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 zoom chat to commute it with others throughout 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 name by clicking on the three dots next 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 or panelist, you can do that by clicking on the Q and a function at the bottom of your screen.

Following this webinar, we will receive an email with all the material -- you will receive enamel with all the material we reviewed today, the recording and transcript as well as an evaluation that we ask that you please complete in response to today's shared learning group. At this time, I am going to hand the floor over to Doctor Stacy Nonnemacher who is going to start today's presentation. Stacy, it is all yours.

INTRODUCTION AND WHAT IS THE LINK CENTER

DR. STACY NONNEMACHER:

Thanks so much. Hello, good afternoon, everyone. Afternoon here in Pennsylvania. I'm not sure in your part of the world. Thank you so much for joining us. We are really excited to have you here for our second series of shared learning groups.

By way of an introduction, my name is Stacy, I am with the National Association of State Directors of Developmental Disability Services, NASDDDS and I am sitting in front of a white background. I'm a middle-aged white woman. I have glasses on, a gray sweater with a pink shirt underneath.

As Stephanie said, today we are going to talk about supports for trauma as part of the work that we are doing through The Link Center. Which is a grant effort funded by the Administration for Community Living. We only have an hour and 1/2 together so we don't have time to do a deep dive into the topic but we are really looking forward to starting the conversation about how to get you the tools, information and resources related to trauma as we seek to bridge the IDD, intellectual disability -- intellectual development of disability, brain injury, other differences and mental health systems.

We identify that this topic may be triggering for some so please take care of you and please let us know in the chat if there is anything we can do to change the words that we can use, especially as we are meeting today. We are constantly growing and learning with our efforts through The Link Center.

We know that even the word trigger may be triggering for some. So, we invite you all to share and react in the chat and we welcome all sorts of participation, understanding that some of you may desire to actively engage and some may desire to just listen and witness. We welcome all of that in this community and our time together.

A couple things about the shared learning groups. This is the second quarterly meeting that we have been hosting. We hosted some meetings in October. We host four meetings per quarter. One for direct support professionals, one for clinical professionals, and we hosted those yesterday, one for people with lived experience and for families of lived experience. -- People with lived experience.

The information in all of these presentations is essentially the same. We have tailored it a bit for the audience, particularly changing discussion questions for each of the groups. Making the content really relevant for you.

This presentation and to the content you are going to be seeing today is a collaboration among The Link Center partners and that includes people's lived experience, researchers and people who work on policy issues. I can't wait for you to meet some of our partners and colleagues in this work.

As Stephanie said, and it bears repeating, we are recording and transcribing the meeting. We will share the recording and transcription and any other materials that we show you today after the meeting and we highly encourage you in your own communities to share all of this information. We really want it to get out far and wide.

I have the honor to turn the microphone over to Perri Spencer. A mentally ill, autistic self-advocate, AAC user and member of The Link Center steering committee. They are a graduate of (unknown term) College project SEARCH a program focusing on teaching valuable employment skills to people with intellectual develop until disability's and other disabilities. Perri worked as a support professional and are currently searching for a new work opportunities that would further enhance their skill set and help them to grow as an advocate. Thank you so much for joining us and I will turn the mic over to you.

PERRI SPENCER:

I am a white person with short, light brown hair. I'm wearing an orange long-sleeved shirt. My pronouns are he/him. We are going to talk about trauma. Trauma is when bad things happen to us where we see -- or we see bad things happening to someone else. We may feel scared, hurt or upset when bad things happen to us. This is OK.

We may also feel scared, hurt or upset when we are reminded of bad things happening. This is also OK. Discussions of trauma are difficult, and it is OK 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 IDD for short and mental illness. Existing as someone within IDD and mental illness comes with trauma that is not often talked about. Some people don't know that these experiences are traumatic.

Ahead, there will be talk of unmet needs and discrimination towards people with IDD 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 people who are nonspeaking. But can affect everyone with IDD 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. Everyone should be able to make decisions about their life, including people with IBD and mental illness. -- IDD 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 support needs limits the choices of people with IDD and mental illness. Jackson may not have the choice of whether to cook dinner using the stove or the microwave when his 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 OK for people to think that. People should ask when you need help with instead of thinking that you can't do certain things.

The last traumatic thing is ableism. Ableism is when someone discriminate 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 worker instead of you when you go out. Even though it is not OK, some people may not know unless you tell them.

There are also things that even nondisabled people know are not OK. 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 OK 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 IDD and mental illness safe. If we don't talk about it, we can't change it.

It is important to know that people with IDD and mental illness are at a much higher risk of abuse than people without IDD. There are a few reasons why I think that is. Firstly, people with IDD and mental illness may not know what abuse looks like. For example, someone may not know that 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 IDD 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 IDD and mental illness does know that they are being abused, they may not have the tools to report abuse. This is especially true for people who are not speaking. 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 IDT and mental illness also may not know who to report the abuse to. Or how to say what happened in a way that others will understand.

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

People with IDD and mental illness deserve correct information of abuse and help from supporters to stay safe. Some people may have a hard time staying safe even with current information and support because of their disability. Supporters should be looking out 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 doesn't 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's during the resistance to the storm that the tree is in crisis. After the storm, bent and soaked in rain, branches snap 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.

Sharing lived experience. This meeting will be talking about ways 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 is necessary for your comfort and care.

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

STACY NONNEMACHER:

Thank you so much for setting the stage for the topic today and for your incredibly powerful words. We appreciate you sharing. And speaking of sharing, I noticed that some of you did introduce yourself in the chat and I invite the rest of you to put your name and any group or association membership you may have in the chat. We are looking to embrace the concept of shared in these shared learning groups. By way of an agenda today, we will take a couple of minutes to talk about The Link Center. Some of you may be more familiar with the grant and work of The Link Center than others. We will talk a little about what we are doing and what we have been up to.

Then we will spend a lot of our time talking about supports for trauma and why are we talking about supports for trauma. We are going to share some resources and really want to put out there that there are many resources out there around trauma informed care, trauma informed approaches. Mostly those resources are in the mental health field. We have some in the developmental disability field and really what we have been learning about is that trauma informed care and approaches is not diagnosed as specific. We will talk about the fact that trauma does not discriminate in a moment. They really are universal practices to trauma informed care and approaches for all of us. So we acknowledge that there is a lack or dearth of resources related specifically to trauma and people with intellectual development disability, brain injury and other communication differences and mental health conditions. We are, part of the work we are doing at The Link Center is working with others, experts and people who have been thinking about how to be better support people with co-occurring conditions to fill the void or gap.

In the meantime today we are looking to share some things that we have been finding, that we really want to expose you to if you haven't been exposed to it yet.

Then we will and our time together with a group exercise. Hopefully, putting out there a relevant challenge to you all that is related to trauma and your role and talking to solutions and ways that we can get multiple perspectives into supporting somebody who may have experienced trauma.

So I will say this now, we will say it again later, but we really open up the invitation to you all with lived experience and in your role in supporting someone with trauma. Asking that you share any of your go to resources. Whether it is trainings, websites, any sort of information or places that you go to to get information about supports for trauma. Again, we are looking to you as a community that is out there as a supporter to really share what you tap into because at The Link Center we really want to elevate those things and also, identify where are those gaps or voids that we could potentially be filling?

As I mentioned I will talk a little bit about The Link Center. I mentioned in the introduction that The Link Center is a grant, a five-year grant and we are about a year and 1/2 into our time. It is funded to the administration for community living. What we are really looking to do in really a global way is how can we better support individuals with I/DD, brain injury and other communication differences and rental health conditions. Those folks with co-occurring conditions.

That is a big undertaking. There is lots of work we can be doing and that is why we have all of these partner organizations doing it with us. The lead partners NASDDDS is the organization I am affiliated with and the second lead partners and NADD, National Association of Dual Diagnosis and you will hear from some of my colleagues today from the NASMHPD, in addition to those partners, we are putting an eye on diversity, equity and inclusion and we have some partners that are really helping us do that. You will hear from one of our partners today from Green Mountain Self-Advocates, Autistic Self Advocacy Network is involved. National Association of State Head Injury Administrators and CommunicationFIRST. We are really wanting to put a keen eye on what we are putting out there. What we said we would accomplish with the grant and are we meeting the needs of the communities that really is also trying to find better ways to support people with co-occurring conditions.

To help us do that we have the national Center for START Services, Sonoran Center of Excellence and the OSU Nisonger Center. We are very grateful to be doing this work alongside these really wonderful people with lots of expertise and experience. We have three goals of The Link Center. Really broad goals. The first one is looking at systems change. When we talk about folks with co-occurring conditions, these are often people who have needs that span or cross multiple systems whether it is the developmental disability system, mental health system, the medical system and often times, in my experience, as a clinical practitioner, often times it is a system barrier to getting someone's needs met. In a very holistic person centered way. One of our goals at The Link Center is to incite systems change and improve policies, system design and service coordination for people. We are doing some of that work through our partnerships with federal partners like CMS, ACL, Administration for Community Living as well.

A second goal of The Link Center is to really build capacity of direct support professionals and also of clinical practitioners in all systems. We often know that there is some really great expertise in systems and expertise of mental health practitioners and expertise of people who understand how to support individuals with developmental disabilities. But we know there is a dearth or really a lack of people who understand how to support somebody holistically and have the experience and expertise and the tools to do that.

We are really looking through our efforts to build the capacity far and wide and build a diverse workforce.

Lastly, through the systems change in through building capacity, we are really hoping that we can improve access. Get people the services and supports they need because there are, there is a workforce that can meet their needs because the system is able to provide services and supports to meet their needs in a person centered, culturally and linguistically appropriate way.

How are we going to do that? We have a few activities that is part of the grant and I've already said we are really putting NI on diversity, equity and inclusion as well as continuous quality improvement and really understanding, are we hitting the mark? So, one of the ways that we are going to do that and I know Stephanie already mentioned that, it bears repeating, we are going to have an evaluation at the end of today's meeting to let us know what was your experience with this shared learning group? And we are going to be doing that throughout all of our activities, through The Link Center again, to ensure that we are meeting the needs of the communities, of the supporters and individuals who have co-occurring conditions.

We are also very, very lucky to have a steering committee comprised solely of people with lived experience who really guide this work. And you have already met Perri and really participate and engage with us in understanding the needs of people. Also understanding everything from language to what our peoples experience in this world and how can The Link Center make a difference and meet the goals we have set out to do.

We have committed to quarterly shared learning groups as we are doing today and really grounding that in the opportunity for us to share what we are learning with you all and give you some tools and give you some resources but also for us to hear from you all and again, capitalize on that shared part of the learning group.

We are also tapping into people who are out there who are also thinking about how do we better support people with co-occurring conditions and people who are doing research, people who are building good models and services for people with co-occurring conditions. So, we are constantly pulling in and talking to expert contributors as we are learning about the needs. What is needed out there.

Finally, we are taking a look at what is out there in terms of resources. And elevating that and also, as I mentioned earlier, identifying where the gaps are and where the needs are and how we could work with these expert contributors or steering committee, our partner to fill the gaps or those voids. And really have that inform our national repository or hub website soon to be launched, live and up and running for you all to access. Having a national repository for information, for training, for resources for people to access over time. Again, looking to bridge systems, to better support people with co-occurring.

Since we are opportunists and we have are you all here together, to that end, we would really like to take a second and ask you as we develop resources and information, we are curious, how do you like to get your information? We know it looks different and we are asking all the audiences that we are targeting with these shared learning groups. If you take a second and answer the question that would be great.

-- If you are thinking "other" if you're able to let us know in the chat what that means for you. OK, great. Thank you so much for taking the time and that is really good information for us to understand how people really want to receive the information that we are developing and putting out there.

Alright, so, a few goals and outcomes of our time together today, again, we are going to be sharing what we have learned about supports for trauma, targeting some resources that we have identified. And talking about why are we even talking about supporting someone considering their trauma.

And then we are also looking for your input. Again, in the chat, please if there is a place you go to and you have information or you have thoughts around what the needs are or what we should be targeting and thinking about related to supports for trauma, please use the chat and engage in there, we'd love to hear from you and there will be an opportunity at the end through the group exercise, to help us come up with solutions and really hear from you all based upon your experiences, how you would react to a challenge that we post you related to someone experiencing trauma.

Here is where I get to turn it over to Doctor Brian Sims, a partner of ours through the national Association of State mental health program directors. Dr Sims thank you for joining us.

PRESENTATIONS

DR BRIAN SIMS:

Thank you Stacy, and thank you for the wonderful opportunity. I first want to embrace the discussion that was placed in the beginning and how informative it is and putting the framework on what we will talk about today.

I am Brian Sims a psychiatrist by trade. I am currently one of the senior medical advisors for the National Association of State Mental Health Program Directors and I am thrilled to be a part of the discussion where we can do some form of overview about trauma. To help people to really grasp the connections here that are necessary and helpful. To describing me, my pronouns are he/him/his, I'm an older Black man with gray-black hair and glasses and have a great, sweater/shirt on and my background is (Indiscernible). Why are we talking about support for trauma? I think everyone in the audience can connect to the fact that trauma informed elements are necessary. In part because of the pervasiveness of trauma throughout all of our measures and with everyone that we work with.

We also know that any kinds of discussions of trauma can be triggering for individuals, and as was pointed out earlier, even the word triggering can be triggering.

But we want to understand a bit more about where we can go with our discussions. If we go to the first slide, I want to talk a little bit about what is the issue about. Can we go to the first slide, please? Alright. Wonderful. What I want to do is freeze the slide to make sure that we see it as what is the issue and the need for the general population? I will tease it down to the I/DD mental health collaboration but I want to look at the general. Because we can put a balance there, if you would have it.

But to understand trauma, for many of us, we know about trauma-informed care, we know a little bit about trauma, but what are we really working with? A number of years ago a panel was convened up a diverse group of individuals to come up with the definition that they felt was excellent in terms of addressing what trauma is all about.

What they came up was a definition that began with the word individual. If there is anything that we understand about trauma it is that it is extremely individualized. We know it can happen to people of all ages, all genders, races, ethnicities, and sexual orientations. When we look at that altogether it says that no one is immune to potentially trauma issues involved in their life.

It says individual trauma which can result from a single event can be traumatizing for some and for others it may involve several or series of events or a set of circumstances. It is what happens next, in the definition, it is experienced by the individual as potentially harmful or physically harmful to them.

That is the piece that we want to freeze. We understand that one person's experience may be wholly different from another person experience. They may both have the exact same experience, but one may view it in a traumatic sense, and the other may not. This is how we look at how we work with trauma in general.

We also understand in the definition that it can have long-lasting adverse effects. These adverse effects can affect an individual's functioning and mental, physical, social, emotional and spiritual well-being. We don't want to ever leave out the understanding of the power of spirituality in any of our dealings with any of the people that we work with. Next slide.

When we also look in the general population, if we tease it into gender, we find that women are twice as likely to develop posttraumatic stress disorder than men. We also know that 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 witnesses to death or injury.

When we look at these lenses, what we are doing is defining, essentially, an entire population to suggest, in one sense, if you are with or in support of someone, you can pretty much make a good guess that trauma exists. And you are going to be right about 90 to 95% of the time. Next slide, please.

When we tease it out into our BIPOC population, Black, Indigenous, people of color, we are looking at how that particular population begins to show trauma as well. In the Black population, Black folks are more likely to experience PTSD in their lifetimes. If we take it into minority youth, not just Black youth, all minority youth, they are more likely to experience trauma. Including historical trauma, we will speak more on historical trauma later.

Immigration stressors, we don't think too much about that, but it is huge in terms of the trauma situations that often exist in the age group. Natural and man-made disasters. Discrimination, violence, and we also know that minority youth are less likely to access mental and medical healthcare. These are things that we factor into everyone that we work with. Next slide.

We also know that Black and Latino young men experience violence, poverty, incarceration, lack of access to healthcare, marginalization, and low social status much more than other people. We also know that when we take a look at the types of trauma, we focus on historic and intergenerational trauma, because there is trauma that has been passed down from older individuals to younger folks.

We look at our Indigenous populations, tribal nations, we see American Indians and Alaska natives also experience increased risk of trauma. Even today.

We look at our LGBTQ+ individuals, and they are nearly 4 times more likely to experience violent assault than their cisgender or heterosexual counterparts.

We are looking at a lot of evidence to show us that trauma is extremely important to be addressed. So as we go into our populations, we go into an understanding the prevalence of trauma is extremely high. Let's go to the next slide.

What is the issue right now when we talk about people with disability? What we are doing is taking all of the data that I just shared with you a few moments ago and looking at how it relates to the disabled population.

In the population what we see is that people with ID are 3 to 4 times more likely than people without it to experience adverse effects. Such as abuse, neglect, medical trauma, these are issues that I'm sure all of you are already connected with, already understand, but it bears relevance because we are trying to make a connection now. We are trying, through The Link Center, to do a collaboration that mental health services that have been available for the non-ID population can now (indiscernible) to that of the ID population so we get those resources crossing over.

We also know that within the population, 85 to 90% mental health support have a history of trauma. So we are looking at almost the entire population in need of trauma informed care. And forms of treatment. Next slide.

One of the pathways to getting there is to go with what SAMHSA, the substance abuse mental health service Association, that governs mental health and substance abuse across the country, convened a group of diverse professionals to orchestrate how a trauma-informed approach would look. What was created from that endeavor was a guideline for the practice of trauma-informed care. In any setting.

It's a wonderful document that we reference and is easy to get a hold of but within the document I want to briefly talk about a couple of the bullet points that came out of it and that was the establishment of six principles of a trauma-informed approach.

In the six principles we are going to go back and forth because I want to take a look at what it means to the person that you are working with. But also it means to us as the person who is working with them as to what we need to do to ensure that our approach is also in a trauma-informed fashion.

We start with the first one, before we even go, with talking about safety, I want to ask a question. It's a question that I don't want an immediate response to but keep it in the back of your mind in terms of every time we approach our loved ones or anyone who has a history of mental illness or DD or combination thereof. That is, do we as people who are working with them believe in their recovery? Believe in their healing? Believe they can change? That things can improve?

What you want to do is make sure that image is what is going to be projected to whomever it is you are working with. So if we start with the safety, next slide please, if we start with safety it is about feeling physically and emotionally safe. If you're working with someone, what is very clear is that they don't feel safe. It's impossible to establish trust. It is impossible to get that connection.

Healing can't take place if people don't feel safe. What we are doing is doing a balance. What can we do to enhance that? How can you ensure that your love one feel safe in their physical settings and with others around them?

Do they have, for instance, this is one example of many things that could be utilized, do they have a private place that they can go to? Some self-regulating techniques? Some de-escalation techniques? And a myriad of these things are really important to overview. Because they are readily available, for those that would like to have them.

But I would also like you to do when you have the time is linked to these lived experience videos because they can be very helpful. They are told from the perspective of seekers of service that can let you know what kinds of things worked with them, to help them to common self regulate. Let's move to the next slide.

We are now talking about trustworthiness and transparency. This is huge. It's about being open and honest. The purpose of being open and honest is to try to establish trust. You want to be able to build trust. You want to be able to have that connection with that person so that they then see you as an advocate. As a partner in the treatment. How do you create that trusting relationship with your loved one?

One of the ways is to encourage them to talk. The interesting part is that we not only would like to see people get them to talk, we also need to listen. As we are talking to them, listen and give feedback as to how they respond. So you can understand what is happening to them. You know how to support them better.

I spent a number of years working in corrections and I used to talk to the inmates about this piece and I would say, what happened to you? Rather than what is wrong with you or otherwise, and they would begin to tell me the story about how they got arrested. But when I reframed it to ask what happened to you, it's amazing the amount of not only information they were willing and able to share, but how would enhance the trust that was established between us. Next slide.

The third principle we will talk about is about peer support. Peer support in this room can be huge. If you are able to find individuals who have a mutual assimilation with that individual, you can find a lot of healing. That healing happens with relationships with people that they see as their equals.

It is hard sometimes if we have not ourselves had the experience of the person we are working with or talking to were trying to help. Having a peer that has had a similar situation or is currently involved in a similar situation can be a real healing process.

Do they have, for instance, someone they can talk to, someone they can call about how they are feeling? Someone who has been through the experience to help give them guidance and support and let them know that even though the pathway they see might not be going in the greatest direction, it can be better. It can move towards healing.

In this, you want to say that sometimes peer support can be tremendously helpful. Let's move to the next.

Thank you. The next one, regarding collaboration is when we tell to families, peers, everyone that we can. It is about sharing power and decision-making. Quite often what happens is we tend to go into what we think is wonderful treatment of the people that we love and are trying to help, but we do it in a very direct manner. It tends to be more instructive than cooperative.

Are we judgment free? Do we go into our discussions with our loved ones in a nonjudgmental fashion? Do you respect and try not to control them? To say that they must do it this way? Do you open the line for a more open discussion with them?

One of the measures that you can do is regularly ask them, what is important to you? So you can find better ways to help them, better ways to support them, better ways to help them to start moving towards the goals you would like to have set.

It is a partnering agreement. What it is saying is that you are not just going to blanket Lee do exactly what that individual is asking you to do or what they say, you are partnering and balancing things. So that they feel that they have the ability to be heard. We are now in empowerment, voice and choice. This is kind of a buildup from the previous slide saying that when you have collaboration, you are actually giving the individual the message that says "I recognize that you have many strengths." I recognize that you have a voice, I recognize that you have things that can be incredibly helpful in our collaborative effort to help you to propel forward.

That is empowerment, because once we give them that empowerment, do you feel like sometimes your loved one has places where they make their own decisions?

Do you see that? And when you see that you acknowledge that strength? Do you respect the choice and this is kind of hard, do you respect the choice even if you don't agree with it? To respected doesn't mean you have to go with it but it says I hear what you are saying and I understand it. Then you can bring in those things that may need to be reframed in order to help the person to do it in a manner that is going to be safe.

Your loved one in the example given, your loved one chose to stay in their apartment alone and doesn't go out for the holidays and while you may not agree with that, you support their decision and asked them what they need or want to do in order to celebrate.

Sometimes, it really is great that we see this example because sometimes it pushes us to do things that are little bit out of our box or wheel or how comfortable we feel. But this is a great way to open that again, the recognition that you care about how they feel, you respect how they feel.

And on the last slide, I always say this but cultural, historical and gender issues could be spoken about for 17 hours because it is such a critical piece of understanding. If the person you are working with, if your loved one or otherwise, if you have cultural aspects to your discussions, you are trying as best as you can to try to get past the potential stereotypes and biases that can often be related to certain cultures. Offering gender responsive services but also talking in a framework of healing and cultural connection. And recognizing and addressing, here we go, the historical trauma and Gender identity. Many people we are working with are talking to, having respect in terms of the connection and a trauma informed approach. What you are doing is saying I may not know what culture you are in, I don't know about the specifics of your culture but I respect where you are. If you give an example, I went across the country to New Zealand and what we understood from their is that many of the culture there that with Maori and they were individuals that had their own set of understandings and how they dealt with things. In not saying "no you are wrong and this is what it should be." This is ways that we bolster the connection and ensure the communication is there to give hope and help them to move towards self advocacy, healing, self-regulation.

Thank you very much and now I am going to turn things over to Max Barrows from Green Mountain self advocates, a partner with The Link Center. Go ahead.

MAX BARROWS:

Thank you very much and noted, I am Max Barrows the outreach director for Green Mountain self advocates. I am a person on the autism spectrum and I am a young Black man and in their late 30s was sharp like here. I am wearing a very light blue with thin blue stripes, colored dress shirt with a dark blue tie with red and white stripes.

So, I will be talking about a tool that we developed and this will be a tool that will help people manage their triggers. Next slide please.

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 the tool, it is a two page handout and helps people decide what to say when they remember something 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 when you remember back things, you might feel sad, mad, or scared for a while. Our purpose is, of the 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 your triggers. And we have found that knowing your triggers can help you understand why you got upset.

So, how do we 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 the 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 OK 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 for me, talk to myself. You know, I myself, for me, it can be calming to do an energy release which is what I call it. That is, whenever there is energy that builds up in me from a long, overwhelming day, I may take the time and space to release it. I let my body feel itself I how it responds to my thoughts and I just let it out. It may look like some of the repetitive behavioral patterns that can come with autism such as jumping, rocking, hand flapping. I am only talking for myself and through my personal experience. But that is my definition of an energy release. My personal one.

Helpful support, this includes what others can do to help me be OK. 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 the. 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? What 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 OK 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 somewhere where you can find it easily.

How do you share with others? Well, for me, I would share with the people I spent time with. It is important to let the people you trust know what they can do to be supportive. I personally, would wanted 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.

Checking in: this is something I am finally going to get into. I am going to talk about checking in with other supporters. When it comes to checking in, it is not a time to give me lots of instructions or to school me in 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? What did you do that makes you feel OK?

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 may need to, you need to help us figure out what we think and what we want to do by asking questions or giving us information in a neutral way. For example, if someone wants ideas about calming down, you can say "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.

Over time, we build trust and that is the goal. So, on that note, thank you so much 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:

Thank you. Good afternoon or good morning depending on where you are. My name is Wendy Morris and I'm a senior behavioral health advisor and work with Doctor Sims at the National Association for State Mental Health Program Directors. I'm an older white woman, gray hair, pulled back in a bun, I have a purple shirt with white polka dots and purple glasses and a white background behind me.

Great to be here today. We are going to have a group exercise. Max is going to read a short case example and there will be a question at the end and what we are hoping to get folks to react to it, share your ideas and thoughts, and we welcome you to raise your hand online and you can come off of mute, you can turn your camera on or leave it off, whatever you're comfortable with, we will monitor the chat, you can share either virtually or in the chat your thoughts and there are couple of things in Q and a and we will make time to get to those as well. But as Stacey said in the beginning, I invite you to engage in whatever level you are comfortable. With that, I will turn it over to Max to read our case example.

MAX BARROWS:

“My son is 30 years old and has a brain injury that makes it difficult for him to concentrate and regulate his moat. He talks a lot about moving out of our family home into his own apartment like his older brother. I tend to encourage him to continue living with me and his father because I'm fearful that someone will take advantage of him again. I know that we won't always be around to protect him. But, I also fear that because he does not trust many people, he would just stay in this apartment by himself and withdraw. What should I do?”

Please, if you have an answer, you can put it in the chat and we will read it. But also feel free to raise your hand online. Or on the race hand icon on your screen, on the bottom. We will call and you and we can definitely make sure that we get your answers.

WENDY MORRIS:

There are not right and wrong answers. We are just looking to create dialogue and hear from you all.

MAX BARROWS:

I got one in the chat that says sometimes the hardest thing to do is the right thing. He should be given a chance to live independently with supports in place if that is his goal. I've got another one that says, this is from Nicole, listen and support him, Nicole says "listen and support him in his wants in his life to live as independently as possible." The last one I read was from Katie.

I got another one from Valencia miles and she says "encourage his wish to be independent, maybe help them find an assisted living type situation.

WENDY MORRIS:

Those are all great, love to see everybody supporting that decision and making sure it is person centered. One thing that is in the vignette is that it says the parents are afraid that someone will take advantage of him again. Which of course, indicates there has been some past incident. So how might we deal with not just our own fear about ensuring that he will be safe?

And there is another chat that says "I agree with Katie, talk to him about what moving out looks like, what are his fears, what support says he need, help them access those supports, talk to him about your fears for him also and how you can mitigate those risks of being taken advantage of. That is great.

MAX BARROWS:

Once again you can feel free to raise your hand and we will call on you if you want to say your answer out loud. Don't you love how the thinking years are on people's heads?

WENDY MORRIS:

Absolutely. I wonder if you might think about how you could use the tools that Max introduced to have some of these conversations about fears and what kinds of supports he might need and so on and so forth.

MAX BARROWS:

I got one from Caroline in the chat, and answer, "charting the life course tools would be help, charting his vision for a good life but also identifying how people, his strengths and assets in technology could be used to at least safeguard him from being exploited financially.

PERRI SPENCER:

it looks like we have a couple of things in the Q&A from Mary who has to leave the meeting now but she put in hopefully The Link Center will be including information for people that have minimal or no language and cognitive deficit, difficulty understanding. I certainly agree that that cohort, and she says this cohort needs attention.

MAX BARROWS:

I got another thing in chat from Marilyn and they said "access a supported community like in Durham with wraparound services to parents and sons for safety and counseling."

Lucinda says "a local Center for Independent Living might be able to help him and the parents in the process. Local peer support groups and seeking teaching about those topics from an outside organization might also be helpful."

Karen says "work with him to find a way to ease into living on his own. Maybe at first he just lives in his own place a couple days a week and as others have said, work together to come up with a safety plan."

Regina says, "to piggyback on the person centered approach, to consider options for him, maybe talking to him about the support group and some activities that support his subcultural interests."

WENDY MORRIS:

So many great ideas. I'm wondering, and I'm guessing there are, folks in our audience who have some experience doing some of these very things and if maybe that is part of what is generating your ideas. I also wonder if you have comments, again, you could come off of mute and tell us or put in the chat, where would you recommend people look for these types of support in their community? How did you access them? Did you go online, did you talk to some of the providers that work with your loved one? And I think this question was posed earlier, what is your go to place for information when you're trying to sort this type of thing out in your own family?

MAX BARROWS:

There is an added comment from Regina, "support groups and peer to peer support connections are available through a local brain injury Association." It may have been a separate comment. (unknown name) says I used the MCO which handles Medicaid support services. MCO and LME, if you don't mind putting in the chat with those stand for as an accommodation. Because I get off a bit super abbreviations mixed up, no offense.

SPEAKER:

MCO is managed care organization, I don't know about LME. Licensed…? I don't know. Local management entity Managed Care Organization.

MAX BARROWS:

Thank you so much.

SPEAKER:

You had it right.

MAX BARROWS:

I corrected myself. This is from Lucinda, "I am a Googler, but working in the aging and disability networks, I am aware of many of the organizations that we utilize. I also learned from my daughter's school and my sister who is a special education teacher." Mary says "I follow autism NJ, New Jersey, counsel on severe autism state counsel undevelopable disabilities for resources."

SPEAKER:

One of the comments you read I think by Regina who mentioned peer to peer support, really goes along with some of the principles that Brian… Doctor Brian Sims talked about earlier. Another question to the group, what about the family? What kind of supports might be available for the family? We have talked a lot about the individual, but the family is disclosing that she and the father, the mother and father have some anxiety and fear, concern about their son, very conflicted about this decision, where are some places, are they the same or different where you get support for yourself?

Marilyn says the North Carolina Autism Society, great.

MAX BARROWS:

Karen says "is there a family network nearby? Can you find other parenting talk to who -- parents to talk to who have been through this challenge?"

WENDY MORRIS:

The National Association for Mental Illness is another organization that some communities have for folks who have co-occurring disorders. And love the idea of peer support for families.

We have about 10 minutes left. We want to continue to encourage people to come off of mute and have a conversation, dialogue with us a little bit. Even if there is a question we have not asked that you would like to post to the other people joining the shared learning group today. We want to learn from each other and…

Or maybe you have ideas you would like to talk about as Mary did in the Q and A, pointing out that maybe we need to be sure to have some attention to people with severe communication deficits.

SPEAKER:

This is Nicole. This is such a great conversation. I was thinking from the perspective of the parents that always make sure that if something in your child's life was traumatizing, it most likely traumatized you. So there's a lot of apprehension here with these parents about allowing their son to live again on his own, because they are most likely worried about how that will impact their life. So that is there trauma, and not his trauma.

So it's important to go see a therapist and talk about that so that it does not become one thing, like your son has a life, they may have an intellectual disability but this is their life and it is separate from yours. That's something I had to work hard on in my therapy sessions so that looks as my son is 13 and I still work towards that goal. It was important for me to understand and work towards, he will always have his own life separate from mine. And his goals and his life, I need to listen what those are. They may change over time, but I always want to be here to support him in his most independent life.

I live in Georgia. It has been hard to find resources. But I did find a community of people who are like-minded to us, we want to live inclusive, they are called extra special people, and because of them having this really strong hold, I am in Athens, Georgia, it's almost inclusive community, so I would say early on try to get your family and the community that is inclusive with supports. You may have to move several times. That is what my family had to do and I always told myself through everything that I'm in good company, even though I cannot see these people, I will eventually find the resources I need to serve my family.

But going to what… A lot of what Max said, make sure you are listening to the individual and not just saying what you think is right.

WENDY MORRIS:

You made so many beautiful and important points. The point you made about when your child or loved one experiences trauma, you experience trauma, sometimes we forget that it does not have to happen to us for us to experience it in a difficult and painful way. So that's a really good point. I love how you brought up to be sure that you get support and assistance for yourself to work through some of those feelings.

I also love what you said about listening to the person and tagging on all those points that Max made. I think there is a couple more chats.

MAX BARROWS:

The only other chance I can see is the one acknowledging Nicole from Sheila. But Karen Thapar says: if he has support staff that can make it their number one focus to help the son develop natural supports, find other groups that share his interests and talents and get him involved. Make healthy connections before moving out.

WENDY MORRIS:

That's great and kind of goes in hand with what Nicole was saying. She and her family had to find natural supports. So many great ideas.

MAX BARROWS:

Does anyone have any other ideas or opinions? Or whatever you would like to share?

WENDY MORRIS:

We do still have about five more minutes so there is plenty of time.

MAX BARROWS:

For me to take in what I learn from everybody on this call. Instead of just talking at you all the time. Considering that we try not to do that.

WENDY MORRIS:

Because we are capturing everything so that everything that is said today whether it is in the chat or verbally, we will be able to, that will inform the work of The Link Center to cc point, we love that shared learning peace. We know we can learn from you so please share your insights and thoughts with us.

So I think maybe we could turn it over for the last word. I see one more chat which was, asking for a website. We are going to get to that and Deb will share the web address. Do you want to take over? Take you everybody.

CLOSING

DR. DEB PINALS:

I am happy to. Hi everybody I'm Deb Pinals a clinical consultant to The Link Center and I'm a psychiatrist. I also work as a senior medical and forensic advisor. So I am really thrilled with the discussion and what came out of it. It was very interesting to hear just going to go through a few items and before I do some housekeeping at the end. Telling you a little more about myself, I have short dark hair and I'm wearing glasses and a beaded necklace and a dark sweater today.

Again, just very happy to hear the input. So, just want to remind you, please continue to add to the chat, what are your go to resources, training, websites and where you get information and supports about trauma that will help us develop the materials and really inform us about where you go for information that supports you about trauma.

And to answer that prior question, a reminder of the email address, the website is not yet up but it is coming soon. Until then, the email address is The Link Center@NASDDDS.org so feel free to meet -- reach us by email while we wait for the website to be posted.

Thank you again for participating today. Today's were wonderful, yesterday we had the DSP

And clinical folks and later today will have another one of these hearing the perspectives of individuals on support for trauma. In October we did a shared learning group on supporting someone in crisis. And stay tuned because we have more to come, in April will be doing shared learning groups on supporting someone through a transition and in August, will do shared learning group on supporting the whole person.

We would welcome you to come back and provide your input to help inform the development of The Link Center.

On the slide deck are some resources and references that were used that you might want to look up later. We are providing those for you as well.

And again, just want to acknowledge Perri and Max and all the partners at The Link Center for contributing to the preparation of and content for the meeting. Thank you all for your participation, it has been fantastic. There is a QR code that will allow you to fill out a survey. There is also a link that has been placed in the chat. Please, please, please, fill out the survey, it will help us understand how we did with the shared learning group and help us improve further sessions. We can't do it without your input. Take a moment to complete that and thank you again very much for your participation.

I think that is the last word that I have. So we can close out.

THANK YOU