



NCAPPS Webinar Transcript: “Improving Brain Injury Systems: Stories from a NCAPPS Learning Collaborative”

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SPEAKERS

Krystal Blair, Michele Coston, Rodney Smith, Regina Desmond, Alixe Bonardi, Danielle Reed, Rolf Halbfell, Barbara Recknagel, Carrie Bambrough

Alixé Bonardi 00:00

Greetings, everyone, and welcome to today's NCAPPS webinar, improving brain injury systems, stories from the NCAPPS Learning Collaborative. Next slide, please. We're very excited to have you here. My name is Alex Bonardi, I am a white woman. sitting in my office, I'm wearing a black shirt white. And I have medium length brown hair. We're joined here today with by my colleague Bevin Croft, who will be joining us later in the webinar, who is the co-director of the National Center on Advancing Person-Centered Practices and Systems. We're delighted that all of you are joining today to learn about one of the activities that we have been running through NCAPPS and want to thank our sponsors for NCAPPS the Administration for Community Living, and Centers for Medicare and Medicaid Services. all NCAPPS, webinars are free and open to the public. And we are delighted that you all are here today. Thank you. Next slide, please. To give some framing, I want to remind everyone, particularly people who are new, thank you for joining, and for people who are familiar with NCAPPS that our goal 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. And that happens in many different ways, including supports and services for people with brain injury. And that's what we're going to be talking about today. Next slide please. Just a few logistics about this webinar. As if you have the chat feature open, you will see some information about the fact that this webinar is being captioned. You can access captioning by hitting the live transcript button at the bottom of your zoom window. Towards the end of this webinar, we will have an



opportunity we hope for time for our speakers to respond to questions. If you have any questions or comments, please don't hesitate to enter them into chat. Chat often becomes a lively source for both adding questions for the panelists. And also sharing resources information and making some tremendous connections. This webinar is also captioned in Spanish as well. With the link that has been entered into chat, you can access the Spanish captioning as well. We have live polls and evaluation questions as part of this webinar. And we really look forward to your participation during those polling times as well. Next slide, please. After the webinar, we are always interested in hearing back from you at this this link and NCAPPS@hsri.org. Please note that email address is not monitored during the webinar. So, if you have issues, it's best to hear through chat. And there will also be the recording along with a PDF version of the slides and a plain language summary available on our website. All of that information is also in chat. Next slide please. So, let's get started with understanding who is here with us today. We'll be bringing up a poll in just a minute. And we ask that you respond in what role you self-identify. Feel free to select all that apply. And we'll give people a minute to respond so that we know who all is here today in this webinar. (pause for poll) Thank you for taking the time to complete the poll. We'll give people another five seconds or so. Okay. And let's take a look at who we have here today, we have pretty much even split of people who identify as government employees and social workers, counselors, or care managers again, could be some overlap there as well. We have a number of people, small number of people who identify as brain injury survivors, self-advocates, or advocates, thank you for joining us here, as well as family members or loved ones, of a person who uses long term supports and services. And additionally, person with a disability person who uses long term services. Thank you for joining us. We've got a few people joining us who self-identify as being a person with a disability. A few researcher analysts, and some people who are providers of services as well. Thank you all for your participation. That's tremendously helpful for our speakers to also understand who we're talking with today. So next slide, please. I'm going to briefly give a brief overview of what the learning collaboratives is that we're going to be talking about. So, what is a learning collaborative, the National Center on advancing person practice centered practices and systems has been using learning collaborative structure that's based on the Institute for Healthcare



Improvement, breakthrough series Learning Collaborative. Building from that structure, we organized a learning collaborative in which teams from around the country came together with experts who we invited to join the learning collaborative to share their insights. As I've mentioned, this is modified from the Institute of Healthcare Improvement model. And we base our work on the model for improvement called which refer to as Plan, Do Study Act. Next slide, please. So how did this Learning Collaborative work? We supported teams as they develop their own local aims or goals, based on a global aim for the whole learning collaborative. And then really, the teams dove into selecting strategies to implement, based on their local aims, came together monthly to talk about the work that they were doing to gain expert input and expertise from faculty, and work together towards what we call the global aim; and that was to expand and enhance person-centered community-based supports for people with brain injury through four main strategies. The first was to engage people with lived experience in self advocacy and system change. Second was to incorporate and improve person-centered needs identification working directly to improve the person-centered needs identification, and planning process. Third, establish person-centered planning best practice honestly, and fourth, to improve and expand person-centered services and supports within the communities in which our teams were working. Next slide, please. And continuing how the learning collaborative worked, teams develop their own strategies. They collected and reported data on the strategies that they were testing. As I've mentioned, there were monthly coaching calls in which teams learn from each other and with experts, expert faculty. We had extended learning sessions in which teams could come together and spend a good amount of time to talk about their own challenges and successes. And we recently wrapped up the learning collaborative with a summit in August of 2021, to reflect and share what they've learned through what we've called storyboards. And this will be the basis of the content from a number of the teams that we're hearing from today. The final image on the slide that we have here, I would like to describe briefly, that is an image of the model for improvement, which starts with three key questions. What are we trying to accomplish? How will we know that a change is an improvement? So, what might we be looking to measure to know if we're doing headed in the right direction? And what change can we make that will result in an



improvement? Those are the strategies that teams worked on to develop and then test using a process in which they would plan what they would do, they would actually do it, they would take a look at how things went, and then they would decide on whether they would keep doing that or try something different. That's the ACT part. Next slide. At this point, I would like to move on to introduce our speakers. We have representatives from three teams that were part of the learning collaborative, and I will share with you right now the brief overview of our speakers. First, from our team from West Virginia, we have Barb Recknagel, who is the traumatic brain injury waiver manager in West Virginia employed by Kepro. Her responsibilities include initial and ongoing development of the traumatic brain injury program to assist West Virginia Department of Health and Human Services. Next, we have Gina Desmond, who is a Senior Advocate with Disability Rights of West Virginia. She's been involved with Disability Rights West Virginia since July 2011, and currently works in advocacy systems accessibility, housing rights, access to home and community-based services among others. Next, we have Rodney Smith, also of West Virginia, who you'll be hearing from a little bit later as a panel as a as a moderator of our panel. Ronnie is a US Army veteran father, grandfather, traumatic brain injury survivor, and advocate. He sustained a brain injury when a pickup truck failed to see him and cross the road in front of his motorcycle. Rodney got involved with the brain injury program in West Virginia with the hope that he could help people with traumatic brain injury and their families to have better lives and avoid the frustrations he went through trying to find help after his accident. Next, I'm going to move to our team from Alaska includes Danielle Reed, who is the Director of Community Services at the UAA Center for Human Development. She serves as the lead on the Alaska Traumatic Brain Injury State Partnership Grant and also oversees the Disability Abuse Response Team, and Friendships and Dating program at the Center for Human Development. Next, we have Michelle Koston, who is a TABI Resource Navigator at Ask Access Alaska, Inc. She currently serves on the boarding board of the Housing and Homeless Coalition, and with the Suicide Prevention Team, among other teams in Alaska. As the daughter of a stroke survivor, Michelle is passionate about her work in peer support. Next, we have Krystal Blair, is the South Central, independent living manager with Access Alaska. And she leads a team of advocates providing all aspects of independent living including



information and referral services, peer support, and independent skills living training. Finally, I'm going to introduce our team from Utah. We're moving all around the states here. First, we have Rolf Halbfell, who manages the acquired brain injury and physical disabilities, Medicaid Home and Community Based Services waiver. And he's currently employed as a program administrator with the state of Utah. And finally, we have Carrie Bambrough, who's the Quality Management administrator at the Utah Department of Health of Human Services. Thank you all for joining. This is an exciting group of people with a deep, deep knowledge in state systems for people with brain injury. And we look forward to hearing from what you have to share. So, with that, I'd like to turn it over to Danielle Reed from the great state of Alaska to talk about their own experience there.

Danielle Reed 13:38

Great, thank you. I am Danielle Reed joining me from Alaska. And I want to acknowledge that I work and live on the lands of the Dena'ina on people here in Alaska. And also, that our imagery that we chose for our storyboard is scaling Mount Tabi. So first, Tabi is a term that we use here in Alaska. It's been a very long-standing term here to note that we are serving both people with traumatic injuries but also non traumatic injuries too. So acquired injuries as well, and also just acknowledging that Denali is what we're talking about. We're going to use that imagery today is scaling up or climbing Denali, and Denali is the tallest mountain in North America over 20,000 feet tall and it is quite an experience to climb it and also that it is the Denali as the Koyukon language. So, there's five different Athabaskan languages that surround that area and it means the tall one or the high one and so that is what we are going to refer to today. And I am also sorry I forgot to also give you, my description. I am a white woman with medium to long length, dark blonde hair and wearing a cream sweater and I have glasses is and I'm going to let our Krystal introduce herself and then Michelle.



Krystal Blair 15:10

My name is Krystal Blair and as it was already stated, I am the South Central Independent Living manager for access Alaska which is a center for independent living. And I am currently, not currently, a white woman with long dark brown hair glasses and I'm currently wearing a green sweater. Miss Michelle?

Michele Coston 15:39

Hi. So, I'm Michelle, I work for excess Alaska. I am the traumatic and acquired brain injury Resource Navigator in the Fairbanks area. So, a description, I am a black woman with long braids. They are purple and red, and I'm wearing a red shirt today.

Danielle Reed 16:07

Thank you can go to the next slide. And so first, before heading out on any sort of climbing expedition, you're going- oops previous slide please. You are going to define who your team is. Who are you going with? And so, this was our expedition team. This is who we took along on our Learning Collaborative journey with us. We had representation from our Disability Law Center, Dave Fleurant is the executive director there, we had Kristina Jager from our Senior, and Disability Services office and they serve as lead agency in our state for TBI, and we work very closely with them. I am from our you said our University Center for Excellence in Developmental Disabilities here at the University of Alaska Anchorage, and we had the previous executive director for the Alaska Brain Injury Network, which is our sort of our resource network here in Alaska, we had representation from our Division of Vocational Rehabilitation, Michael Pretz, and then we had Kimberly about she is with many like association in the Northwest Arctic, in our state, and is a TABI case manager there. And then we had Krystal and Michelle who are with us today that are with independent living with Access Alaska and also our state grantee for providing TBI resource facilitation. And then we had of course, Wade Holt, who is a survivor and also a business owner. That is, is from the Anchorage area. Go to the next slide, please. So, when we first started out with a learning collaborative, it was asked to come up with three different aims. And so, this is our what we call our route selection. So, there are



many ways to climb Denali, some of them easier, some of them harder. And so, we looked at okay, what are areas of focus for our group? Where do we see need? You know, what, what are things that we've talked about? And so, we have both looked at three different topics. We looked a lot at peer support services, and how do we better improve services, regardless of people's location, we are a large state, we are a very rural state we have run into, you know, during COVID, especially, we are down to one's virtual support group in our state. And so, looking at how can we better serve people across our state? How can we develop, you know, peer mentorship programs? So that was also a goal to so not just peer support, but in training peer support specialists, but how can we grow a peer mentorship program and start to pilot that in our in our state? And then lastly, looking at employment services, looking statewide at vocational rehab programs, and how can we increase their best practices and skills to serve individuals with brain injury and have successful completion in their program? Next slide. And I'm going to turn it over to Michele.

Michele Coston 19:16

Like Danny said, there are several ways to climb Denali. And I'm going to talk about the second unit in which we could possibly take to get there. So, I'm sorry, I forgot to turn my video on. It's my butterflies and everything are really bad. So just bear with me. So, as we looked out, we gathered information from our existing peer mentors in Colorado, North Dakota and mean, speaking with FIM who have programs that are up and running. We gained a lot of information. We were able to discuss it amongst ourselves And then we were able to put together a pilot program. And it's a pilot program that is adaptable. Because here there are three Skills Center for Independent Living. And it is created so that each seal could adapted underneath their name and make their pilot program and run it. And we can gather information for the first year about peer support, and then create a better program afterwards. And then the last thing that we needed to do is secure funding to run our pilot program which we're still currently working on. And I'll turn that back over I think to Danny?

**Danielle Reed 20:56**

Can we go to the next slide please? And I believe Krystal is going to walk us through the next few.

Krystal Blair 21:11

So, DVR was also a major part of one of our aims, like Danny was saying, and their goal of DVR was to basically improve services for individuals with TBI and with a with ABI as well. So, they did that in multiple ways throughout the last two years. One of the biggest things that they did was provided a statewide training to all their staff in 2019 by Dr. Susan Wolf from Arizona. They also provided some follow up training in the fall of 2020 on vocational rehab in TBI from Florida, which included updated information that they were able to expand on. DVR constantly collaborates with medical experts to effectively serve all individuals and especially those with traumatic brain injuries. They offer a comprehensive evaluation that's four hours a day, four days a week for three weeks to fully assess and identify strengths, abilities, aptitudes, and interests over time. DVR also just recently developed and were able to complete a training with access Alaska to support individuals receiving services from both if agencies effectively, there's training involved every DVR case manager throughout the state of Alaska, as well as every Independent Living advocate throughout the independent living program at Access Alaska, to ensure that we were working collaboratively... collaboratively, excuse me, for our consumers with traumatic brain injuries. DVR is always offering opportunities for their staff to gain continuing education credits that include strategies for working with people experiencing TBI as well. They enhance its documentation form to meet the specifics for an individual experiencing head injury. So, are you having a traumatic brain injury? Is it an acquired injury, like Danny had also discussed earlier, because we do work with individuals who have traumatic and non-traumatic brain injuries as well? DVR is also making sure that their documentation is user friendly. Everything we do is person centered. So, we want to make sure that all of our consumers and DVRs consumers are able to understand the paperwork that they're having to fill out, understand the assessments that they're having to fill out, and if they have questions, there will



always be somebody on hand to actually answer those questions to you at the time that you have that question. Next slide. So, like any time somebody is going on an expedition and especially if you're going to climb a mountain, there's going to be some obstacles or challenges. Usually weather is a big challenge, especially up here in Denali, because Denali does have its own weather, especially the higher up you go. For the Alaska team working on these aims over the last year and a half. COVID-19 was our biggest weather challenge. We were unable to meet as much as we needed to, we were unable to get things started at a quicker rate just due to the lack of timeframe and the lack of opportunity that COVID-19 presented everybody. Next slide please. So, the way that some of our will they both access Alaska and DVR, excuse me, we're able to track the progress of what we were hoping to gain through the milk, but also what we're hoping to gain once the mentorship program gets off base and gets on point. So, through the Center for Independent Living, we work through seal suite, which is a data tracking management system. So, we're able to keep control or excuse me keep contact with all of our consumers that work in our specific programs. When it comes to peer support and our peer mentorship program, we're able to assign them into that specific program and then track that program. We can track it through three month and annual self-evaluations; and then as Michelle had mentioned, if there are things that need to be changed after that first annual evaluation, we're able to and have the ability to make those changes to make the program better for all involved. DVR uses it with making sure that their staff are trained, making sure their counselors are they have enough counselors to begin with, especially in today's society with the number of people like not having jobs and things like that as well. So, ensuring that they have the amount of counselors they need, and that they're all, they're all trained more than effectively. And then the number of individuals with Tabby and APIs are served by vocational rehab in Alaska. The goal of that in the data process of that is to make sure that those numbers continue to be there, that we have the ability to serve all of those consumers and turn it over I believe it is Michelle?

**Michele Coston 25:53**

Slide please. Other states, wow. That was that was a lot of fun. It was hard work. The other states that we spoke with, um, and please forgive me, I can't remember off the top of my head. I know Maine was involved, and Colorado, and I know there was one more so church it to my head, not to my heart. But their imprint, not having to create something from the ground up. Being able to adapt somebody else's program, being able to pull information that's already been tried and true, um, was way better way better for us than starting, you know, from inventing the wheel when we didn't have to. And so, I think it was great that we were able to speak with the other states and I and that they share their expertise with us. Our local program and working with DVR to get this pilot program up and running is our goal. And we hope to have it up and running by January. We're just waiting for some investors, and that is how we are looking at the moment. And then once we get it up and running, we'll be able to send everybody what our feedback is. Next slide. And I believe that's Danny.

Danielle Reed 27:23

Great, thanks, Michelle. So lessons learned that we had through this process, and like any climb up a large mountain, it requires patience, and you climb a mountain one step at a time, you don't run or scale unless if you're doing mount marathon, which is a whole different thing here in Alaska, whether you're running up mountains, but when you are climbing Denali, you were doing it one step at a time and as a team, and that is critical in order to reach the summit. So, through this process, you know, really relying on the expertise of the individuals that were part of our team and taking into consideration all of their perspectives as well as you know, especially the perspective of those with lived experience on our on our team. And often that that experience and that tension of like wanting change and wanting change now but recognizing that sometimes systems take time to build and to do it in a meaningful way, we need to make sure we're doing that in one step at a time. And so, it's not a sprint, but that it takes planning. And I will turn it over to Michelle to close us out and then we'll pass on to the next state.



Michele Coston 28:38

Next slide, please. To have a fully functioning peer support and mentorship program for independent individuals experiencing brain injury is my next greatest feat. That is That is our goal. And as I said, we hope that we can get this funding together and that we can have it established in January. And ongoing training for DVR staff and our staff as well as well as the peer mentors will come as needed. They will the peer mentors will be trained first before they engage with the peer mentees, and then it will be ongoing just like regular people that need see us will do the same thing except that they just want to see. Thanks, guys in West Virginia, take it away.

Regina Desmond 29:41

So, Hi, I'm Gina Desmond, Senior Advocate with Disability Rights of West Virginia. West Virginia's designated protection and advocacy system for people with disabilities. I am a 40-year-old white woman who wears plastic rimmed glasses, I have shorter length brown hair that is pulled back into a ponytail, I'm also wearing a white polo shirt. Behind me My background is blurred, it is a gray wall with two pieces of art. In 2019, after a NASHA conference, Barbara Recknagel with Kepro brought back information on NCAPPS to West Virginia's Medicaid Traumatic Brain Injury waiver, Quality Improvement Advisory Council for consideration. The advisory council thought that this Learning Collaborative was an excellent opportunity to increase the traumatic brain injury waivers Person Centered supports and services. So, we packed for a road trip. Next Barbara and Robert will give information on how the West Virginia team through this quality improvement Advisory Council is constructed. I invite you to join the West Virginia team on our brain injury Learning Collaborative road trip.

Barbara Recknagel 30:54

Thanks, Gina. I am a white woman. I'm in my mid-60s, I wear glasses. My hair is kind of brownish, reddish blonde, some different colors here. Shoulder length and I'm wearing a black and white top and today I'm in the conference room. And next slide please. So, we want to introduce you to our work crew. This is our



learning collaborative team that worked together, and we were of course guided by NCAPPS, Brain Injury Learning Collaborative charter, that outline the roles and responsibilities for any team who wanted to undertake this, this process. So, I want to introduce you to our lived experienced advisors who is Rodney Smith, which you have already heard from Robbie, Brian Anderson, who is a survivor of brain injury and Carolyn Blekko. She's a caregiver and she's a family member have an adult son with a brain injury. Now our next group of folks were what we call our implementation specialists. And those were people who had knowledge of local systems and programs and knew how to make sure that positive change was going to happen. And that included Gina Desmond from the Disability Rights of West Virginia, and Teresa McDonald from the Bureau of Medical Services, who is the TBI waiver and the Personal Care Program Manager. We also had reporting specialists who as it sounds, they were responsible to collect and report data on selected measures. And that was Delina Arthur through Kepro in Miranda Talkington through WBUCED. Then we hit we tapped on people to be what we like to call our subject matter experts and that was, Carrie Childress. She is an associate professor in the Department of Communication Disorders at Marshall. Courtney Lanham, she's a training specialist for the Center for Excellence in Disability. We had a MSW student to join us in the process. And we also had coordinated counsel for Independent Living, and West Virginia choice who are both TBI waiver providers represented on our collaborative, as well as public partnership. And the day-to-day leader role was one that is one that I assumed. Next slide, please. So, our team charted three road trips. So, we were we kind of had an ambition and we decided that we were going to work on three different efforts to so the first was that we want to engage people with lived experience in self advocacy and system change. And we were looking at with our larger brain injury population in the state, and that was looking at self-advocacy skills, training, and information. Our next trip was to incorporate and improve Person Centered needs identification, and we were looking at spiffy specifically for a TBI waiver program and was looking at what type of person-centered discovery tools of could we be using with our members. And then our third trip had to do with establishing person centered planning best practice again for the TBI waiver program. And we focused on a key strategy of plans that would promote dignity of risk. Next slide, please. So, we want to share with you a little



bit about the specific goals that drove our collaborative road trips. And I want to start with the advertisement that we have here about person centered planning. That was one of our specific goals that we were working on. And we did want to identify Person Centered discovery tools are what we did through our Learning Collaborative is that we determined that there were two tools based upon our members feedback that We were going to start to incorporate. The other thing we wanted to make sure that happened under person centered planning is that we provided the knowledge and skills-based training sessions for our TBI waiver case managers. And we made a point to make sure that those trainings emphasize some of the key the key factors here that person centered planning is driven by what's important to the person. And if we use some person centered or service discovery tools, we can find out what is important to the person. The other thing that we worked on is finding ways to balance dignity of risks, dignity of care, and how to continue to achieve compliance, the CMS performance measures around health, safety, and welfare. We also worked at self-advocacy, getting information out to people with live experience, on self-advocacy and offer training to brain injury groups in the state. And we had to modify that a little bit, again, with the COVID 19 pandemic, we didn't have so many groups meeting. So, what we did instead is that we kind of change that focus, and we develop a brochure that is now available for members. And thank you, you just put that that link on there. And I appreciate that. And but the billboard that I think I want to bring your attention to the most is the one that's there up in the top, on the right-hand side, this is nothing about me without me live experience wanted huge value. And, and I just want to point out that our lived experience advisors, their involvement, input, and insight offered critical guidance. And without them, we would have been lost on this trip. Next slide, please. So, this slide is going to talk a little bit about how did we know that we were on the right route? How did we know that we were on track and what we were hoping to have to accomplish? And this had to of course, look at our data this had to do with what did we measure? And it speaks to what Alex talked about earlier with the model of improvement. But we did a pilot project. For 10 months, we incorporated three-person centered discovery tools in part of the planning process with our TBI waiver members. And after their service planning meeting Delina Kepro data strategist person, she contacted each member, and we had a series of five open



ended questions. And we asked them, What were their feelings about the tools that we use. And I want to share with you what was said from our pilot participants. And this is how we knew we were on track. The pilot participants felt that the person-centered discovery tools help their case managers in understanding what was important to them. And the pilot participants stated that their service plan included all the things that were important to them. And the pilot, participants indicated that the morning ritual and the good day bad tool was very helpful. We piloted three, the two that they felt were the most helpful, were the two that's on is on the slide here. We also wanted to make sure that we were providing the knowledge and skills to our case managers. So, we have conducted two training sessions so far. And you can see from the data that the case managers report that they feel that the training had better prepare them to perform their job, and their knowledge of the topic had improved. And the last thing that we want to show for our data that that it that we had made a change in this working is that not only did we develop the self-advocacy brochures, but people have actually asked for them and we have sent out brochures and at this point, I'm going to turn it over to Regina to finish up.

Regina Desmond 39:16

Okay, next slide please. Alright, so how did we get here? So, the West Virginia team, we split into three workgroups one for each of our aims or goals. Keep row barber keep with keep row as the advisory council members to volunteer as subject matter experts and in a workgroup of their choice if they were able. So, for example, I as an advocate by profession, asked to join the workgroup on developing the self-advocacy tool. On my work group was also an individual from the Center for Excellence and disabilities and a person with live experience. So, for us for our first aim, again, as Barbara just said they select the tools and then ran a pilot project and then again followed up with the individuals after, after reviewing those different tools to see what they like best what worked for them. And what came out of it was to use the good day, bad day and morning ritual tools. So based on those recommendations, that was brought back to the Advisory Council who approved those recommendations and now Bureau for medical services has backed has endorsed the Council's recommendations and is incorporating that into the members service plans. Bureau for medical services



has required that at least one case manager from each agency attend planning meetings with the member to complete those tools. And keep Pro has developed and designed to training materials, handouts, video recordings of a person with lived experience, Rodney you've already met and who you'll get to hear more from later. And Courtney with the CD, they have recorded a training on how to use the tools. And they also sought approval for social worker and continuing education CE use. So, for our second goal, the Center for Excellence and disability had an intern complete a resource literature review for existing training materials, you know, cost versus free, we don't want to recreate the wheel, and then developed a working definition of dignity of risk. That includes components of dignity of risk. And again, all of that information and training was brought back to the quality improvement advisory council. So that's where we all kept heading back to. And so, us as a council we reviewed, edited, and approved a working definition of dignity of risk. The CTD has also developed a provider link, requesting information on difficult situations that providers are having with their members. So that that can be incorporated into future trainings. For our thorough third aim, the aim that I was involved in, we began with reviewing disability rights of West Virginia's existing self-advocacy training materials, for trainings that we have done in the past, we I met with the Center for extended disabilities and kind of pared all that down into which was difficult, but we paired all that down into an into a brochure. And then we presented that again, back to the quality improvement Advisory Council. We received approval for the wording and then I sent it off to our graphics person to develop the brochure itself. Once the brochure is once we thought was complete through this plan, do study act that endcaps kind of encouraged us to do. Barbara and I went back and reviewed this final project, our final product with individuals with lived experience, and we found that some adjustments were needed to be made. So again, we did that, and we developed two completely separate products. Um, they're similar, they say the same thing. And both links to those have been placed into the chat as self-advocacy brochure, and then one that is more easily readable in a digital format. Yeah, those products again, are both in the chat. Alright, next slide, please. So, summit course, important lessons that we learned. Pretty much everybody that I've talked to that's been part of this collaborative has had both personal and professional growth, including myself, you know, we really were reminded, and it



was reinforced that we must have a person with lived experience at the table and involved at all levels in order for any true and meaningful change to occur. And we were reminded that each brain injury is different. You know, there's the saying if you know, one brain injury, you know, one brain injury, with again, with the development of the self-advocacy brochure, the individual that I met with, had to reschedule with him several times due to weather related headaches, and then he kept apologizing which of course he didn't have to do. And then once we talked, it was a long meeting. And it took me a little bit to kind of figure out what he was trying to tell me. But eventually I understood that he was having trouble reading a brochure on a digital format because we were talking about sending these out. And that would also be by email given in today's, you know, digital world because people, you know, we're not meeting in person. And he was saying about how he had trouble reading the content in the format that brochures are, you know, in PDF. So once had kind of that aha moment, again, we recreate we created a whole separate product. Barbara also reached out to a couple other individuals. And we had to work around, you know, some of West Virginia's fantastic Internet access issues. But again, if we had not taken the time, the real time to do extra outreaches with individuals, we potentially could have alienated a whole group of individuals again, unintentionally, we thought we were done, we thought the product was great and complete. And then it found out that we had a subpar product. And now I have what we what I think is a very good product, which I'm sure will change over time. For the Person Center tools, again, three product products were piloted, and we were I think I was personally expecting to hear that one tool was good. And we got feedback that two tools were great. And that's excellent. So, we did have case managers and agencies piloting those tools during their service planning meetings. And so, the information from those tools that case managers will be sharing with the individuals on the waiver's personal attendance. So again, they can have a better understanding of what is important to the member, which will hopefully lead to them receiving a higher quality of services. Next slide, please. So, sustainability, you've heard me say it a lot already. This road trip all began in 2019 at the Medicaid, traumatic brain injury waiver quality improvement advisory councils. And it all throughout this whole process, we keep going back there. And at those meetings is where this will sustain and expand the Advisory Council really as the center of the project. Every



piece of work was reviewed back and then we received feedback review and recommendations from everybody on that council. We didn't move anything without reviewing we didn't move forward with anything without reviewing with them first. Person Centered Training Series is targeted for Traumatic Brain Injury waiver programs and Bureau for Medical Services supported this training to count towards case manager training requirements based on new policy implementation in 2021. So Kepro is working to develop training materials, handouts and again the videos I had mentioned earlier starring Rodney alright the council has asked that training be expanded to personal attendance staff, but that has been placed on hold until 2022. All right, last slide. So, if you would like to go on a summer road trip with us, um, some things that we plan on doing to kind of hold and expand is the program manager at Bureau for Medical Services. She is also over West Virginia's personal care program. So, she is planning on taking some of the information that that that we have learned and the good day bad day, morning ritual programs, and presenting it to the Personal Care Program and hopefully expanding it over to there. We also have goals of trying to get these systems into our other home and community-based ways waiver services. So, the intellectual developmental disabilities waiver, the aged and disabled waiver program, and the children with serious emotional disorder waiver program. We played a support case manager through additional trainings and mentorship sessions, and then of course, our dressing bumps in the road as they arrive. For example, a service plan recently was submitted without completion of the good day, bad day, morning ritual tools. So Kepro reached out to the case manager to find out why it wasn't completed. And they are working with the Center for Excellence the disabilities and doing some one-on-one technical assistance with them in order to find out best ways to complete the tools with the member who happens to be nonverbal. And Kepro also keeping data and we're watching for other trends as well. And again, all of this is brought back to the Advisory Council. Thank you and now we will hear about Utah's Learning Collaborative.

**Carrie Bambrough 49:51**

Hi, thanks, Gina. I'm Carrie Bambrough and I'm with Utah. I'm a white female with long brownish blonde hair. I'm wearing a red sweater; I'm sitting in my office and behind me is a half white half purple wall. First of all, I just want to say what a great opportunity it was to participate in this Learning Collaborative, we were able to, I think, accomplish quite a bit. And we learned a lot from the process that we went through, as well as what other states we're doing. On our slideshow, you'll see some beautiful hot air balloons. And we chose this theme to represent our journey that we went through in the spirit of Disney's up sort of that we have a dream and getting there sometimes can be a challenge, there's bumps in the road. But as long as we keep pursuing through, hopefully we make it to the end. Next slide, please. So, this was our team, and probably as many of the collaborative's experience, we did have some staff changes throughout our time doing this, but for the most part, we were able to maintain at least representation from all of these agencies. So, we have Ralph, who's presenting today with me, and he's from the Division of Services for People with Disabilities. And we were able to have a couple of representatives from that agency. We had the Department of Health, so Tracy Barney, myself, who's also with I'm with Department of Human Services. We had some private providers that provide services for people with brain injuries, so Christie carpenter with Phoenix services. And then we also had some with lived experience, which was a great addition and of course, needs to be on there. And then a representative from the brain injury alliance of Utah, that did change a couple of times, but they were able to stay part of this collaborative. And then just a few other representatives from the Department of Health. All right, next slide, please. So, when our aims when we first started this collaborative, we had developed these aims. And of course, we, in the spirit of this learning collaborative, and the way that the plan does study act plan works is we had to kind of change and of course, with COVID, starting, it sort of changed our trajectory a little bit. But when we began, our idea was to develop this Person Center planning idea throughout the state of Utah. So, the Division of Services for People with disabilities were currently working with NCAPPS through a TA grant. And they had started working the Charting the Life Course and into implementing those tools in their system. And



we wanted to try to take that and expand it out to kind of outside of that system, and how can we use that same idea and these turning the life course, tools outside of DSP. And so that was sort of our original plan is, is how can we do that? So, our first aim was to introduce our team to what Charting the Life Course was, what is person-centered planning, make sure we're all on the same page. And then our second aim was to kind of go into more detail about each of those tools. Train more of those on the team about what does this mean. And how can we move this forward? And is this the direction we want to go? So that was our second aim? And then once we kind of did that, we decided, yes, okay, we want to use these tools. But we're, there's a lot of tools within turning the life course. So as West Virginia did, we wanted to pilot a few of those tools. So that was our aim. Number three was to start with a tool, test it across, we started with our resource facilitation group, we had a, Utah does have a fund a TBI fund that funds resource facilitation. And so, we started with that group. But this is about the time that we were in the height of COVID. And everything shut down. And so, we were able to test a few people, but not as many as we had hoped. And then our aim for was to implement the tools. But this is where we sort of had to pivot. And I know Ross will talk about that a little bit later. But this is where we had to change our direction. And the other thing that we found was hurting to test the tools is the resource facilitators didn't have enough experience or education on person centered planning in general and what charting the life course tools were even though we trained them, and so we kind of had to take a step back and decide, okay, we need to implement better persons that are planning and thinking training. And so next slide, slide please. So that sort of became more of our goal is to develop a training and guidance for bringing into professionals to incorporate person centered planning processes, with individuals with brain injury, and we were able to coordinate with NASHIA, which is the National Association of State Head Injury Administrators and they helped us develop a person-centered planning and thinking training that we are now incorporating into our Utah brain injury Council and our goal was sort of to move forward and to be able to train professional brain injury professionals on person centered planning and thinking. Our goal number two was to combine this learning collaborative with the TA grant that and that's sort of our next steps that we're hoping to be able to do with the DSPD TA grant that they have a massive Division of Services



for People with Disabilities, and so that we can kind of continue this effort moving forward. And then our last goal was to which Ralph will talk about a little bit as well as how we move this forward is to have so UBIC is our Utah Brain Injury Council. And it is out Utah's steering committee or sort of the committee that Utah has established that helps us to identify needs within Utah, and then establish processes and strategies to help meet those needs. And so, we had introduced you but to this collaborative idea that we've been working on and then trying to get them to take ownership and the lead so that we can continue this effort moving forward. And sorry, I just saw the chat, UBIC stands for Utah Brain Injury Council, and I can type that in there too. And, and then so that we can continue this ongoing, person-centered planning and thinking training and approach for agencies across the state of Utah and outside of just the disability services that was already happening. And I will turn the time over to Ralph.

Rolf Halbfell 56:41

Hello, everybody, sorry, I had a hard time finding my mouse. Um, my name is Rolf, the same name as a character in sound of the music if that means anything to somebody. I'm a white European that immigrated in 1996 to the United States of America and never have regretted it. I'm glad to be here. I'm glad for the nice hospitality that I've received. I'm, I like to wear Harley sweaters, as you can see, right. And I'm on my I'm on the fifth floor in my office with the beautiful view over to the mountains, the Wasatch Mountains. I'm an avid hiker, I hike every weekend to mountain sights meadows, to experience the fall leaves and so forth. I am a veteran. I've served in the infantry for the country for a few years. Military service is in our blood as a family, my parents, my parents serve as well as my uncle as well. I'm also survival brain injury just like Rodney as when he introduced himself, I had a motorcycle accident on the German Autobahn where I lay down my bike with about 80 to 90 miles an hour. But I was wearing full leather and a helmet. But a helmet doesn't prevent everything. But it could have killed me if I wouldn't have won one. So, I'm very much of an advocate to wear helmet and protective gear to protect people as much as possible, enjoying their hobbies. So, we already heard a lot from Carrie here. And again, to kind of go back to our theme as Carrie was explaining flight. And flight didn't come overnight. Right? It happens from grace to grace, from period to period, from



epoch to epoch from century to century, right there was a great learning experience, the great learning curve, which brings us right to the next slides, which is how did we as a team Utah actually measure our progress. Now, you have heard from many, many teams already what they have done. And at a certain point, it can come you know, as, as you behold this present these presentations, you know, it can become very confusing, confusing. And I like to compare it like you know, you try to drink from a fire hydrant that just went off. Right, try to do that. So, it's like a tsunami coming into the beach. And just to keep it kind of simple, as simple as possible. And we the best measure that we had was actually introduced by endcaps, which is the PDSA cycle that you may have already picked up on some teams using which really stands for Plan, Do Study Act, right. And what that really means is, you know, from when you think back of the aims that Carrie just introduced, right, every aim, you know, in the background, you have to have that PDSA cycle, right? The plan, what was behind it, how you to actually create their team, what did we try to achieve? What did we plan to do, and how can we best accomplish that issue? Right. And the plan was, who are we actually want to have as team First, what will make this the same sense? Which team member if we selected them? You know, I could bring what kind of work skill to the team that we can build on, you know, and to be most productive and effective? Of course, when are we trying to accomplish something? Where are we going to come accomplish something? What are our timelines? How we're going to study that? Do we need to study that? And, you know, are we even as a team? Are we even on the same page? What will it take to be on the same page? Right, and we had some real interesting discussions especially, that's where the, the living experience brain injury person that we had on board and still have on the board, you know, was so helpful, because as a professional, you start thinking administratively you think about, you know, all these things on an administrative level policymaking level, you know, of what needs to be done. And you completely start minimizing, you know, all the other issues that actually could have a preceding role or play a preceding role to everything else. Right. Which is really, you know, well, have you thought about, you know, that people have a certain routine. Have you thought about, you know, that folks need a simple language? Have you thought about that the some of the things that you have been suggesting in this team meeting, you know, how



applicable is that actually, right? Because if we don't have the survivor with brain injury in our midst, we are going to completely miss the boat, right? And all that time and invested, and the work done, may be in vain. So, we invested all this time for nothing, you know, or, you know, we put something there that's not going to be used or underused, right. So, the PDSA cycle, and I will come on to another slide in a minute of what that actually helped us with. But that was so helpful to keep us on course, like just like a balloon, going, you know, with the wind in certain directions, to keep us on course, and be able to do a course correction. Right, so that we keep on course and go and achieve our plan, our goal that our aims that Kerry was talking about in the right way. And what other measures have we used other than the PDSA cycle where there were many, just to just to share a couple here that are also included on that slide. One was we completed and developed a discovery tool, a weekly summary report, like an essay kind of questionnaire, very simple, very simple to ask the interviewer and to ask the interviewee, after, after such a discovery tool, and we went with a Charting the Life course discovery tools for Person centered planning, they could give feedback on how they felt, did we even did was that even applicable to a person like did it wasn't helpful to a person to identify their natural support system to identify their community resources to identify agencies that may have they have that already gave them help? Or were of no help? And how to go about right? What are their likes, what are the dislikes, what are their routines, you know, that was a shock to those that have already responded to that, we have had nothing but great, great feedback on that? Because a lot of depending on the cognitive deficit, that a person with brain injury may present themselves with, you know, some are very visual, very color oriented. And that's exactly what the charting the life course discovery tools for person-centered planning are, right, and they could very much associate with them, you know, identify themselves with it. And it was much easier, you know, to do it have with having something to present themselves with, with a piece with a paper, something that they could identify with, to really come to point to lay out their life. Basically, this is what I need. This is what I want. And this is why I need this and how I need this and with the amount, duration, and frequency. The other measures that we put together a manual, a train the trainer manual for resource facilitators, resource facilitators, the folks that are with various agencies throughout the state of Utah. And as



Carrie already mentioned, you know, they were all paid through the TBI fund. That's how it was funded and is going to continue to be funded. And in that manner, you know, they are able to use that train to train a manual that was put together with an Anastasia Atwoods then with NASIA and NCAPPS. You know, that really trained everyone and made it applicable to resource facilitators so that they can actually use it with folks in the community. And that really has proven a great deal. And we have a tracker there. We know how many people log on to what module who took, what course, and so forth and so forth. So, it's, it's, it's just an amazing ride so far. Next slide, please. So, methods we use to accomplish change, right? One was, of course, a PDSA cycle, the other one, the train the trainer manual. But you know what, when it really comes to push to shove, where really the rubber meets the road, it's really what I put in the middle. And this is why I put it in the middle, even though you see many, many things going around there. But really, the big part is recognizing that people respond different to changes, we do those that don't have a brain injury, but also those that have a brain injury, right? We all like our routines, we like our living environment, right. And if somebody comes in tell us how to do differently, and that we need to do things differently, that could come to conflict, right? We also accomplish changes through, and we have this coming up on November 1. And second, our Brain Injury Alliance's annual brain injury con, where we've sent a lot of case managers, caseworker psychologists, you know, from all kinds of field professionals from the field therapists, occupational therapists, speech language pathologists, to these conferences. And part of this year's conference is our day three, that specifically geared to a workshop on person-centered planning and charting the life course. And that is due entirely due to the help with NCAAPS who this wonderful Learning Collaborative that we're talking about today, that that actually was put in place. And we are able, on that level now to teach folks about persona planning at such a conference. What a wonderful opportunity. That is. I could talk much more, let's go to the next slide. Lessons learned, of course, we there, there's more than just four lessons learned, right? As Carrie kind of introduced yourself, and me to it. It's like, you know, we had an issue with the PDSA cycles that yes, that was due to COVID. But, you know, it was really interesting, because the PDSA cycle all of a sudden showed that the train the trainer manual, should have really come first, before we actually train resource



facilitators on how to offer these tools. So, we had our sequence actually changed, switched, right. And so, we did train the resource facilitators, but after times, you know, they came back saying, I have no idea what you just talked about, or I'm still confused. And we were sitting together as a team. And we're like, what did we miss here? And opening up and our aims and our PDSA cycles were like, Oh, my goodness, it makes no perfect sense. Because if we were to swim in a change, planning, cycle three with planning cycle four, that would have been no confusion, or if there would have still been confusion, it would have been much more in a limited way than what we experienced. So, thank heavens to this PDSA cycle, we were able to do a course correction to avoid the storm. That's why you have that balloon going towards that thunderstorm, which is of course turbulence, you know, the issue that I was just talking about representing that, and really do a course correction to get away from that storm and to go back to better weather conditions, right to have a nice and easy flight, and to help people with brain injuries better. Next slide. So, our aspirations for the future as a state of Utah? Well, Carrie already mentioned that, but we just were approved. Thank you NCAPPS, folks, we love you. In partnership with the NCAPPS Technical Assistance Grant, Utah just was approved for an extension for another two years. So, we are partnering now because as you heard the Learning Collaborative is sadly or has already expired. It didn't die but expired. And so, we were able to hop on with the TA grant to keep itself sustaining. Right? We also are as equally exciting. We are partnering with the Utah brain Injury Council that Kari already mentioned. And through the UBIC, the Utah Brain Injury Council, we have so many folks, so many awesome professionals on board already that we have trained already ready to go to their agencies and to do this training and introduces turning to their particular individual agencies. And let me just name make mention of those agencies that are actually participate in this because this is really wonderfully distributed. We have folks from the governor's council from the Utah Governor's Council for People with Disabilities. We have the Division of Mental Health and Substance Abuse on it. Of course, the SPD. We have the Utah Center for Assistive Technology on board. We have the Violence Injury Prevention Program on board, the TBI fund, the Utah Department of Health, the Office of Quality design, the Division of Aging and adult services, the Utah State Board of Education, the VR hospital, the Veterans Affairs Medical Center, we



have several private agencies such as the Brain Injury Alliance, cognitive functioning cognitive X, the Disability Law Center, and we have even hospital setting on board with the Intermountain Healthcare System which is a Utah based hospital chain that offers a lot of services to people with brain injury as well. So, we have a wide array in place, trained and ready to go. So be more trained to go out to their particular agencies to reach out. As you can imagine Utah as a state that has several areas, urban areas across the Wasatch Front were Salt Lake, Provo, Orem, and all those areas up to Clear Field. And then of course, we have frontier areas, and we have rural areas. And so that way, you know, with incorporating all these agencies, we are able to have reach out into the far corners across the state, and to identify resources to make more resources available, and to really hope and work towards a change in the state of Utah to a be more make people more aware of brain injury, and to help people meet their goals, individual goals, to Person centered planning for people with brain injury. That was it for me, I hope you like this presentation.

Alixé Bonardi 1:11:53

Thank you, Rolf. Tremendous presentations from each of our three teams. And thank you again to our teams from Alaska from West Virginia and from Utah. I'd like to move us to the panel discussion part of our session today. This is a little bit less formal. And to lead us through the panel discussion, I'm turning it over to Rodney Smith. Right over to you Rod.

Rodney Smith 1:12:28

Thank you Alixe, I and to turn everything back on. I am from West Virginia, a survivor of traumatic brain injury in 2008. As she described it was pretty traumatic event, of course, but I'm glad it was selected to help the learning collaborative with the panel discussion here, we've got a few things we want to talk about and that we discussed. As we went through the thing here and was making our preparation for things, we want to discuss that made an influence, made, you know, that influenced us that made us think about things we wanted to share with people and what we learned from this, and how we can help other people do things like this type in the future themselves, too. First question we'll go with here. What are the key things that are needed to create shared learning activities? And I think we'll start this off with Regina from West Virginia.



Regina Desmond 1:13:40

So, for us, it is important you must have people who are invested for West Virginia. This was through the group of people that are on our Traumatic Brain Injury waiver Quality Improvement Advisory Council. And it was also clear from the get-go for us that we want better services for the individuals who receive these brain injury waiver services. And we're lucky enough that the individuals on our advisory council were all likeminded and we see the importance in collaboration.

Rodney Smith 1:14:21

Thank you, Regina. That's very helpful to all that are involved in this thing. And from Alaska Michelle you have some input on that?

Michele Coston 1:14:32

She pretty much everything on the nail. I just want to add that you need people with open minds, or a clean slate, willing to work and get in there and do what's necessary. Not people that are into bureaucracy and like to have a whole lot of meetings. It's people that need to see that this is important, and we need to get things done. Make a plan then activate.

Rodney Smith 1:15:09

Okay, how about you Rolf? Got some input from Utah on that?

Rolf Halbfell 1:15:13

Yeah, it's always a privilege to go last because a lot of it already has been said, Right? Just to say it really, you want folks that are self-motivated and engaged in this in these costs, right to really make a change, and to really understand or try to understand the person with brain injury, right? That really is what matters. Again, like I said, during my presentation, when we presented, when we went over the slides, you know, make sure you base everything the person is in the center, right? And everybody learns differently in different ways, right, and we need to recognize that we actually have posted a cultural aspect of, of folks in the state of Utah, we have a whole training manual on that as well, a handbook, an



online handbook, that kind of emphasizes it. It's, it's, we need to know about each other, and especially folks that we serve in the state, you know, can vary on various cultural levels. And that's what we need to recognize in order to respect people, you know, to validate their concerns and to act accordingly.

Rodney Smith 1:16:34

Okay, that's very important. And yeah, it kind of ties in with the next question that what have you learned from having brain injury survivors on your team? And you touched on a lot? A lot of that already, Rolf. But is there more you can add to that?

Rolf Halbfell 1:16:50

Sure. I always can add, um, you know, language matters, right? Everybody function on a different cognitive level, right? People with brain injury in general, need a longer response time. We need to give that to them. Are we having the patience to wait for that response, right? We do a work with a lot with precision direction, you probably have heard of that, right? For example, Jack was a brain injury needs to get his coat on and get onto the van to go with the others into the activity. Well, Jack doesn't understand what's going on, because he gets easily confused due to the brain injury. Well, here comes the precision direction, right? Jack, please put on your coat. No. And then we wait three to five seconds to see because it takes an injured brain so much longer to respond. Right? It's kind of like me talking to my four-year-old daughter, right? Kaylee, go get out of bed, brush your teeth, get the cereal, you know, get in the van so we can take you to school? What would Kaylee do? What she, you end up with? You know, there's, I mean, she maybe eats the cereal and then goes to the van and forgets everything else. Right? It's really as it we got to learn, and I include myself on that, keep the patients to make this happen to have people with brain injury succeed.

Rodney Smith 1:18:16

Yeah, that that's, we had a lot of that during my rehab if you give me three things. And you might get two of them back on a good day.



Rolf Halbfell 1:18:24

Correct? Yes.

Rodney Smith 1:18:26

Okay. Thanks for all. Virginia, you got something to add on that you put chimed in on this as well, during your during the time you're speaking. I'm sure there's more to it.

Regina Desmond 1:18:36

Yes, we definitely there is value in different perspectives, it is really important to get multiple individuals' feedback. And of course, as professionals, we need to remember to actively listen and to hear what individuals are saying they are the expert, you are the expert on your brain injury. It, we also learned that it's important to schedule breaks during meetings, that's been great, particularly in this now zoom filled world, you know, schedule breaks times away from the computers. Also, we expertise is needed in order to assure that we're providing services that are meaningful to those with lived experience, you know, we don't want to provide unmeaningful, you know, services. And so of course, real people first services takes time, as Rolf said, to ask and listen. We want to make sure we develop systems that are centered around individuals with lived experience based on their feedback for what works and what's important to them.

Rodney Smith 1:19:38

Okay, most definitely. Okay, Danny, what do you got from the Alaska side there? I know things are different up there. So?

Danielle Reed 1:19:46

yeah, so um, so much of what Lawson Gina said, I think were things I was just going to touch on. You know, I think understanding you know, for us in Alaska, you know, gaining that different perspective, right, we have urban areas like eight Anchorage, we don't have a level one hospital, we have level two trauma hospitals. So, people are sent out of state sometimes for services or for treatment. And understanding that each person's journey is a little bit different,



and they have different access to services across our state. And so, learning from their different experiences, you know, if you're coming from a village, where you were, you know, fly-in only that experience is so different from somebody in the Anchorage area. And so, for us, you know, gaining that perspective across our state is really important, and including that perspective in our council is important. And then I would add, you know, that, you know, within our, what we learned specifically from the individual involved with us, what was so great was his ability to just say, okay, so what, what does this mean? What does this mean for the person with the lived experience? And so even in creating this presentation, he was like, why are we doing this? You know, why are we spending all this time on this presentation, we should be changing supports, we should be implementing this program. And it's true, we should. And we had a big discussion around that, you know, what is the importance of sharing this knowledge? So, you know, we gained so much from talking with, you know, peer mentors and other states, Maria, and Carol, both faculty on the NCAPPS team, their perspectives in what peer mentorship was for them, and what they have learned through that process was so impactful. And so, you know, how can we continue that? How can we share that knowledge as we develop our Peer Mentor Program? And, and I think it's just it's a hugely, it's been hugely valuable.

Rodney Smith 1:21:38

To be learned from us. Okay, next thing, there's a saying, mighty oaks grow from Little Acorns. What is the acorn or seed that got planted, that you really want to grow to continue this work? Well, you think, Barb.

Barbara Recknagel 1:21:58

So... thanks, Rodney. So, the seed that got firmly planted in West Virginia for West Virginia, as simple as it sounds, it goes back to the fundamental underlining person centered approach, which is nothing about us without us. We experience the benefits of true real involvement of folks with live experience. And when I say that that firmly planted, like Gina said, I really thought we were doing this, but this kind of got cemented even more that involving folks with live experience is not just about filling a spot on a work group. It's about engaging, encouraging, supporting, accommodating, and above all, listening to the live experienced



advisors, and that we should never give up seeking input because someone may seem to be not interested or not involved. Because it could be how we're approaching it. isn't, isn't working for that individual. So, we have we have learned and going forward, we know that any meaningful lasting system change must include the person that's going to be impacted. And we know that that's the cornerstone for real change. And we're looking forward to that system change in West Virginia.

Rodney Smith 1:23:42

Thanks, Barb, I hope I contributed to our team well enough for you. Krystal, Alaska? What do you got on that?

Krystal Blair 1:23:56

Kind of going off Barb was saying with person-centered. I think the biggest thing that we were able to take away is that we have to have individuals with lived experience taking our peer mentorship program. And as the main point, we more often than not we work with individuals who are case managers advocates direct supports for providers who more often than not, do not have that lived experience. So, to start a peer mentorship program with an individual with a traumatic and or acquired brain injury, to work with another individual with the same thing is more beneficial because they have that lived experience. So, the seed that we want to continue to grow is to have more lived experienced individuals to have that personal experience to be able to work with our other individuals to be able to share their experiences share their pros and their cons of all programs and resources that are available to them within the state of Alaska. So, mine will be just a continuation of trying to improve services for individuals with lived experiences by other individuals.