

## **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 in Zoom to communicate with other attendees and hosts in the webinar. You can mute the chat by clicking on chat at the bottom of your screen. Please be aware that your chat will appear in the chat if you make a comment and if you want to change your display name, you can do that by clicking on the three little dots next to your name and selecting rename. We will have representatives from The Link Center watching the chat and responding today. If you want to ask a question or comment privately, you can do that by clicking on the Q&A function at the bottom of your screen.

Following this webinar, you will receive an e-mail with the recording and the transcript and an evaluation in response to today's shared learning group. At this time, I'm going to hand the floor over to Doctor Stacy Nonnemacher who is going to make today's presentation. Stacy, the floor is yours.

## **INTRODUCTION AND WHAT IS THE LINK CENTER**

DR. STACY NONNEMACHER:

Thank you for joining us. This is the second round of shared learning groups that we are hosting through The Link Center. The Link Center is a grant funded by the Administration for Community Living. For those who don't know me, I'm Stacy Nonnemacher and I'm with the National Association of State Directors of Developmental Disabilities Services, NASDDDS. And just by way of a visual description, I'm sitting in front of a white Zoom background. I'm a middle-aged woman wearing glasses, brown hair, below my shoulders, straight. Today, I'm wearing a white turtleneck with black stripes and a black sweater. Again, thank you.

We know this may be triggering for some, so take care of yourself, please let us know in the chat if there is anything we can do to change the words that we use today. We know that the word "trigger" may be triggering to some. We invite you to share and we're welcome to all sort of participation in the meeting. Some of you may just desire to listen and witness, others may want to be actively engaged. As my 18-year-old says, you do you, and we welcome all of that in this community.



The content that we developed for the presentation is a collaboration, this includes researchers and people who work on policy issues. We always have people asking, we are recording today's meeting. We will have a transcription of the meeting and share the recording, the transcription and the materials with you after the meeting and we encourage you to share that far and wide with your colleagues, families, individuals that you support. Now, I have the honor to turn the mic over to Perri Spencer, a AAC member. They are a graduate of Tabor college project search, a program dedicated to teaching skills to people with developmental disabilities and other disabilities. Perri is searching for a new work opportunity that would even further enhance their skill set and allow them to grow as an advocate. So, Perri, let me turn it over to you. It is so great to have you here.

PERRI SPENCER:

I am a white person with short light brown hair. I'm wearing a greenish-gray coat. My pronouns are he, him. We are going to talk about trauma. Trauma is when bad things happen to us where 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 bad 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 mentor trauma that can come from having a developmental disability or I/DD. Existing with I/DD or mental illness is something that often is not talked about. Ahead, we will talk about unmet needs and discrimination against 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 nonspeaking. It 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 where you want to live. It makes a person feel very out of control and scared. 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 isn't there because he can't because his need to use the stove is not being met at all times. The choices of people with I/DD and mental illness, Jackson may not have the choice of whether to use the stove or microwave when his worker is not present. It is also traumatic when people assume you are incapable or cannot do things when they are not talk towing. People may think you can't do anything for yourself or if 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 treats you unfairly because you are disabled. There are little ways that people will treat you unfairly. For example, someone may talk to your worker instead of you when you go out. Some people may not know unless you tell them. There are some things that nondisabled people know that is not okay, not giving someone a job because they are disabled. Ableism is found in all parts of life because 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 how to keep people with I/DD and mental illness safe. If we don't talk about it, we can't change it.

It is important to know that people with I/DD and mental illness are at a much higher risk of abuse than people without I/DD. There are a few reasons why they are, first, people with I/DD or mental illness may not know what abuse looks like. Friction someone may not know someone taking their money or controlling their money without giving them choices of how to spend it is abuse. It is important to teach people with I/DD and mental illness what abuse looks like, so they know how to report it. Even a person 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 can't report sexual abuse. A person with I/DD and mental illness may not know who to report the abuse to or how to say what happened in a way that others will understand.

People with I/DD and mental illness are often denied sex education. This makes for reporting abuse more difficult. Someone may not know sexual abuse is happening without information about sex that the person can understand. People with I/DD and mental illness need and deserve correct investigation 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 correct information and support because of their disability. Supporters should be looking out for changes in a person that may be signs that abuse 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 doesn't matter what they did or didn't 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's during the time 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.



If I compare myself to the tree, I know my strength is in my roots." Monica Wafford, survivor.

Sharing lived experience. This meeting will be talking about ways that people deal with trauma and strategies people use to address trauma. Take care of yourself and allow silence to be a safe space and feel empowered to do what's necessary for your comfort and care.

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

We emphasize 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:

Perri, thanks so much for setting the stage and grounding us in our topic today. Incredibly powerful. Appreciate doing this work with you. So, today's agenda, if you want to take a second and introduce yourself in the chat that would be great. You can put your name in there, any group association, affiliations that you want to include, that's great. We want to know who is here and who joined us. We'll start off by talking about what The Link Center is and we'll get into the meat of what our work together today and talk about supports for trauma.

There's many resources that are out there, primarily in the mental health field or mostly in the mental health field. And what we're really learning as we're thinking about The Link Center and this topic is that, there are universal practices to trauma-informed approaches that aren't necessarily diagnostic specific. Even though we're talking about individuals with co-occurring needs and there's a lack of resources related to trauma and people with co-occurring conditions, we do know there are some things that today we're going to share with you, and also we can evaluate, right. Also, we know there is some work we need to be doing to fill that void or gap, and again, in the meantime, while we're doing that with our partners at The Link Center, we're going to share some things today, expose you to some things that are already out there and some things that folks like Perri and some of our other partners have developed for you all to use in your practice and in your today day.

We will also spend some time doing a group exercise, sharing hopefully relevant case or situation where we can talk about challenges but mostly solutions to supporting people who have experienced trauma. So, this is the first of many prompts to ask you all, as we're walking through the content today, we have an open invitation. Use the chat to share any of your go-to resources, trainings, website, information that you have when you think about supporting someone who has experienced trauma. Again, part of The Link Center is to expose what is out there and relevant to



people with co-occurring conditions like I/DD, brain injury and mental health conditions and we're using you all in this shared learning experience to really share what you may have within your toolbox, within your arsenal of resources and information.

So, I'm just going to take a moment to talk about The Link Center for those who haven't heard about The Link Center. Again, I said this at the outset, this is a grant that is funded through the Administration for Community Living. It is a five-year grant. We're about a year and a half into the grant. It's really exciting work. It is a place where we get to dig in and think about how can we better support people with co-occurring conditions.

And we can't do that work without many partners working with us to do things like develop these shared learning groups and some of the other activities that I will talk about in just a moment. So, the leading partners of the grant is NASDDDS, the organization that I'm affiliated with. NADD, the National Association for Dual Diagnosis and NASMHPD, National Association of State Mental Health Program Directors, and you will hear from some of our colleagues from NASMHPD today.

People are multidimensional and we are also putting a keen on eye diversity, equity and inclusion in the work we're doing through The Link Center and have amazing partner organizations who are helping us do that and you will hear from some colleagues from Green Mountain Self Advocates today. We have Autistic Self-Advocacy Network, the National Association of State Head Injury Administrators and CommunicationFIRST. And then finally, we're really wanting to be sure that we have our checks in place that is telling us we're meeting the needs of the communities that we're seeking to impact, and also doing what we said we were going to do as part of the grant. So, we have some partners helping to that end as well that is the National Center for START Services, Sonoran Center of Excellence, and The Ohio State University Nisonger Center. We are very fortunate to have amazing partners who have also been thinking about how do we better support individuals with co-occurring conditions.

So, there are three main goals of The Link Center. The first is around systems change. When we talk about supporting individuals with co-occurring conditions like intellectual development disabilities, other differences and co-occurring mental health conditions, medical conditions, we know that, that requires, and you know this as clinicians very well, that requires coordination at relationships across systems to get people what they need. But oftentimes, and again in my experience and I'm sure yours as well, that system poses a barrier to getting people what they need.

So, we're really seeking through The Link Center to improve policies, service design and services coordination for people who have co-occurring conditions. We're also looking to build capacity. Build capacity of Direct Support Professionals, as well as clinical practitioners, so that people can, supporters can support people in a more holistic way instead of, what we tend to do right now in our field, we have people out there that are great mental health practitioners. We have people out there who are very experienced and expertise in supporting people from more of a habilitative



or developmental disability lenses. But what we're really look to do is build a diverse workforce to support people with co-occurring conditions.

And we're thinking if we make some systems change and we build this capacity, this is only going to increase service access for people. So, improving access to get people the services and supports they need and the systems that are able to provide it. And doing that in a very person centered, culturally and linguistic appropriate way.

So, ambitious goals but we have many activities as part of The Link Center that we are engaging in, again, with a keen lens of diversity, equity and inclusion, and around that quality improvement. Stephanie also mentioned, bears repeating that at the end of the session today, you will receive an email from Zoom with the evaluation to let us know what you thought about your experience during the meeting today. We'll also have a QR Code at the end in the slide deck that you can access the evaluation there as well. Just one example how we're continuously look for feedback on the work we're doing.

We're also engaging and leaning into the lived experience, so Perri has been introduced and one of our 12 Steering Committee members who has been integral in helping us guide the work, making sure what we're doing is relevant, making sure what we're doing is timely, you know, could not have built this content without Perri and others really contributing and putting in that lived experience perspective.

And then we'll have these quarterly shared learning groups ongoing. We have some coming up, we will talk about that at the end as well. But really shared learning groups as a way for us not to just talk about The Link Center has been unearthing in resources and training but capitalize on the shared part, which is to pull from you all, from your expertise, from your day-to-day experience, what we should be focusing on, what can we evaluate and what can we take for action with The Link Center. And ongoing, we're constantly engaging with other people who are experts in this field, who have been thinking about thousand better support people with co-occurring conditions to really, also inform this work that we're doing.

And then finally, I will just mention that we have really been taking a hard look at what's out there in terms of resources, information related to supporting people with co-occurring conditions. Also, bringing to the forefront and highlighting those resources, information, training that is out there that mental health practitioners can benefit from to learn more about individuals with I/DD or brain injury and vice versa. So, we're doing all of this resource development and dissemination and it is culminating in having this website or a resource hub, if you will, that fingers crossed we'll have that up and available to the public soon, not just yet. But looking to create this national repository for resources for you all. I will just take a moment because we have a captive audience to launch a poll and give it a couple of minutes here. We're interested as we develop these resources and materials and share information, we're really curious generally how people like to get their information. We know this could look different for different



people, very individualized, different groups of people, so again, we're taking the opportunity because we have you all here today. So, I will just give it a minute.

And for those of you who are choosing "other," I would like to hear what that is, if you're willing to share that in the chat, that would be great.

Great. Looks like we're slowing down. Thank you so much. We appreciate that. It's very informative to our work moving forward. Okay, so the goals for today is we're going to share what we're doing at The Link Center related to supports for trauma, what we've sort of been identifying as some things we want to expose you to as far as resources and information and we want to get your input. We will have a group exercise at the end and that is one way we will do that. Please throughout our time together today identify any needed resources or information that The Link Center could be thinking about and putting some effort in researching and disseminating where that is available. Now, I get to turn it over to one of our partners from the National Association of State Mental Health Program Directors. Turning it over to Dr. Brian Sims. Thank you so much, Brian.

## **PRESENTATIONS**

DR. SIMS:

Thank you, Stacy and good day to everyone. Such a privilege to be part of this and I'm thrilled to be able to provide this particular segment. I am Dr. Brian Sims. I'm a psychiatrist. I'm the senior medical advisory with the National Association of State Mental Health Program Directors. My pronouns are he, him, his. I am an older black male with glasses, gray-black hair, gray shirt and my background is white.

I am thrilled to be a part of this discussion today, because my background really centers around trauma-informed care. I've been in the business of working in the field of psychiatry for about 30 years. In that timeframe, I've spent time working with a group of notable individuals, so we have had the opportunity to move from center to center and spot to spot and enforcing the utilization of trauma-informed practices in the things that we do.

What we're going to do is talk a little bit today about why we're really talking about supports for trauma in this realm. One of the things that we do know already is the universality of trauma. Trauma is pervasive. It is in every single facet of treatment that we all see. These are things we already know. So, as we move forward, we're going to take a look at it from the lens of general population and kind of hone it down a little bit more.

I first of all want to give credit to Perri because I think the explanation there and his timeliness in providing that information gives the groundwork and gives the



validity in talking about trauma-informed care. We want to thank him for that. We want to mention any of the language that may be triggering, please avail yourself and take care of yourself. Next slide, please.

As we look at trauma in general, I'm talking about general population or public. We know already it is pervasive. There are a lot of things that people have heard of trauma-informed care. Everyone knows trauma is extremely pervasive but we do know it can permeate anywhere. It can get to individuals of all ages, of all genders, of race, ethnicity, sexual orientation. Can pervade every single aspect of what we look at. So, when we taking a look at the treatment strategies, one of the strategies that is fortifying for us is the knowledge that if we consider the people we work as having a history of trauma, it is very likely that you're going to be correct about 90% of the time.

In that, we need to go backwards just a tad to take a look at the definition of trauma. It sets the stage. And this definition that I'm about to quote really comes from the work of SAMHSA, substance abuse mental hygiene administration that years ago began to take a look at trauma as an issue of implementing something that could help, at that time, to reduce or eliminate seclusion or restraints that were occurring in various of our facilities.

What happened was they convened a number of individual. persons with lived experiences, clinical professionals and they came up with a universal definition of trauma. In it, what you see is the first word is individual, and that's the thing we learn about trauma. One person's trauma is not another person's trauma at all. Individual traumas and individual trauma results from an event or possibility a series of events or a set of circumstances that is experienced by the individual as physically or emotionally harmful. I want to pause there because what it is saying is one person's experience maybe different from another. There may be one who has the same experience as the next person but takes it in in a different way. What may be otherwise traumatic for a person may not be traumatic for another individual.

The other portion of that definition is about it being harmful and having long lasting adverse effects and it affects the individual's functioning, mental, social, emotional, and spiritual wellbeing. I put the spiritual not at last because I would put it at last but it is to acknowledge in all of our dealings in the people we serve, we need to have an understanding of the importance of spirituality within this whole realm of treatment strategies. Next slide please.

We know women are two times more likely to develop post-traumatic stress. When you look at the population, women report higher rates of sexual assault or child sex abuse. When we look at men, men are more likely to experience accidents, physical assault, combat, disasters or be a witness to death or injury. We're looking at it as men/women. As we go to the next slide, we will tease it down and look at our BIPOC population, our black and indigenous people of color. Black are more likely to experience PTSD in their lifetime. If we look at minority youth, not just black youth



but all in general, minority youth are more likely to experience trauma. What we will drill down on is the historical trauma, taking a look at the past, the immigration stressors, the natural and manmade disasters minority youth are less likely to questions medical and mental health care. these are things we already know when working with the general population.

If we look at black and Latino young men and what we see is they experience violence, poverty, incarceration. They have a lack of access to health care, as we mentioned earlier. The marginalization and the low social status, and it is at a much higher degree than the general population. If we take a look at the historic and intergenerational trauma and this is passed down from older to younger, we see a huge issue involving historical trauma, so it is one of those things that we want to put our focus into when we are working with individuals, not just individuals of color or otherwise but looking at all histories.

We want to look at our indigenous population, the American Indians, the Alaska natives because they experience increases, their risk of experience trauma right now. And these are things that many of us being treated -- being treatment individuals don't have the skill sets when we go into these populations but we need to learn. When we look at LGBTQI+ individuals, they are nearly four times more likely to experience violent assault than the cities gender, heterosexual counter part. These are things we know already but it broadens our understanding that trauma does not select populations, does not select individuals and all trauma is very pervasive. Next slide.

Let's take a look at what happens when we're looking at those with disabilities, because those with disabilities, we know are three to four times more likely than people without disabilities to experience adverse effects such as abuse, neglect and medical trauma. We also know that within that population, the adults of that population, 85% to 90% of them who get mental health support will have a history of trauma. So, it is making our, I suppose if we want to look at what our methodology is going to be, it makes it fairly simple, if we're meeting an individual with I/DD, we can pretty much assume that trauma is a significant portion of that individual's life. We want to make sure what we're doing is putting the services with a focus on what we can do to assist in the population. Next slide, please.

Now, the one assumption we do not want to make is that these individuals cannot be helped. Sometimes, we have the age-old perspective that those with disabilities will have disabilities that they cannot learn, they cannot heal, they cannot find recovery. If that is true then we're not looking at trauma-informed care in a proper fashion, because what we do know is proper trauma-informed techniques and strategies do help with healing.

So, one of the questions we ask all groups, we can ask the clinical service providers, we can talk to the direct service providers, we can look at all of our groups and ask this simple based question. Do we believe in the people we serve? Because if we believe in the people we serve, we know whatever strategies or techniques we're going



to put into place are going to help those individuals to strive, to move them towards healing, that recovery is, indeed possible. This provides the mantra of what SAMHSA operated with when they developed a guidance for trauma-informed practices. Now, this particular guidance was developed over ten years ago with a coalition of individuals with all walks of life who came in and talked about how to make this trauma-informed perspectives more active and more relevant towards the people that we serve. And in that guidance package, which is public domain, it is easy to acquire, you can read through the entire package, you can see what is called six key principles of trauma-informed approach.

In the six principles, I briefly run through those particular principles, we're looking at how we, as providers, can be able to give a trauma-informed interaction and treatment strategies with the people we serve. Next slide.

The first one we want to work with is safety, and safety is so huge when you're comparing it to the other factors that we're listing in the principles. One thing that is very certain if a person doesn't feel safe then healing can't take place. But not only can healing not take place, if they don't feel safe there can be no trust, there can be no connection. So, we put this one first with deliberateness to look at, what things can we do as clinical providers to enhance the safety for our individuals. I do want to point out each of these slides has at the bottom a person with lived experience that has a video. I really encourage you to take a look at those videos. They are very powerful but they are very much helpful in giving that affiliation and association and strengthening how, when we do operate with these six principle, how much of a difference it makes and how receptive individuals are.

So, when you meet someone in your line of work, how can you respect their need for safety? One of the ways is look at the environment. Look at what is around you at the time. Is it appealing? Make sure it is not harsh. Make sure it is not driving away. Sometimes we go to the emergency room in the good old days and one of the things you see all around the emergency rooms were signs that say, these are signs that you were having a heart attack, these are the signs that you have high blood, these are the signs that you are a diabetic. You can come into the emergency room not knowing what your symptoms are and they can read the signs and they get worse because it is triggering for them. You also want to provide information and give them time to speak. You will hear that over and over again as we go through the different principles here is that ability to express empathy is such a powerful tool to utilize. Next slide, please.

Now, let's take a look at trustworthiness and transparency. Again, reference the lived experience video that is there. It's about being open and honest with the goal of actually building trust. Because sometimes it is just difficult. We go in as clinicians expecting the person to divulge everything to us, not realizing with many of them, it is an extremely difficult thing to do. We need to be open and honest because our goal is to get them to connect. So, how do we do that? One of the things is helping to establish trust. And that trust can come when you have clear expectations, when you have clear boundaries and you are good with your word. So, if you



say you're going to meet with someone at a certain time, you are there because once they see the reliability, they see the care, they see the concern, that can really enhance the trust. And then providing information as it is known. Sometimes in our treatment strategy, we project what we think is the best thing for the person and say, you will succeed if you do it this way when in reality, we're not listening. We need to open this up in trustworthiness. Next slide, please 37.

Now, we will look at peer support, because this helps to build mutual, healing relationships. They are able to connect with those who they see as equals with them. This is a really good premise with veterans. We saw a lot of this with veteran treatment where veterans only want to speak to other veterans because the feeling was they could better understand what that person was experiencing more than the clinical professional who may not have a military background. So, when we do that, keep in mind, as a clinical professional the value of the peer support, and if you don't have enough information, seek it out. Go and look at what the values can be with peer support, speak to other clinicians who might be using peer support as to how to enhance it and utilize it in your own service. And then have those peer supports available directly through a series of contact lists or otherwise. It can be extremely helpful as the person sees that you are bringing in individuals to assist them that can do more than enhance the trust that individual has and their willingness to continue to share. Next slide, please.

Let's move to collaboration and mutuality. This is about sharing power and decision making. This is one of the tripping points sometimes for clinical professionals. I know it was for me when I started because I was dictating to individuals what I thought that was the best treatment strategy for them. I was not giving them a voice in a response. So, we need to talk about the sharing, the partnering with individuals, so we know we have informed consent and so forth, so we're going to talk about medication, risks and benefits and how different people can respond to that is important for us to know. Because how they come to a decision to embrace what you're saying might be different from person to person. But provide information about the decisions and remind them again about the ownership piece of the decision. How you and they can work together. A lot of times, it is really helpful to be able to say to a person, I think this is a tragedy that might be helpful, but in the same token, if it isn't, we'll move to another one. Give them hope, give them the understanding that this collaboration depends on a give and take relationship.

Next slide. And as we go to empowerment, voice and choice, and this is now on our end as professionals to recognize their strengths, and use them to help them to be more self-regulatory. To be more of a self-advocate. You have heard, I'm sure a number of times, the great treatments that you offer, the wonderful strategies you put into place, you can't go home with that individual. So, it is important that we offer them some degree of empowerment, so they are able to take those tools out and be able to address things as they approach them. So, how do we do that as clinical



professionals? How about putting up principle, putting out information that will help them. It might be signs, it might be brochures, it might be pictures. It is a direct thing that is concrete that they can see or hold on to or provide as a support for them.

But then again, you also want to ask them, because remember they are going out into their world and that world is going to affect them in a certain way and isn't it good to know how they would plan to respond to the type of world they are going to see when they go out there. Look at their abilities, do things that help to give them pride, and the last slide, please.

We go into cultural, historical and gender issues. This is huge category and as I've said before, we can take up our entire time talking about these issues but what is important is to try to move past our stereotypes, our biases. Offer a gender responsive service. Using the healing power of cultural connection, it's important for us to be respectful of culture and to address historical trauma and gender identity. So, in one sense, in the back and forth and the empowerment piece, have the person explain their history, have them talk about their culture, work with the family and other supporters to understand those cultural values and then check yourself. Check your own oval system, so we make sure we're avoiding any significant judgment that we may have. All right.

And now, at this times, I will turn things over to Max Barrows from Green Mountain Self Advocates, a partner in The Link Center. Thank you all.

MAX BARROWS:

Thank you, Brian Sims for that. And so, I'm Max Barrows and I just want to quickly introduce myself. I am a young black man. There is a white background behind me. I am wearing a light blue dress collared shirt with a dark blue tie with red and white diagonal stripes and I have short black hair, so I wanted to point that out.

And we will go to the next slide. So, I'm going to talk about a new tool that we developed on managing triggers. Next slide. When I say, 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, this tool, so it is easy for most people to use. So, this is the new tool that we use to manage triggers.

So, you may be wondering what is this tool. It is a two-page handout. It helps people to make a plan for what to do and say if they get upset when they remember something bad or from the past, you past, you know, bad from the past. Triggers can be people, places, smells, sounds, tastes, or things. For example, if someone who hurt you smelled 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 and 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, you know, how the things that trigger -- how to try to figure out how things



that trigger them. When possible, a person can try to stay away from those things but, you know, for sure, you might not be able to avoid all your triggers. And we found that knowing your triggers can help you understand why you got upset. So, I wanted to point that out.

Next is how do you use this tool? The tool begins by asking a person to identify their triggers, the question is, what are my triggers? So, this could 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, taking a long walk, sitting alone in a quiet space, listening to music, and talk to yourself, which is what I do. For me, it can be calming, you know, to do what I call an energy release, which is when, you know, when there are thoughts that come to mind and just after an overwhelming day. I use those thoughts to kind of feel myself, you know, feel my body and my body, you know, allows me to release energy, any kind of energy that builds up from an overwhelming day and it can be seen as, like, in some people who are autistic, hand flapping, jumping, body rocking and the list goes on.

And 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're upset. It can be anyone. I personally want someone who I trust.

Who should not support me? Who do I not want to support me when I'm upset? For me, people who do not understand me in that regard. When do you use this tool? You may be wondering when, 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. You know, 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 somewhere or someplace where you can find it easily. How do you share it with others? When it comes to sharing with others, for me, I would share it with the people I spend time with. It is important to let 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, you know, in your home or in your pocket or put on your cell phone. So, those are things to keep in mind.

Finally, I'm going to talk about checking in. Checking in with others who support us. When it comes to checking in, it is not a time to give me a lot of instructions or to school me in what you think I should do. It is a time for listening. And here are some natural questions to ask to keep the conversation going while doing so, or neutral, I should say. How do -- how did that make you feel? What do you think? What's important to you? Do you need more information? What have you tried that works for



you? What do you do that makes you feel okay? You know, 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 easy to tell me what to do but it does not help us. You need to help us figure out what we this and what we want by asking us questions or giving us information in a neutral way. For example, if someone wants ideas about calming down, you can say, you know, well, you need to focus on what works for you but some people try walking, some people try music, 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 on how we are feeling. We tell our supporters what they can do, and say to support us.

Overtime, we build trust and that's the goal. So, thanks for listening to me and at this time, I will now turn it over to Wendy to co-lead with me through a group exercise, which I hope you find fun.

### **ACTIVITY/GROUP EXERCISE**

WENDY MORRIS:

Thank you, Max. I'm Wendy Morris. I'm a Senior Behavioral Advisor for NASMHPD, National Association of State Mental Health Program Directors. I'm a middle-aged white woman. I have gray hair pulled back in a messy bun, a black turtleneck with colorful scarf and purple glasses. As Max said, we want to present the group exercise. It's going to be a very brief case example with questions to follow and we're just looking for people to react to it. You can do it by raising your hand and Max or one of us will call on it, you with put it in the chat and we will read it out loud. You are welcome to come off of camera. You're welcome to stay invisible, right, to the group if you choose. We encourage you to engage just how you're comfortable. We have about 25 minutes to do this exercise, so lots of time for good discussion.

So, with that, I will turn it, if we go to the next slide, Max will read our study.

MAX BARROWS:

"I am a mental health practitioner. Alice was in my office recently. Alice is a 25-year-old woman with a diagnosis of Autism Spectrum Disorder. She was referred by her PCP or primary care physician because she had been experiencing high blood pressure, panic attacks, insomnia, nightmares, and depressive symptoms, including social isolation and loneliness. Alice said her job in the service industry is stressful and doesn't pay enough to afford rent and necessities. She also said, looking for another job elsewhere would take her away from her parents and siblings, with whom she lives with.



Her grandparents immigrated to the United States 60 years ago, leaving a country that was not safe seeking better opportunities for their families. Her family has consistently struggled with a new country and language, poverty, and food insecurity. When I asked her about her childhood, Alice said her parents loved her and pushed her hard to succeed but she also said they often were angry and sullen. Her PCP, her primary care physician noted she may be showing signs of PTSD or post-traumatic stress disorder. Do you agree? If so, how should treatment proceed? "

So, again, do you agree or if so, how should treatment proceed? You can answer by un-muting yourself or putting your answer in chat. If you're going to un-mute yourself just raise your hand or just say it. I will make sure I will get to your answers as much as I can because I love learning from you all.

WENDY MORRIS: There is always a few moments of silence before the first volunteer gets the courage to speak.

MAX BARROWS: That means they are thinking.

WENDY MORRIS: There is a hand up.

MAX BARROWS: I have Shabina Hussein.

SPEAKER: Thank you for the opportunity to share my thoughts on this case. I feel as if she is being pressured by the family. She has PTSD because her parents have been pushing her a little bit too much, and she feels they are often angry and sullen. She should be made comfortable in the way she likes to be without judging her and making her feel more, you know, safe in the environment to be -- to relax and be what she wants to be instead of pushing her too much in a certain way. Her parents were immigrants, so they had to succeed with different languages and different environment, culturally, it is kind of a culture shock when immigrants come here, so they had to deal with that and that was transported down a generation to their daughter, and it is difficult for her to cope with autism and stress.

WENDY MORRIS: Thank you.

MAX BARROWS: I got Kristin next and then I will go to chat.

SPEAKER: I think as a clinician, I would need more information as far as actual PTSD as a diagnosis, but generational trauma I think is important here to look at. And probably, taking some time with her to find out more to know more areas of her life and possibly do some family therapist -- therapy as well.

WENDY MORRIS: I think you said go to chat next.

MAX BARROWS: Yeah.

WENDY MORRIS: I have two in here, one says there are many layers of peer support opportunities, so I would love to hear from more on everybody on that. The



second one, I would recommend considering possibly anxiety screening, which goes along with the comment right there, that we probably need to do more assessment. There is another one that says, starting with biological concerns to rule out high blood pressure contributing to anxiety and panic attacks, which is such a great point, right? We don't want to assume, which is the horse and which is the cart what is causing what, so it is good to look at the physical health as well.

MAX BARROWS: Anybody else want to have, you know, anybody else have an answer for the story on Alice?

WENDY MORRIS: I think there may be different diagnoses that are contributing to PTSD symptoms. Food insecurity and poverty alone supports a PTSD diagnosis.

MAX BARROWS: Feel free to un-mute yourself and, you know, say your answer and just, like, if you can, if you will raise your hand by the raise hand icon.

WENDY MORRIS: thank you. I want to remind everyone for what Stacy said, this is shared learning. There is no right or wrong answers. This is not seeking us what you know. We want to learn from you what your thoughts are and maybe there are things you want to know more about or give us some guidance on things that The Link Center can do to help support practitioners in dealing with these kinds of clinical cases.

MAX BARROWS: I got a hand up. go ahead.

SPEAKER: I was just thinking, we talk a lot about treating the symptoms and not the diagnosis, right. It is a good question, does she have PTSD, that kind of thing? What you can see people doing in the chat is pulling apart some of those layers and trying to think of, what are some ways we can support each of these things that she is feeling because it doesn't really matter, right, where it comes from. Of course, it does but you know what I mean. There is not a pill for PTSD, so nobody is looking to solve that one thing. They are trying to pull back some of those biological, psychological and social layers, so I think in each of those sections, so we, you know, I mentioned earlier treating the high blood pressure, right, is that contributing to the panic attack, maybe some of her insomnia nightmares. There are things she can do, I think like group maybe some other immigrants or refugees in the area that they could -- there's a therapy group or something where they could get together and share experiences or talk about things that make them -- things that are triggers to them, right? Similar to what you were saying about veterans, like, I only want to hear from a veteran if I'm having difficulties with my PTSD. I want a lived experience person to talk to me through that, so that peer support piece but they might have to go a little bit deeper into where she lives to find that specific type of support that's there.

WENDY MORRIS: That's great. So, Max, we have several more comments in the chat. So, one says this is from Mora, yes, feeling all of the pressure of life and interacting with her family on top of her history of a dangerous living situation trauma seems likely. Family might be traumatized. Such a good point, trust is so importantly. Next is from



Alicia. I think there is PTSD, poverty and environmental trauma as well. I also do believe additional screening is necessary. So, that has been a trend for sure in the comments. Karen says in addition to treating her medical needs and providing therapy, connect her with peer support group where people have a background similar to Alice's, so she can learn from others or from her culture. Next is Cody, says agree. there appears to be a growing body of evidence for accumulated trauma in many individuals due to the prevalence of co-occurring conditions and how it affects a person's ability to process experiences. In that vein, it may be PTSD or alternative trauma diagnosis. Trauma responses are also becoming more common explanations for what may traditionally be assumed of the be a "behavior" which is helping with the tendency towards diagnostic overshadowing. Regina, thank you for the detail and very accurate definition. I think that, Brian, that might have been in response to an earlier comment where someone gave a pretty comprehensive definition to trauma. Megan, I would love to have someone work with the tool that you shared with us. That kind of prompts one of the things we talked about as we were preparing for today's shared learning group, then is, as clinicians, do you -- each individual feel like you have the experience, knowledge and tools you need to work with someone historical trauma with different experiences than you have? Do you think that is a factor in maybe trying to find another practitioner who may be able to assist you with Alice or do folks have thoughts on that?

MAX BARROWS: Again, chat is also available. We're keeping track of chat but feel free to raise your hand and un-mute yourself and say what it is that you think of. Go ahead, David Grady.

SPEAKER: Hello. Can you hear me?

MAX BARROWS: Yes, I can.

SPEAKER: I appreciate these comments. I think they are spot-on. I think we need to remember the Autism Spectrum Disorder and maybe consider a solution-focused approach with consideration of long-term goal of improving her job situation, which might be a more person-centered vocation a discovery approach. In terms of the cultural -- her cultural background, I would definitely get consultation or support from somebody who is familiar with that culture and the trauma experienced by that culture. But we can help her adopt skills that can help her manage the panic attacks and begin to focus on strategies, so she can have her best life might be helpful.

WENDY MORRIS: Some other chat from Justin. It says agree strongly with what has been shared so far. Poverty alone is the largest daily triggering event that contributes to the listed symptoms. I think this would read as PTSD in those who don't have autism. Perri, who you heard from earlier, it is important to acknowledge her autism because these compound on each other. Because of the autism, if she does have PTSD or another mental illness, some things may work differently for her in her healing journey. Regina says I appreciate your point more about the families trauma. The unit is sharing



experiences and the stress of poverty, food insecurity and linguistic needs on top of the historical trauma may be exacerbated Alice's current experiences.

I think that was another question we talked about, I believe, Max, was, you know, how do we need to support the family, right? I don't know if people want to respond to that but that was a good comment.

MAX BARROWS: Yeah, once again, you can un-mute yourself, raise your hand on the raise hand icon. I will call on you.

Go ahead, Shabina.

SPEAKER: Assisting the family, I would send in a social worker who is culturally sensitive, maybe a different language they speak, so that person has a common language they can share, probably the social worker can reach out to the family if they are willing to have an appointment with them at home or at a common site where they can meet together and discuss what are the needs for food or housing trouble that the social worker can refer to them for food stamps or for housing vouchers or whatever the family -- what kind of situation the family is in and what kind of support can be provided if there is an unemployment issue there with family members, if they can guide them or help them develop their resumes and stuff, you know, there could be several options to support the family, and Troy to understand from the perspective of the client, Alice, like how the family should -- what the family needs for Alice to do better instead of just improving Alice's situation and condition. Thank you.

MAX BARROWS: You're welcome. Anybody else?

How about this? How about this question? How would you use the tool that I introduced earlier with Alice?

MAX BARROWS: Here we go, Wendy's question, this is from Megan, does the tool that you shared with us include the plain language that Max gave. I missed seeing the image but heard Max talking about. I'm thinking about a plain language one-pager for clients to understand trauma and one-pager for mental health providers and another one for residential community support providers to coach them in talking about the idea of trauma. This is written in plain language. The tool that I shared is written in plain language, so it is easy for most people to use.

WENDY MORRIS: And I think, if I understood the question, maybe they were asking if there is a plain language resource to go along with it that explains trauma.

If not, that is something we can look at developing, right? Those are great suggestions.

MAX BARROWS: Yeah, I mean, I would hope there is. it would definitely be useful because I think plain language helps everybody in general.



WENDY MORRIS: So, you're getting a lot of action in the -- Max, in the chat. I think someone wants to put the tool up again and they have a couple more questions.

MAX BARROWS: Yeah, I can show that.

WENDY MORRIS: Is there somebody, Stacy, who can put that back up again for us?

STACY NONNEMACHER: Yep, we will pull that up. Give us one second. It is also in the chat if anyone wants to download it from the chat as well.

MAX BARROWS: All right, there are other things in chat that come up and one is from Cody and they said, it would help to provide the family resources related to supporting, understanding the nuances of co-occurring needs in persons with ASD, Autism Spectrum Disorder, including strategies for navigating whole-person care, and encouraging a collaborative biopsychosocial approach among her providers, navigating insurance, especially when Autism Spectrum Disorder might overshadow her other needs or vice versa, and finding community supports to assist in her overall wellbeing. And then Karen says, you could give her some choices. She could fill it out together or with you or a trusted person, maybe this is a good way to get the conversation going with her family. Alice could share it with her family if she wants to.

WENDY MORRIS: Did you want to come off of mute and have a discussion or ask some questions about it or wanting to take another glance?

We have about five minutes left, I think. So, we got time for some discussion.

So, I think Meghan has her hand up.

SPEAKER: Thank you so much for reposting the tool that is very helpful to see because that helped to answer my question. I love this explanation of what are triggers, so I think what I am thinking about is an explanation of what trauma is in plain language and then accompanying materials for mental health providers who are treating trauma and to coach them to use plain language in trauma treatment. And I am thinking about service providers, daily support personnel or residential providers who may not be treating trauma but who may be a person supporting someone in walking through the triggers. So, some sort of companion for them to think about or understand trauma and how to talk about it in a plain language way I think would be amazing.

WENDY MORRIS: That is a great suggestion and exactly the kind of feedback we're hoping to get from these. We've got several things in the chat, the tool was downloaded. Stephanie downloaded or put it in the chat, so you can have it. Annette says the tool can be a good educational resource to help her understand the concept of tool, which we just talked about. Brian Sims says there is domain information on the NASMHPD and it is under the center for policy and practice, it is written in plain language with reference to the guidance for trauma informed environment document. Regina says I hope to reiterate that the concept of "trauma" is not always transferable from culture to culture. Such a good point. In other words, we don't



all view trauma in the same way because someone may view trauma and another person may view it as normal. It is important to research the trauma in the culture. It is about experience, so what is traumatic for me won't necessarily be traumatic to another person. Jeanne says it will be great for the whole family to identify their triggers individually and as a family to understand as an individual and as a whole will help that I recall interactions on a daily basis. Meghan says this is an awesome tool. I think we can take the tool back down if we want. Thank you. We still have about two minutes left if there are -- if anyone wanted to talk and hasn't had a chance. You're almost out of time but you can always text or e-mail and we will have more information about that in a bit.

So, we can sit in slips for a minute. I don't want to end early if there are other comments. This has been great. I will say you all have made really, really significant contributions and very different from the session we had earlier today with DSPs, so I think it's really interesting and exciting for us to really gain all of these different perspectives from people and different groups of people. It's going help us assure there is information that is going to be useful to everybody when the website comes up. Max did you have closing comments? I think we're down to one minute.

MAX BARROWS: I -- the only closing comments I have is thank you all for, you know, coming on here, taking the time to attend this training and, you know, I hope you take this back to the good work you do.

WENDY MORRIS: All right, I guess with that, Max, we are to turn it over to Dr. Deb Pinals for the final word.

## **CLOSING**

DR DEB PINALS:

Great discussion. My name is Dr. Deb Pinals, I'm a clinical clinic consultant to NASDDDS and I work for NASMHPD. I'm a middle-aged woman with short, dark hair wearing a brownish sweater and big square earrings and have glasses on as well. What I want to remind you this chat is really helpful for us. Please put in the chat what are your go-to resources, any trainings, websites or places you get information about trauma, so we can really look at those and maybe include those, and really appreciate your input on that.

Also, just to remind you, and this is also in the chat, until the website is available, you can you reach us by email at [thelinkcenter@nasddd.org](mailto:thelinkcenter@nasddd.org). And the website is coming soon, so stay tuned. Also want to give you a heads up about the upcoming shared learning groups. We finished our supporting someone in crisis back in October. We're now doing these trauma shared learning groups. We have two more tomorrow on this very same topic of trauma, one with families to get their input and one



with individuals and we're looking forward to hearing those perspectives as well and putting all of the pieces of the puzzle together. In April, there will be another set of shared learning groups, so we hope you come back. In April, the topic will be supporting someone through a transition. We know that transitions can be very challenging on so many levels, and so we're excited to hear some input around that. We're already working with partners to help develop that shared learning group. And in August, we have another set of shared learning groups about supporting the whole person, and so please stay tuned. Please mark those dates on your calendar. Please join us again. Your input is incredibly valuable.

The slide set has these resources if you're interest until seeing more, these are the references that were used and big shout out to Perri, Max, and all of the partners at The Link Center for contributing in the preparation and content of this meeting. Really looking forward to digesting the chat.

Please remember to scan this QR Code. If you can take a moment to do that and then fill out the survey to tell us what your thoughts are about this. It will help us because we use your input very closely to help improve all of our future session and everything we are developing. This is a collaborative effort and without your input, we can't do as well. So, please take a moment to put your camera from your phone on this QR Code and click on the link to fill out the survey.

And I think with that, that's the final word.

THANK YOU

