OPENING

Welcome, everyone. Thank you so much for joining The Link Center for this shared learning group. Today we are focused on the topic of supports for trauma. I'm going to go over a few housekeeping items while we get started today. We have live captioning and ASL interpreters present today. The session will be recorded in the recording and transcript will be shared with all attendees. The PowerPoint and any documents from today will also be shared with everyone via email. We welcome you to revisit the content yourself and share it with your colleagues.

Attendees cannot see the names of other attendees and all attendees are muted. Please use the chat function throughout the webinar to communicate with other attendees and with the host during the webinar. You can use the chat by clicking on chat at the bottom of your screen. Please be aware that your name will appear in the chat if you make a comment. And you can change your display name if you want to by clicking the three little dots next to your name and selecting rename. We will have representatives from the Link Center watching the chat and responding throughout the session today.

If you would like to submit a question or comment privately to the host of panelists you can do that by clicking on the Q&A function at the bottom of your screen and submitting your comment anonymously.

Following the webinar you will receive an email with the material we will review today, recording, and a transcript along with an evaluation that we ask you to please complete in response to today's shared learning group.

At this time I will hand the floor over to Dr. Stacy Nonnemacher who is going to start today's presentation. Stacy, the floor is yours.

INTRODUCTION AND WHAT IS THE LINK CENTER

DR. STACY NONNEMACHER: Thank you Stephanie. Hi everyone, think so much for joining us today. We are so grateful you from the time. We will be talking about the Link Center, a grant funded by the Administration for Community Living. And just by way of an introduction I am Stacy Nonnemacher. As Stacy mentioned, I am with the national association of State Directors of developmental disability services, NASDDDS. And I am a middle-aged white woman wearing glasses. I have brown straight shoulder length hair. I am wearing a gray sweater with a pink shirt underneath, and I am in front of a white Zoom background.

Today we will be talking about supports for trauma. And while we will not have enough time in our hour and a half to do a deep dive into the topic,

we do have enough time to start the conversation about how to get you all some tools and information and resources related to trauma.

We know that the conversation today in the content may be triggering for some. So please, please take care of yourself. And please let us know in the chat if there is anything we can do to change the words we use as we are meeting today. You know, we know that even the word trigger may be triggering for some. So please give us your thoughts and your reactions. And we invite you to share and do that in the chat.

And really truly we welcome all sorts of participation today. We know that some of you may be here to actively engage, and some of you may desire to just listen and witness. And that is okay. We welcome all of that in this community.

So little bit about shared learning groups. This is the second quarterly meeting of shared learning groups that we are holding. We did a series of shared learning groups in October, and we focused on crisis services. This series of meetings like we said focuses on supports for trauma. This is the fourth meeting we are holding. We held a meeting yesterday with direct support professionals. We held one yesterday with clinical professionals. We held one just a little bit ago for families of people with lived experience, and now we have this shared learning group with you all.

The information and the content in all four of the presentations, this PowerPoint, is the same. We did tailor it just a little bit, changed the discussion questions to make everything relevant for each of the groups.

So this presentation and the content and everything we are showing you is a collaboration and work done by the Link Center partners. And that includes people with lived experience, that includes researchers, and also people who work on policy issues.

As Stephanie said, we are recording today. We will transcribe the meeting as well. Transcribing means writing down all of the words that people say in the meeting. So we will have the recording, we will have the transcription, and any materials we show you today. That will all be emailed to you after the meeting.

We do encourage you to share all of this information. The recording, the transcription, and all of these resources with other people in your life.

Now I get to turn the microphone over to Perri Spencer, a mentally ill Autistic self-advocate, a ACE user, and a member of the Link Center steering committee. They are a graduate of Taylor college project search, a program focused on teaching employment skills to people with intellectual and developmental disabilities and other disabilities. Perri work as a direct support professional, and they are currently searching for a new work opportunity that would even further enhance their skill set and allow them to grow as an advocate.

So I am turning it over to you, Perri. Thanks so much for being here.

PERRI SPENCER:

I am a white person was short like brown hair. I am wearing a gray-ish green coat. My pronouns are he/him.

We are going to talk about trauma. Trauma is when that things happen to us or we see bad things happening to someone else. We may feel scared, hurt, or upset when bad things happen to us. This is okay. We may also feel scared, hurt, or upset when we are reminded of that things happening. This is also okay. Discussions of trauma are difficult and it is okay if you need to take a break.

I want to talk about the inherent trauma that can come from having an intellectual or developmental disability, or I/DD for short, and mental illness. Existing as someone with I/DD and Mytilus comes with trauma that is not a doctor about. Some people don't know that these experiences are traumatic. I Heather will be talk of unmet needs and discrimination towards people with I/DD and mental illness. Be gentle with yourself.

The first thing that is traumatic is not being able to say what you want or need. This happens most to people who are non-speaking but can affect everyone with I/DD and mental illness. It is very difficult and leads to not getting your needs met, frustration, and meltdowns.

Another thing that is traumatic is a lack of choices and autonomy which is the freedom to make choices about your own life. It is very scary to not

have control over basic things like what you want to eat for dinner and major things like where you want to live. It makes a person feel very out of control and scared to. Everyone should be able to make decisions about their life including people with I/DD and mental illness.

Something else that is traumatic is not getting your support needs met. For example, Jackson lives on his own and needs help to use the stove. But his support worker only comes some days. He may want to use the stove on days where his worker is not there. But can't do that safely because his need to have help while using the stove is not being met at all times. Having unmet supports limits the choices of people with I/DD and mental illness. Jackson may not have a choice of whether to cook dinner using the stove or the microwave one worker is not present.

It is also traumatic when people assume you are incapable or cannot do things without talking to you. Especially when it is people who are supposed to be supporting you. People may think that you can't do anything for yourself or because you can't use speech you can't understand or say anything. This is not true and it is not okay for people to think that. People should ask what you need help with instead of thinking you can't do certain things.

The last traumatic thing is ableism. Ableism is when someone discriminates against you or treat you unfairly because you are disabled. There are little ways people will treat you unfairly. For example, someone may talk to your coworker or instead of you when you go out. Even though it is not okay. Some people may not know unless you tell them. There are also things that even non-disabled people know are not okay like a boss not giving someone a job because they are disabled.

Ableism is found in all parts of life because the people who make laws have bad feelings about disabled people.

Next I want to talk about abuse and keeping people safe from abuse. It is a scary thing to think about and it is okay if you need to step out, especially if you are an abuse survivor. However, it is important that we talk about abuse and are two key people with I/DD and mental illness safe. If we don't talk about it, we can change it.

It is important to know that people with I/DD and mental illness are a much higher risk of abuse than people without I/DD. There are a few reasons why I think that is.

First, people with I/DD and mental illness may not know what abuse looks like. For example someone may not know that someone taking their money or controlling the money without giving them choices of how to spend it is abuse. It is important to teach people with I/DD and mental illness about what abuse can look like so they know when abuse is happening and how to report it.

Another problem is that even if a person with I/DD and mental illness does know they are being abused, they might not have the tools to report abuse. This is especially true for people who are nonspeaking. Communication devices with symbols do not have the correct names for genitals. This may not seem like a big deal, but it means that someone who uses a device cannot report sexual abuse. A person with I/DD and mental illness also may not know who to report the abuse to or how to say what happened in a way others will understand.

People with I/DD and mental illness are often denied sex education. This makes reporting abuse more difficult. Someone might not even know that sexual abuse is happening without information about sex that the person can understand.

People with I/DD and mental illness need and deserve correct information about abuse and help from supporters to stay safe. Some people with I/DD and mental illness may have a hard time staying safe even with current information and support because of their disability. Supporters should be looking at for changes in a person that may be signs that abuse has occurred. However, it is not a replacement for teaching people about abuse and how to report it.

It is important to remember that abuse is never the victim's fault. It does not matter what they did or did not do. Believe people when they tell you about abuse. That is most important.

"The difference between crisis and trauma. When a tree stands against the storm it is during this term the resistant to the storm that the tree is in crisis. After the storm bent and soaked in rain branches snapped and completely torn away, now the tree knows trauma. I compare myself to the tree. I know my strength is in my roots." Monica Wafford, survivor.

This meeting will be talking about trauma and strategies people use to address trauma. Take care of yourself and allow silence to be a safe space. Feel empowered to do what is necessary for your comfort and care.

We celebrate our individuality, our diverse culture, and our singularity will be celebrate the discoveries realized in our collective humanity. We know that we are each unique with our own experiences in the world.

We celebrate -- we empathize with experienced traumas that hinder our resilience. Some people have experienced trauma that makes it hard to recover and move forward.

We listen with open minds and compassion, without judgment or blame.

DR. STACY NONNEMACHER:

Thanks so much, Perri. Thanks for really setting the stage on our topic for today, supports for trauma. And thank you for your incredibly powerful words.

If people feel comfortable and are willing to introduce themselves, please type in the chat your name or any group, association, or membership you may be a part of that you want to share as well. We would love to see who is joining us today.

By way of an agenda, I am going to take a few minutes and talk about The Link Center. Some of you may have heard about The Link Center before. I will just talk a little bit about it. And then we will really get into the topic today, supports for trauma. And we will talk about why we are talking about trauma. We will share some resources that we have found that are out there that we want to share with you all.

We acknowledge that there are many resources out there related to trauma informed care, trauma informed approaches. Mostly in the mental health field. Some in the intellectual and developmental disability field, some of the brain injury field.

But what we have really been finding is what is out there is really not specific to a diagnosis. That there is really practices or strategies or supports that are

good for everybody. And so we are going to share some things from that perspective today, from really that lens today.

Although The Link Center is really tasked at bridging systems, bringing systems together to support people who have co-occurring conditions like intellectual and developmental disabilities, brain injuries, other communication differences, and mental health conditions, we know that there is not a lot out there in terms of resources specific to those folks and trauma.

But as part of The Link Center we are going to be working towards that end building some resources and materials, and we will share one with you today as well, as well as some other things again that we have been finding and I think will be useful to you all.

We will end today asking you to engage with us, participate, share with us in reaction and response to a challenge we are going to pose to you all about someone who has experienced trauma.

So we will be ending our time together doing that group exercise.

We are going to say this now and we will say it again later. We encourage you and invite you all to use the chat if you think of a resource or you think of any piece of information that you have come across that has been helpful to understanding trauma generally, maybe even understanding your own trauma. Please, please share that in the chat.

These are called shared learning groups, and I want to point out the shared part of that title. We are really looking for an opportunity to share what we are doing at The Link Center, but then have you all share with us what you have been thinking, what you have been tapping into or things you have been finding that have been helpful that we could be thinking about through our work at The Link Center.

So what is The Link Center? Again I mentioned before that The Link Center is a grant and it is funded for the Administration for Community Living. It is a five-year grant and we are about a year and a half into that grant. And it is really looking to bridge systems, pull systems together to better support people with co-occurring conditions.

And luckily we are doing this work with a lot of partners. The main partners are NASDDDS, that is who I am associated with. NADD, the National Association for Dual Diagnosis, and the NASMHPD, the National Association of State Mental Health Directors. You will meet some of our colleagues and partners today as well as meeting some of our other partners that really help us keep an eye on diversity, equity, and inclusion. So you will meet Max from Green Mountain Self-Advocates. Another partner is the Autistic Self Advocacy Network who was instrumental in helping us ensure that all of our materials are plain language for these meetings. We also partner with the National Association of State Head Injury Administrators, and CommunicationFIRST.

Part of what we do at The Link Center is we want to ensure and be sure that we are really giving people what they need and doing it in a way that accounts for quality. And we have some partners who help us do that. We have the National Center for START Services. We have the Sonoran Center of Excellence, as well as the Ohio State University Nisonger Center.

So we are very lucky that there was a lot of really wonderful partners that think about this and also how we can help support people with co-occurring conditions.

There are three goals for The Link Center. The first one is systems change. And what we mean by that is that oftentimes people with co-occurring conditions or more than one condition require or need services and supports from lots of different systems, whether it is the developmental disabilities system, the mental health system, the medical system. And in my experience often times people getting those services and supports from multiple systems can be tricky or difficult.

So part of the work of The Link Center is really looking at how can we improve that. And that is looking at the policies, that is looking at service design and how systems are designed, and how we can better access those services.

A second goal is looking at building capacity. That means making sure that there are skilled people out there who can support people with co-occurring conditions. And so to that end we are going to put effort and work into getting information, to getting resources to direct support professionals and clinical professionals as well so that we have more people who are able to support individuals who have more than one condition.

And then finally we are hoping that if we make some systems change, if we have a diverse and skilled workforce to support people who have co-occurring conditions, that people will be able to access services that they need. So we are looking to get people the services that they need through building capacity, through systems change efforts, and get people person centered culturally and linguistically appropriate services that they need.

So how are we going to do that? Well, there is quite a few activities that we are doing through the grant. Again on the left side of your screen you will see, I am repeating it, but we are putting an eye on diversity, equity, and inclusion and everything that we do. And also continuously ongoing looking at are we doing what we want, what we wanted to do, what we set out to do, and are we meeting the needs of people with co-occurring conditions, supporters of people with co-occurring conditions, and others.

And we do that through it says here project management and evaluation. Stephanie mentioned that at the end of today's time together we are going to offer a survey to you all so you can tell us about your experience with these meetings.

We are going to use those types of feedback and everything that we do so that we get the information that can inform and guide what we do next time.

And speaking of guiding the work of The Link Center, we are very, very fortunate to have a steering committee made solely of people with lived experience. And not only do they contribute to all of these activities -- we met Perri, Perri is one of our steering committee members, and they contributed to all of this content today. So publicly thank you Perri for doing that, it has been a wonderful learning experience for me and I think we put together some really great content for you all. But generally the steering committee is guiding the work ongoing that we do with The Link Center.

Another activity is every quarter we are committing to holding shared learning groups like this one so that again we can share what we are doing as The Link Center and things that we are finding, and for you all who are out there day in and day out as supporters, as people with lived experience so that you can share with us what do you all need? What is out there, what can we elevate, what is not out there that we can think about taking action.

We are also tapping into and engaging meeting with other people who are thinking about how can we better support individuals with co-occurring conditions, and we call them our expert contributors.

And then finally we are really looking for resources, trainings, information that is out there that is specific to how do we support somebody with co-occurring conditions, acknowledging that when I say that, that is a wide spectrum of people, right? When I say brain injury, when I say intellectual and developmental disabilities, when I say communication differences, there is a spectrum of people within just those groups that I mentioned, right?

So we are really looking out there to see what information is out there, what can we take and put on a website, a coming soon website. It is not up yet but we will have a Link Center website. And we are hoping that that website will be a national repository or a place for us to put all of this resource and information for people to be able to access.

And you will also see today that we are identifying what is not out there and creating materials and resources, and that will be up on the website as well.

Before I turn it over I am just going to take the opportunity or the time to post a poll. Really we are interested as we do developers resources and materials and share information, we are curious how you like to get your information. So just take a second and let us know what you are thinking. If you choose other, that's okay. You could just let us know when the chat what you mean, that would also be great.

This is wonderful, great response. This is super helpful to us, very informative to us in terms of letting us understand how we should be putting information out, which is a big part of our work at the Link Center.

So hopefully now you have a little bit of background on The Link Center if you didn't before. And I get to just talk a little bit more about the shared learning groups before I turn it over. I have said this before, I'm going to repeat it, but really what we are hoping that you get out of today is that you understand in terms of supports for trauma some of the things that we have to offer you by resources and information and training.

And then we also want your input. So again, if there is any resources or information that you go to when you think about supports for trauma, please, please put that in the chat. We are collecting that.

And then during the group exercise we are going to ask you to help identify potential solutions to a challenge that we are going to present. And that really helps us understand your experience in relation to supports for trauma, and really the direction we need to be going as The Link Center.

So now I get to turn it over to Dr. Brian Sims who is a partner of ours who the National Association of State Mental Health Program Directors. Dr. Sims, thank you so much.

PRESENTATIONS

DR. BRIAN SIMS:

Thank you Stacy, and again thank you to the Link Center and a special thanks to the steering committee. Just a phenomenal group of individuals to work with that makes it so easy for us to be able to have these kind of conversations.

I am Dr. Brian Sims, I am Senior medical advisor with the National Association of State Mental Health Program Directors. My pronouns are he/him/his, I am an older Black man with glasses, gray black hair, I have a gray sweatshirt on and my background is white.

I wanted to just take a pause for a moment and who we are talking to today, I really don't need to even go into the title here of why we are talking about supports for trauma because each and every person I am speaking with knows trauma, has histories that are involved in it. So what we want to talk more about is how we can be of help to you. And I will just give a brief overview of some of the elements involved in some of the data that is in there with trauma.

But I want to start off on a different note this time around. I want to give you guys a resource to work with. I am part of what we call a crisis jam that works with 988 and so forth, and I was on it today and there was a document that was created through the [can't understand] center. And the title of it is when there is a

crisis, call up here. And I'm going to put that in the chat box a little later, and I welcome you at some point in time to read it over because it is extremely supportive of the work that you do, but also with the acknowledgment that trauma is a back and forth issue. It is not only something that you are trying to help others to navigate through, but you yourself are attempting to navigate through it as well.

So thank you again for all that you do.

Now let's go ahead and move to the first slide if you will please.

What we are going to do is just kind of talk in general about trauma, and the best way to approach it is to go back to that core definition of trauma. What people have understood for a long time to be the definition. And this definition that we have embraced actually came from the efforts of SAMHSA, the substance abuse mental hygiene services administration, to come up with a definition based on a diverse group of individuals who they gathered together. And one of the definitions that came out of this starts off with the word individual.

What we do know about trauma is trauma is not about groups. It is about our individual experiences. So it is individual trauma that results from an event or a series of events, because what we do know is that for some one element of trauma is sufficient to traumatize, 01 experience of trauma can really traumatize an individual. Or for others it may be several. And then for others there may not be anything at all that they experienced during that time which makes the definition much more clear. Because what it says is that a set of circumstances that are experienced by the individual as traumatic. And that is what we want to take a look at, because you can have two people that have exactly the same situation occurred. One may be traumatized while the other is not. And that is just how trauma permeates our entire system.

What it ends up doing is leaving long-lasting effects on our functioning as far as mental functioning, physical functioning, social functioning, emotional functioning, and spiritual well-being. We want to make sure that piece is embraced as well, and understanding and a healthy respect for trauma and its permeation see and a respect for people's spirituality in that.

In this portion we will talk about the general population per se, because what we do understand is its pervasiveness crosses all spectrums, ages, genders, races, ethnicities, sexual orientations. We know that trauma is everywhere.

Let's go to the next slide please.

What we also know is that women in general are two times more likely to develop posttraumatic stress disorder than men. When we also look at the women, they report higher rates of sexual assault, higher rates of child sexual abuse. We know that men are more likely to experience accidents, physical assault, combat, disasters, or be a witness to death or injury.

These elements are known across bedrooms and we see this in all different walks of life.

Next slide please.

One be take a look at teasing our population to specific populations, in particular looking at the BIPOC or black Indigenous people of color, you start to see that lifetime prevalence of PTSD has been shown to be highest among Black populations.

What we also know is that if you look into the minority groups that are represented in our general population, you see they are more likely to experience trauma including historical trauma, and that is something that we will drill down just a little bit more on and need to keep in our focus, they experience immigration stressors, natural and man-made disasters, discrimination and violence. And minority youth are less likely to access medical and mental health care.

So you've got all of this together to really not help people to address the types of trauma that they are experiencing.

Next slide please.

If we keep it within the Black and Latino groupings what we see is they tend to experience more violence, poverty, incarceration, lack of access to care

is reported that before, marginalization, and low social status. Much more than other groups.

Then we go back to the historical, and in this case intergenerational trauma which is trauma passed down from older people to younger people. We look at our Indigenous groupings, our Tribal nations, American Indians and Alaska Natives, their experience puts them at an increased risk on a day-to-day basis of trauma.

Then we take a look at the LGBTQIA+ individuals. They are nearly 4 times more likely to experience violent assault than their cisgender or heterosexual counterparts.

So what we are looking at is that all in all trauma is tremendously pervasive to all groups and in all groups. So let's move to the next slide.

If that is true and it is in all groups, it is no surprise that it is involved heavily in the trauma issue with regards to those with disabilities. It is no surprise to anyone that it would be there. Because what we do know, and a lot of people may not know, is that persons with disabilities are 3 to 4 times more likely than people without disabilities to experience adverse effects. Things such as abuse, neglect, or even medical trauma.

The other piece is something we have seen in the general realm with trauma and it also holds true within the disabled population, and that is that if you consider an adult who approaches for mental health support as having a history of trauma, you are going to be right 85 to 90 percent of the time. So what it does is it keeps our lens open to the fact that those who we serve, we automatically can assume that trauma exists somewhere within their history. So it is important for us to keep our focus on what kinds of methodologies, supports, treatments that we can give. And from our specific roles there are many different things that we can do to really cover this in a greater measure.

Let's go to the next slide.

SAMHSA approximately 10 years ago convened a group of individuals to try to determine how best to approach some of the troubling issues that were going on at that time. Back in that time many people who were hospitalized were placed in seclusion and were restrained, and it was a horrible issue because no one saw any therapeutic benefit in that.

So the implementation of trauma informed care was originally designed to try to reduce or eliminate the need for seclusion or restraint. That then grew from trying to eliminate it to using trauma informed techniques to reduce the likelihood of seclusion and restraints. What we see now is that trauma informed populations encourage individuals to really look at this as a part of how we operate. How do we communicate with one another. And this is critical.

So with this they came up with what are called six principles of a trauma informed approach. And I want you to see this from a dual lens here. I want you to see it from things you may have experienced that you are trying to pass on to another individual because you already have experience with it, but you also look at how the other person may be receiving that information. Is it something that we are thinking enough about so that we can get that connection and establish that trust that is so essential.

So as we look at the six principles -- and these can easily be found in the public domain, or when you look through SAMHSA at the guys for trauma informed approach -- it's a huge manual that includes the six principles. So if we go with the first principle -- next slide please -- it's all about safety.

Many of us can attest that if you don't feel safe, it's hard to trust. If you don't feel safe, it's hard to find healing. If you don't feel safe, is difficult to connect. So we make safety as a primary measure because people need to feel physically and emotionally safe if they are going to make those steps necessary to start to move them towards healing, move them towards improving, move them towards self-regulation.

So how can you let others know about things that make you feel most unsafe. When you look at what has happened with you, how did you communicate that. Are you able to share with someone else. Share with them those things that make you feel uncomfortable. We have seen in many settings when we go across the country and otherwise and look at systems and operations, that quite often many don't feel safe in their systems. It may be because of pictures on the wall. It may be because of conditions that they are experiencing.

But it does not get better unless that dialogue begins about what is safe. And it's a back and forth dialogue. You know this already, that when you communicate with people and they trust you, they will share with you those things that make them feel uncomfortable.

Also you have an opportunity I would ask you to link to these lived experience videos that are on each of these slides. These are persons with lived experience who are giving their take on how important it is for each of the six principles to be in play, and how they have made a change and how that person has begun to address their specific traumas.

Let's go to the next slide please. are the second of the six principles involves trustworthiness and transparency. Wow. Being open and honest with whomever we are talking with. It is one of those things that kind of has a little common sense reversal to it, doesn't it? Because if we look at ourselves and we are in front of someone that we are hoping is going to give us the best treatment that they possibly could, we hope they are going to be honest with us. We hope they are going to be open with us. Because that is the only thing that is going to make us feel like we can put our trust in them.

So how can you be sure that others who want to support or help you are helping by creating a mutual trusting relationship.

It gives the example of you share your story, and again as much as you want to because again when we are doing trauma informed perspectives it is not about getting people to tell their story. It is about having people feel comfortable enough to at their level be able to communicate whatever it is that they are comfortable sharing with you. In order to get them to understand what happened and how to move to the next stages, how to be helped.

Next slide please.

We go with peers support, and this is a really important element because it really defines some of the wonderful work that is being done all over the country. And some of the things that persons with lived experience, peer support has been huge. Because what you are doing is building mutual healing relationships with those that can identify with what you have been through. And as you discuss that, and I have to share with you that I spent a number of years working with a wonderful team, it used to be called the national Center for trauma informed care, and Dr. John [can't understand] was our project manager. And we will travel over the country. And on our team was always a person who went over the overview for trauma. There was a person such as myself that would overview the neurobiological aspects of trauma. But we

never went anywhere without taking a person with lived experience, because they brought validation to everything that we were talking about.

And they also brought that mutuality that really helped people to put their trust and be able to get involved more deeply with how they were going to start the healing process.

So you have someone you can call when you need to talk to about how you are feeling at the moment. And then they give you guidance and support since I have already been there. And that is really what you do. You really help people by connecting. It is almost like a veteran's perspective were if you notice in the treatment of veterans, veterans like to talk to other veterans. And you find that the trusting relationship gets lastly established because they feel that that person can understand some of the things they may have experienced.

Let's go to the next slide.

We move now to collaboration and mutuality and the sharing of power. Sharing is such a huge thing when we talk about the principles of trauma informed involvement. Because what you are doing is you are actually empowering that individual to be part of a team, to be a partner in their treatment.

So you asked the question do you have others in your life you listen to you, who are judgment free, respect you and don't try to control you.

Another way to look at it is there someone in your life or are you yourself displaying empathy towards those that you serve. Or do you get empathy from those who speak with you. So when you are talking tell them what is important so you can find better ways to help support yourself and to help support others. This is critical folks, because in this mutual agreement you are gaining a voice and you are gaining that kind of voice that has tremendous power not only to provide for those that you are serving, but to also bolster and build yourself.

Next slide please.

The next one is empowerment, voice, and choice. And in this you are recognizing peoples' strengths, recognizing their experiences, supporting self-advocacy, choice, and self empowerment. This goes to the same thing we talked about in the principles. That we are talking about empowering people.

Each of you has a voice and therefore should be heard and that voice should allow the opportunity to do that connection that can be lifesaving sometimes to other individuals who are seeking answers. And sometimes the providers themselves have never traveled the road of the people that they are serving. So it is wonderful to have available those lived experiences that they can share, because that helps a person not only to be validated but to feel as though they have a choice. To feel as though they have some power.

And the third piece with this is to make sure that you are helping them by giving them tools. Because you can't go home with them. You can go through what they are going through when they are away from you. So it is all about helping to bolster and build what they can do for themselves, okay?

The example given is interesting. You choose to stay at your apartment alone and not go to your family home for the holidays, and yet the support staff understands your decision. And then asks you what you need to what you want to do in order to celebrate. You look at that piece and it is sometimes hard because we have the drive to try to get people to get out and do what we consider to be the normal things or the things that we think that person would most benefit from.

But it is important to note that empowerment is built on allowing that individual at least to verbalize what it is they are seeking. How it is they would like to move. Maybe they are not ready to move that day, but they are willing to talk to you about what it would take to move to the next step. Very important.

And the next slide please, this involves one that takes quite a bit of explanation and we don't have time to really drill down here. But a healthy respect for cultural humility. Looking at historical issues and gender issues. Because these are trauma informed principles that need to be embedded in every interaction we have. Have a healthy respect for the culture of the individual you are speaking with. Have a healthy respect for all of those things that are involved often in historical trauma and gender identity so that you can avoid cultural stereotypes.

Get around those things that color our perspectives on historical trauma. That tend to bias gender issues or otherwise. So access and keep in your wheelhouse as they say the cultural humility. Because that goes a long way for people to be more receptive of what it is you have to say to them.

So I thank you all for the time you have given me. And at this point I'm going to turn things over to Max Barrows from Green Mountain self advocates who is a partner with the Link Center. Thank you all.

MAX BARROWS:

Thank you for that introduction. And yes, as noted I am Max Barrows and I work for Green Mountain Self Advocates. I am a person on the Autism spectrum. And I also am a Black man in their late 30s. I am wearing a kind of very light blue dress collared shirt with blue stripes that are little darker, very thin stripes. And I have on a dark blue tie with red and white diagonal stripes that are very thin. And I have short black hair. So just to put that out there for anybody who may be blind or have difficulty seeking.

All right, the next slide please.

So today I'm going to talk about a new tool for managing triggers. Next slide.

So here is a new tool for managing triggers. And when we use the word triggers, we mean things that make you remember something bad that happened to you. The tool is written in plain language so it is easy for most people to use.

You may be wondering what is this tool. It is a two page handout and it helps people to make a plan for what to do and say if they get upset when they remember something bad from the past. Triggers can be people, places, smells, sounds, tastes, or things. For example, if someone who hurt you smells like smoke or perfume, those smells might make you remember what happened. Triggers can make you feel really scared or anxious. Our minds and bodies might explode with feelings. When you remember bad things, you might feel sad, mad, or scared for a while.

One purpose of this tool is for a person to try to figure out what triggers them. When possible a person can try to stay away from those things. But for sure you

may not be able to avoid all of your triggers. And we have found that knowing your triggers can help you understand why you got upset.

How do you use this tool. The tool begins by asking a person to identify their triggers. The question is what are my triggers. This can be updated as a person gets better at figuring out what reminds them of bad things from the past.

Next a person can make a list of what they can do to be okay when they get upset. These are strategies to use to feel better. For example, take a long walk. Sit alone in a quiet space. Listen to music. And talk to yourself. I talked to myself. For me it can be calming to do an energy release, which is what I call it. And I will explain it just briefly. An energy release for me is when I have an overwhelming day, a lot of things have come to mind. And so I kind of let my body respond to what is on my mind, and it is a way for me to feel my body and then all of that energy that builds up in my body from those thoughts, I let it out. And it can be seen from somebody else's point of view as sometimes the hand flapping, the body rocking, the jumping. However it comes out of me physically. And I'm only speaking for myself when I say this.

Moving on, helpful support. This includes what others can do to help me be okay. For example, for me I want people to help me stay calm by being calm themselves. Also for me please do not ask me a lot of questions. And it helps to tell me I am safe.

Not helpful support, in other words what do others do that is not helpful. For example, please do not try to stop me from talking about the past. Do not ignore or judge my feelings. For me I do not want someone to talk in a loud demanding voice.

Who should support me. Make a list of the people you want to support you when you are upset. It can be anyone. I personally want someone that I trust.

Who should not support me, who do I not want to support me when I am upset. For me people who do not understand me.

When do you use this tool. Go over the completed tool on a regular basis. Support us to practice what we can do to be okay when we get upset. Especially if there are new people in your life. Triggers can come up at any time, so have this tool handy

whenever it is needed. If it helps consider posting it in your room or someplace where you can find it easily.

How do you share it with others. For me I would share it with the people I spend time with. It is important to love the people you trust know what they can do to be supportive. I personally would want it to be a part of my person centered plan. A copy of this can be kept in the home or in your pocket or on your cell phone.

Next I want to get into what is known as checking in. Finally I will talk about checking in with our supporters. When it comes to checking in, it is not a time to give me lots of instructions or to school me and what you think I should do. It is a time for listening.

Here are some neutral questions to ask me to keep the conversation going. How did that make you feel? What do you think? What is important to you? Do you need more information? What have you tried that works for you? And what do you do that makes you feel okay?

The goal is to create a welcoming space so we can say what is on our minds. Now, sometimes a person is seeking out your opinions. They want you to tell them what to do. It can BE see to tell us what to do, but it does not help us. You need to help us figure out what we think and what we want to do my asking questions or giving us information in a neutral way.

For example, if someone wants ideas about calming down, you could say well, you need to focus on what works for you. Some people try walking, some people try music, and some people try deep breathing. The goal is to stay neutral and keep your opinions to yourself. Checking in is helpful for the person and their supporters.

We get others to listen to us. We get emotional support. Our supporters get information and how we are feeling. We tell our supporters what they can do and say to support us. Over time we build trust.

And on that note, thank you for listening to me. And now I will turn it over to Wendy to co-lead us through a group exercise.

ACTIVITY/GROUP EXERCISE

WENDY MORRIS:

Great, thank you so much, Max. That is such a helpful tool.

Hopefully you all can hear me. My name is Wendy Morris and I am a senior behavioral health advisor at the National Association for State Mental Health Program Directors. I work with Dr. Brian Sims at the association but I also work closely with everyone at The Link Center. Such a great project and we are so glad you are here today. We do have a group exercise plant. Max is going to read just a short case study and it will have a question at the end for the group. No right or wrong answers, we are just looking to get your reaction, to hear ideas that you might have and may be sure what has worked with you or what you have seen work with some of your peers or people in your life. And we would invite you to engage in whatever way and level that you are comfortable. So you can use the Zoom function to raise your hand, and we will take you off mute so you can talk. You can do that with your camera on, you can do that with your camera off. We love to see your faces and hear your voices but we know that is not comfortable for everyone.

And you can also use the chat. So if you want to type the in chat your questions or your comments, that would also be great.

We have about 20 minutes for this group exercise. And there are about 35 maybe folks participating. So it's a small group which is fine. But I just really want to encourage you all to participate.

With that I will turn it back to Max to read our case example.

MAX BARROWS: “Rich has an intellectual and developmental disability. He has anxiety and had a very hard time in school. He did not have many friends and people would call him names. When Rich graduated he had a friend who would come to his apartment, eat his food, take his money, uses phone, sleep on his couch without asking, and sometimes hit Rich when he was drinking. The friend ended up in jail for selling drugs. Rich does not like to leave his apartment or see other people. He does not trust

anyone. Which knows he needs a job and that he could lose his apartment if he doesn't get one. What should Rich do? "

And please say what is on your mind to this question in the chat. But also if you would like to, if comfortable unmute yourself. We can call on you. If you want to show your face on camera feel free, but you do not have to if you are not comfortable. Regardless of however you want to share your thoughts or answer the question, feel free to do so. And I'm eager to learn from all of you. Go ahead, Alice.

SPEAKER: Okay, I would say you should try to get into crisis to talk to somebody to help him through the process as he needs help. And he needs a job to stay in his apartment.

I would also think that maybe he can get a job coach to help him get to the job and help him get the supports to stay on the job.

WENDY: Those are great ideas, Alice. Job supports and reaching out for crisis services when he needs those. Finding different places in the community that can help him. Did you have other thoughts, Alice?

SPEAKER: No, I can't think of any off the top of my head.

WENDY: Thank you for the ones you contributed, that is great.

I also see in the chat from Jason, it says are there any remote jobs Rich could do while he is getting remote counseling. That's another good point. So many things right now that we can do virtually.

MAX BARROWS: I see another one in the chat from Elissa. It's is the first thing I would want to know, how has Rich paid for his apartment up to this point? Getting on SSI might be his best option depending on whether he is able to work.

WENDY: Yes, so maybe getting somebody that is able to help them talk about some of those different benefits that he might qualify for and what he could tap into. Great idea.

MAX BARROWS: There is another one in chat from Megan. It says my initial question prior to a reaction is whether or not Rich has any supports, friends or family members, or even supports from when he was in school like their school counselor that they are familiar with having worked with them in the past.

WENDY: Yes, that's a great idea. To first find out what support she has and tap into those. And for the sake of conversation, what if he didn't have those supports. Do you all have ideas on what we ways to build natural supports or to seek out those types of assistance?

MAX BARROWS: And again I love hearing from all of you in chat, and also feel free to raise your hand -- wait a minute, go ahead Mike.

SPEAKER: Hi. Thank you. I don't have enough background, the individual I am assuming is already receiving paid supports. My question is Max, you asked for my personal experience.

MAX BARROWS: I asked just for a thought on this.

SPEAKER: My thought is as a needy person I am doing my best to understand what my own resources are without being a tax on others. I have had quite a number of people living in this building in the past two decades that have been taking advantage, and is a consumer myself I will go to ridiculous ends to satisfy and to make approval from paid supports. And that is very bad. So at this point, Max, I am very old and I have income, I have family income. I guess I'm feeling sorry about myself and I have a strong presence in Quaker meeting and I feel a burden sometimes, and that is just a waste of my time. So for Rich, a developmental disability, the co-occurring acquired condition is anxiety and ennui on a day like this and I'm doing my best. So thank you for doing this, Max.

MAX: Thank you for sharing, Mike.

I see another one in the chat from Elissa. It says to get the supports, getting in a case manager sounds essential. They can connect them to other services. Of course if he is this isolated knowing her to get one of those can be a serious challenge. Often people in circumstances like this and up in the mental health or even legal system because they don't know where to go for help.

Yeah, that can be a bit of a problem. And I know some folks have mentioned supports, and that is very important. Peer supporters is certainly another place, and it sounded like Mike maybe has some peers that are close by. We don't know for sure if Rich does or not. But getting connected with peer support in addition to case managers and employment supports and some of the other things that have been mentioned could be important.

Anybody have thoughts or comments on peers, peer support?

I know that was one of the six principles that Dr. Sims talked about.

And again we know this can be a very difficult conversation to talk about trauma. So we certainly want to acknowledge that for some people this conversation might be difficult.

MAX BARROWS: I got this from Jason. I mean if you can find support groups in person or online.

>> Yes, great.

MAX BARROWS: Elissa says in the chat if he really doesn't trust anyone, someone has got to show him how to relearn the ability to trust. Not trusting anyone is an awful place to be in, and you can't stay there forever.

And then Dawn said certified Peer Support Specialists are people with lived experience who can provide a vast array of resources and support.

WENDY: Such great comments, and I like the one about learning to trust. And I wonder, Max, if another way somebody could maybe use or modify the tool you introduced would be to learn about trauma but also learn about what does it look like if somebody is exploiting me and when do I need to set some boundaries with people. And how do I do that. Because that is a skill, right. You have to trust yourself to be able to set boundaries with people and recognize when people are taking advantage of you. And that can help trust other people.

MAX BARROWS: Right.

>> And thank you, Dawn, for giving a definition of peer support. It is super important we all understand the terms we are using. I can be guilty of sometimes throwing those around and forgetting that not everybody -- it is not common language for everybody, for sure.

MAX BARROWS: Anybody else? All right, I think I got something else.

Mike said in the chat being unable to trust people may be leading others to consider me to be untrustworthy. Bounds. I don't think I will ever get it.

>> It can be a difficult thing, Mike, I think for a lot of us for sure, to figure that out. Personal boundaries, yes. And that is something you can work with a mental health provider or maybe a peer support, exploring what are your personal boundaries. When you feel like you have been pushed too far. It's like trauma, right. Something that I might find in my experiences trauma, and another person like Max might be perfectly comfortable with it. And it's the same with boundaries. Some of us need a lot of personal space and we don't like it when people come very close to us. Other people just want to hug everybody.

So it can be difficult when you like a lot of personal space and you have people who want to kind of invade that and hug. It is hard to learn to say I am not comfortable with you touching me but I am comfortable talking to you. That could be an example of a boundary.

MAX BARROWS: Covid was fun, he added.

Anybody else? Feel free to share in chat or unmute yourself and share aloud.

WENDY: We still have about 10 more minutes that we can use for this time. So again we have a small group, and we know everybody doesn't want to talk. But we would love to take a few more comments or chats.

SPEAKER : I wanted to ask you about the triggers. Can you send me that slide because I think that would be really helpful for me.

>> STACY NONNEMACHER: Correct, the slides and the trigger tool, Alice, will come out to you in an email along with a recording of today and a transcript.

>> Thank you so much.

>> STACY NONNEMACHER: Of course.

>> And at the very end, not to steal any of the final funder, but at the end she will share an email with you so if you have additional questions about the tool, the slides, or whatever we talked about today, you can send an email.

>> Thank you.

>> You are so welcome.

Mike said that can be helpful. Great, we are glad to know that some folks will find the tool useful. I really love the tool that you develop, Max, and I wonder if there are others in our audience that think that might be something they could use. Or maybe you have a friend that you think would benefit from using that, one of your peers that may be liens on you.

MAX BARROWS: I just want to say from earlier, Mike, thanks for sharing your very personal story. I would say take a chance and try to let other people

listen to what you have to say. Give others at your Quaker meeting that you just mentioned a chance to get to know you better. I know it is scary and you might think that they might reject you. But just as you are the kind of guy that listens to other people, think about giving other people a chance. You might be surprised, they might want to help you.

>> That is the trigger point, Max.

We have another chat from just. Jess says I am 21 and in college and away from my family and sisters. For me peer support can be very difficult to find. My sisters are my only peer support because they understand as well. I am the only one of the three of us learning about these things you my schooling. I feel like it is opening a new world for me and my sisters. Thank you. That is beautiful, thank you for sharing that Jess. And we hope that the Link Center will continue to bring information that is useful to you and your family and other folks who are joining us today.

I think we have one more from Karen. She says thank you Mike for bringing up your Quaker meeting. Faith communities can be a good place to connect with someone who is open to listening. Yes, and there are all kinds of faith communities. So that is a terrific resource as well.

MAX BARROWS: I've got one from Elissa. With discussing triggers it's important to understand that cyberbullies really like to make fun of the whole concept of triggers, so talking about triggers openly can set someone up for very nasty encounters online. But there is more. Social media culture says both, quote, your triggers are not anyone else's responsibility to accommodate, and, quote, if you set off someone else's trigger it is your responsibility. Which can both be true.

And then Mike said I want everyone to have access to themselves in my presence so that communications are authenticated from understood and understandable responsibilities. Sure, when friends allow themselves to simply be.

>> And I wanted to respond to Elissa real quickly with her comments about triggers, because it is true. On social media you can definitely get a lot of conflicting advice, as it were, or comments. So you always have to be careful about what you share about yourself and your life on social media, and what you take to heart from social media.

People can be cruel and social media is an easy place for people to be really unkind and mean to one another. And Max, maybe you can chime in too. I think when you talk about triggers and things that are difficult for you, you really need to talk to a trusted person. Somebody that is not anonymous on social media, but a person that you have some history sharing things with that you know can help you.

We still have a couple of minutes.

MAX BARROWS: Anybody else want to respond? Go ahead, Alice.

>> I think it takes a minute --

>> Somebody sent me on Instagram, they sent me something about Palestinian children. So I wrote them a letter and talked to them about how I felt about it. And he said -- he did not say he was sorry, he said everybody else is seeing them. Because I wrote him a letter about the three Palestinian students, it was traumatizing to me. And he was like well, I shouldn't be paralyzed about it. So I wanted to distance myself from that person.

>> That's a really good example, Alice, of setting some personal boundaries. Saying no.

>> Like my friends, he came up here and we saw Mrs. Doubtfire and I was talking about -- the father is talking about how said he would be without his child. And I'm a parent with a disability and the state had took away my child. And he said they took your child away because you are [can't understand] and I told him to go home.

>> Good, I'm glad -- sorry to interrupt, go ahead.

>> We need to be more firm but some people with disabilities find it really hard. I have been an advocate for myself and my friends, and I'm also an advocate for the state to help parents with disabilities. And to help other people with homelessness and people with disabilities.

>> Thank you so much for sharing, Alice. And again, great examples of setting some personal boundaries.

I think our time for this part is up, but thank you so much for all of the great dialogue. And I can see some more comments are coming in. We will capture those. We don't have any more time of to talk about them.

MAX BARROWS: I can read them real quick --

It says social media meme culture makes it hard to talk about trauma and any situation when you are frequently bombarded with the message stop easier trauma as an excuse for bad behavior which is so trendy, when in reality for every one person using trauma as an excuse for abusing other people there is 100 more who are responding to the trauma by withdrawing from other people because they don't want anyone to get hurt. But some people think if you even say the words I have trauma you are going to say so I can't be held accountable.

Thank you for sharing that, and I will turn it over to Deb for closing remarks.

CLOSING

DR. DEB PINALS:

Thank you, what a great discussion. I love these case discussions and I love hearing everybody's input. Just to say a little bit about myself, as I said I am Deb Pinals, clinical advisor to the NASDDDS The Link Center and I also work for NASMHPD as a clinical advisor. I am a short white woman with short dark hair wearing glasses and a beaded necklace and a black sweater today.

I want to just talk a little bit again and remind you to put in the chat anything that you want about your go to resources for trainings, websites, or other information that supports you related to trauma or things you think might be helpful. That would be very helpful to us. So please list anything in the chat that you feel would be helpful in terms of your go to resources to support you for trauma.

Also just a reminder the website is coming soon, but until the website is available you can reach us by email at TheLinkCenter@NASDDDS.org. The Link Center is one word at NASDDDS dot org.

And again just a huge thank you for participating in this shared learning group. It's really important to get your input. We can't do anything without your wisdom and experience. We have already now completed our last of the trauma series from today. We have done this with direct service professionals, clinicians, families, and now you all on trauma.

But we have more shared learning groups ahead. For example on April 23 please mark your calendars, and April 24. We have a shared learning group on supporting someone through a transition. The one for individuals will be on April 24 from 3 o'clock until 4:30 PM.

Then in August we have another shared learning group that is going to be on the theme of supporting the whole person. They will be taking place across August 20 and 21st, the one for individuals will be on August 21 at 3 o'clock until 4:30 PM.

So please, please, please mark your calendar and plan on joining.

This last slide -- well, not the last slide, but the slide is a list of resources that will be available to you. These are some of the resources that have informed our conversation today.

I want to just give a hearty thanks to Perri Spencer from the Link Center steering committee, an awesome job, an awesome job explaining what trauma means and how to think about it.

And Max Barrows from Green Mountain self advocates, of course thank you, a big thank you for helping as well and putting yourself forward.

I also want to give a big shout out to all of the partners of the Link Center for contributing to the preparation of and content for this meeting. We could not do it without our wonderful partners.

Okay, so here is your chance to give more feedback. Please use this QR code or the link that is in the chat to provide responses to our survey that will tell us how you thought this one. And your feedback is incredibly important to help us improve our future sessions. So hold your phone up to the QR code and press the link that pops up, or use the chat link to give us your feedback. The survey won't take that long but it will be really, really helpful as we plan for future events.

And again a big thank you to everyone for participating.

THANK YOU.