptance. Even if you don't know if they had a brain injury because there's so many of us that we, you actually might have had a brain injury at some point.

Eric Washington 1:09:33

Alright, last but not least, Mr. Rodney.

Rodney Smith 1:09:38

This is Rodney. Yeah. Basically, anything to do this whole process of recovery from the brain injury to things, everything you do is another process and you get to start from square one in that process, and spin all the way up when you join something like this. It looks like a pretty overwhelming project. It makes you think, man, I got a lot of acronyms to learn. I got to learn new people. Do I really want to do this? And then you think, well, you make more difference than you think you do. So let's dive in and see what we can do. That's about it, Eric.

Eric Washington 1:10:11

Perfect. I want to thank everyone for listening to this session of TVR celebrity squares. It looks like squares on my screen. And now we're in a question and answer session with I believe, Bevin.

Bevin Croft 1:10:25

Yeah. Hey, thanks. Thank you, Eric. And everyone. And I just want to, just acknowledge, I said it in chat, just the, Maria, a few minutes ago talked about authenticity, and about being authentic. And I just want to honor and thank everyone's authenticity, both what you are sharing here, our panelists, but also what folks are sharing in chat. This is really what this stuff is all about. So thank you. We've gotten some excellent questions. So I'm going to dive right in. The first question I have and anyone who'd like to speak up, please do is, did you find that the culture of the teams that you were on, and thinking particularly about people without brain injuries, that that, did that culture of the teams change as you advocated for yourself?



Rodney Smith 1:11:28

I think mine did. This is Rodney. I think mine did, the more I contributed, the more they listened. And the more that I felt involved in the project, so it did change in a positive way as we went along in the thing.

Bevin Croft 1:11:45

Anyone else want to reflect on how the culture of your team changed?

Eric Washington 1:11:49

I'll say something, Bevin. I believe that, I think that it would naturally have to change just because I think what happened is that we speak a lot about in NCAPPS group about person-centered, and, you know, meeting people where they are, and representing, you know, the entire community. And I think once anyone with a brain injury and injury, start stepping up and, you know, advocating for yourself, I think people would just naturally just say, okay, let's see what you got, you know, you know, I do belong, I do belong here, you know, so I think it naturally would happen. And if it didn't, I just don't think that those people should be a part of the group anymore.

Maria Martinez 1:12:32

Yeah, I seen a change too. I think that's a good thing, though. I think when there's movement, and it revolves, I think it brings in just a lot more engagement with people being able to share their voices. So I think it's really important to see the change. If it stays stagnant, I think it's not beneficial.

Bevin Croft 1:12:54

Thanks, Maria and I'll add, I know I'm not a panelist, but I will add, this is Bevin, that our culture changed, the NCAPPS team, Alex, Connor, Miso and I, our group changed from working with, with you all, with, and particularly with Carrick, not Carrick, Carole, Kelly and Eric otherwise.

Eric Washington 1:13:20

That's our name now, Carrick.

**Bevin Croft 1:13:22**

We had never worked. Yeah. We'd never worked with brain injury survivors before, before before we met you, and I learned so much and we do things quite differently. And Maria, like you said, it is all for the better. Yeah. All right. We've gotten a whole bunch of questions around discrimination. And Austin, a while ago, you talked about your own experience of, you know, being accused of malingering, which is a good word to know and it really means feigning or exaggerating illness or disability. And we got a lot of comments in chat, several, four or five commenters it sharing their own experiences of being accused of malingering. And I think for any invisible disability, this is something we really need to think about. So I would love to hear from each of you or anyone who's experienced this. You know, any, any reflections you have and any takeaways for what that means for working with working with survivors.

Austin Wiley Duncan 1:14:42

I can start if that's alright, since you, you reference me in that comment. I can, so one of the things that I experienced in my team, professional teams, who always know that I have a brain injury, I do tend to lead with that because I found that makes things easier, easier moving forward is that oftentimes when something comes up, something new comes up, and it causes me some sort of reaction, whether it be impairment based or even not. And I try and explain how that changes things in terms of my brain injury, they will say, oh, well, but you said, you know, x. And now you're saying, y. And so referencing back to my point, you need to ask and listen to what the survivor's telling you. Brain injury impairments do change depending on how the person is feeling, what their social circumstances are, things like that. And also, brain injury is not something that's just one thing. So every time something new comes up, they need to tell you about it, or you need to ask them about it, because it might very well be brain injury related. And just because you heard what they said the first time doesn't mean that you're going to know what they're going to say the second time. So you need to always be ready to adapt and shift, depending on what they're telling you their brain injury experiences are.



Bevin Croft 1:16:09

Thanks, Austin. Do others have thoughts on this topic?

Maria Martinez 1:16:16

Bevin, can you repeat it again, please?

Bevin Croft 1:16:19

Yeah, the question is, um, you know, generally, well, it's a two part question. The first is, I want anyone who can to reflect on this idea about malingering and the experience of malingering, exaggerating or feigning your brain injury or being accused of that and how it feels. And what we need to know to be sensitive to that. The larger question is about discrimination being discriminated against for having a brain injury. Any other reflections on that?

Maria Martinez 1:16:49

So I want to touch bases on that a little bit. I think one of the harshest is when a mental health worker tells an individual that they're malingering. And they have to, or you know, they're, they're fighting to find resources that will allow them to receive SSI or what have you. Social security disability, and I, so when a professional and you're, you're depending on them to evaluate you, and they evaluate you as the person that does that. I think that's harmful in anybody's recovery. The other part of the question about discrimination is that, I think when there is a speech impairment, and people are not able to speak clearly, then there's a lot of question about how we are interpreting things that comes, always seems to come back to our mental health, you know, instead of identifying it as an impairment from the brain injury, so I think that's something that's really bothersome to me, and I don't just see it with, I see it with people that, that are in our community. And that's very, very frustrating.

Bevin Croft 1:18:04

Thank you for for bringing that up. And, you know, we saw from the poll at the beginning, there are a lot of professionals here. And so I hope that folks heard that loud and clear, it's harmful to be, to accuse people of malingering and damaging. Thank you. I just want to highlight one quote, came out a chat, Jan



said, "it's simple and free to be generous and kind." What a wonderful alternative to accusing people of being a malingering or discriminating against them. I have another question for you all. Did you organize yourselves as a survivor group, and coordinate and facilitate your own meetings? Or did you ask a mentor to help organize or facilitate and coordinate your meetings? And so I'd love for you guys to share a little more both about how you did that during the learning collaborative. And then also this webinar. How did it come together?

Carole Starr 1:19:04

I can, I can start with that one. So for the, for the survivor group. Each month, Kelly, Eric and I would do a Zoom call. And we would talk about what would we like to talk about for the next month's survivor call. So we, this was a completely survivor-run, driven group that we based our topics on what was going on in the collaborative, what we had just talked about in the, in the coaching calls or in the faculty calls, we base it on our own experiences in groups, what we knew about some of the issues that we had, we had dealt with as being survivors in our teams. And we did a lot of fishbowls where we kind of, where we talked about issues and the rest of the group watched. And then we kind of and we talked about what we learned from those sorts of things. This webinar was was survivor-run that we we we come up with with our points, we work together to figure out what our theme was. We brainstormed our topics we did, Kelly was our poll master. We did a lot of polls with figuring out what which what, which were our most important points. And we took our time with it, you know that as survivors, we don't move at a professional pace. So so this, this webinar did not come together like, like, over the last couple of days. We've been working at this over the last several months. And I think that's a an important point about anything done, you know, survivor-wise that we can't do things at a professional pace, we have to do things at our own pace, we can do really, very well done sorts of things, but not at anybody's pace, but our own. We have to take it one step at a time. Thanks, Kelly, if you want to jump in there.

Kelly Lang 1:20:56

I would just say that the only support we ever got was just using the Zoom link from NCAPPS which Miso had set up for us. That was pretty much it. Like Carole



said, Eric, Carole and I would meet and kind of figure out well, let's try and talk about this. And sometimes the group would go in a different direction, which was fine. That this was a group of people who are very respectful of one another. And we were all, I think we all felt like we were heard.

Eric Washington 1:21:22

Yeah, I agree. I really agree.

Bevin Croft 1:21:27

I just want to add and highlight even the survivor group, the whole concept, talk about culture change of our team we didn't, that wasn't built into the learning collaborative format. That's something that we added because Carole, Kelly, Eric, Carrick insisted, asked, insisted, so again, this was like, start to finish, all of this is them.

Carole Starr 1:21:49

And it came basically, because we got overwhelmed after the first learning session. So I think it's a lesson in that when we get overwhelmed, good things can come out of that. Because that, because then that's when our own advocacy roles kicked in. All right, we're overwhelmed. Now's the time, a time where we need to advocate. That's what we did, and and all the credit to NCAPPS for listening to us, and for saying, okay, how do we, how do we help make this better?

Kelly Lang 1:22:17

I would add because Bevin, I mentioned this before, but I've told so many people this, that I'm so impressed with NCAPPS that when we came to you and told you things, you know, you and Alixe and Miso and Connor, you listened and I knew you listened because you made changes. And obviously you didn't just listen by going, uh-huh, uh-huh, you actually changed things, and you made it happen. So I can't tell you how grateful I think all of us are for that.

Bevin Croft 1:22:46



We're grateful for you. This is a partnership. Um, we have hit the end. We could keep going. We could do another webinar on each of these questions that folks asked, there are questions that we didn't get to, we will get to them in writing. And I will make sure that all of the questions get back to the panel and you all can respond back because I know you have more to say so stay tuned on resources. If you could, before you go, please fill out the poll that's coming up. There's seven questions. We want to hear how this webinar went for you. We take your feedback very seriously. And we are a learning organization. So your answers to these seven questions will help us to improve future webinars. From the bottom of my heart from Alixe, Miso, Connor, Saska, Terry, from NCAPPS and the TBI TARC Traumatic Brain Injury Technical Assistance Resource Center. Thank you for your, for your partnership, for your advocacy, for all that you do. And thanks to everybody for listening and have a great afternoon.

Maria Martinez 1:23:49

Thank you.

Eric Washington 1:23:53

Thank you.

Rodney Smith 1:23:54

Had a good time.

Austin Wiley Duncan 1:23:55

Thanks and goodbye.