STEPHANIE MOTE: Hello, everyone and welcome. Thank you so much for joining The Link Center for this Shared Learning Groups. We are focusing on Supporting Someone in Crisis today. I'm going to go over a few housekeeping items while we get started. We have live captioning and ASL interpreters available today. This session will be recorded, and the transcript will be shared with attendees. The PowerPoint and documents that we reviewed today will also be shared with everyone via email. We welcome you to revisit the content yourself and share it with others.

Attendees cannot see the names of other attendees and all attendees are muted. You can see the hosts and panelists. Feel free to use the chat function in Zoom to communicate with other attendees and hosts during the webinar. You can use the chat function by clicking on the chat box in the bar at the bottom of your screen. Please be aware that your name will appear in the chat if you make a comment. You can change your display name if you want to by clicking the little dots next to your name and selecting rename. We will have representatives from The Link Center watching and responding in the chat throughout the session today. If you would like to submit a question or comment privately anonymously to the hosts and panelists, you can do that by clicking on the Q&A function at the bottom of the screen.

Following this webinar, you will receive the material we reviewed today, recording and transcript, as well as an evaluation that we ask you to please complete and response to today's Shared Learning Groups.

At this time, I will hand the floor over to Mary Sowers, who's going to start today's presentation, Mary, it's all yours.

MARY SOWERS: Thank you so much, Stephanie. Thanks especially to all the folks in attendance today. As a Stephanie mentioned, this is one of The Link Center's Shared Learning Groups. I will talk a bit about what our hope is for these sessions. We are hosting four of the Shared Learning Groups each quarter, aimed at different audiences. Yesterday, we had the pleasure of hosting two meetings. One aimed at Direct Support Professionals, and one aimed at Clinical Professionals who support individuals within intellectual and developmental disabilities and other cognitive and brain injuries and other mental health conditions. Today we are focusing on individuals and families. We are especially grateful that you took time to join us today.

We have kept the content of the sessions consistent. But really changing the discussion to tailor for each audience. The reason for that is that our hope with The Link Center, which is a federally funded -- we are grateful to the Administration for Community Living for their leadership in this area. It is a federally funded project for improving resources and access to services for people who express cognitive or communication differences and mental health conditions.

We want to make sure that individuals and families have the information that they need to engage successfully with Clinical Professionals and Direct Support Professionals effectively support individuals with I/DD or other disabilities in the community.

Our hope with the sessions is to keep the content consistent. Everyone is getting the same information. But we tailor the conversations in a way that's going to make sense and resonate with you in your day to day life.

The information that you are going to see presented today is really a collaboration across some really wonderful partners of The Link Center. It includes individuals with lived experience, people who are researchers, people who work on policy issues. As well as folks who are direct support professionals in different roles. We are glad it for the roles -- input we've had on developing this content.

As Stephanie mentioned, we are recording the information. We will be sharing the transcription of this as well. All the materials will be available to you after the meeting through an email. We would encourage you not only to reflect on the conversation we are going to have today, but to share with others if you think it will be helpful. Hopefully come back with additional ideas as you contemplate what you learn, were here today on the meeting.

I'm actually going to hand off the speaking for a bit to my colleague, Monica Wafford. We are so grateful for Monica joining the work of the Steering Committee. Monica is a member of our Steering Committee. I should mention that The Link Center, the body of work of The Link Center is guided by a steering committee made up of people exclusively with lived experience, to help make sure that the work of the Center is grounded in the things that are most important to people who it impacts.

And so, Monica is going to take us through the next steps. Let me do a bit of introduction for Monica. Monica served as a community advocate for victims of violent crime, with the Central Council (Unknown name) in Alaska. She also served as a coordinator for state of a lox's senior vocational services. She's been a certified peer specialist since 2007. With that, I will have things over to Monica. Thank you Monica for joining us today.

PRESENTATIONS

MONICA WAFFORD:

Thank you, Mary. Since we have families today, I just wanted to touch a little bit on what lived experience means. A lot of people who are certified piers have either lived experience in having a mental health disability themselves, or they have a substance abuse problem that they have overcome and are recovering from. Some of the lived experience, there are love -- other lived experiences.

It is not always just pure support specialists that are in service to people who are people with lived experience. You will find psychiatrists and doctors and all across the board, people with lived experience. I just wanted to touch on that and let you guys know that. Next slide, please.

So, on this meeting, we are going to talk about crisis and strategies people use to address crisis. We want you to take care of yourself. And allow silence to be your safe space. We want you to feel empowered to do what is necessary for your comfort and care.

So, you may have heard about the 988 crisis line. This is for people who find themselves in crisis, and it's an easy number to remember. 988. You dial if you need help. This is something new, and we are glad that it is a nationwide service. Next slide, please.

We are going to talk about crisis planning and supports. We are going to talk about how that should be tailored to the person that is receiving services. Because one size does not fit all. Next slide.

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

And I want to tell you about me a little bit before I go on. And it will be great if he could put in the chat who you are, what you are here. Because this is shared learning, and we want to know who you are also. My experience with crisis has been a have had 2 suicide attempts. For, actually. 2 were with clinical intervention..

I had a mental illness from the time I was a child. And I cannot even remember when I started to have hallucinations and both audio and visual. When I became a pure support specialist, I come up with a plan. It was called prescription positivity. Which is an ongoing process of finding value in life. I found that finding a value in life is like discovering a new currency. It is of value. It is like what I place the value of having my family around me, or my friends near me in America, we are allowed to make our environment what is comfortable for us. Make our space personal. These are the things that I hold dear, and these are the things that give me strength, reason and purpose.

When I felt I couldn't go on with my life, and I had those suicide attempts, I determined that the reason I couldn't go through with my plan to end it was because I valued those treasures in my life more than I did the prospect of death.

So my prescription for finding positivity, and believe it or not, there is some positivity that you can find in the schizoaffective disorder is or schizophrenia. It gives you cool perspective where you have to look at things honestly, because you want to make sure that what you are seeing Israel. --is real. That may sound strange, but that is who I am and that is how I became a peer support specialist.

I learned that I had the ability to empathize with other instead of sympathizing. And I realized as appear that I could use the tools that could work for me. My insight give me the ability to calculate those tools available for my clients.

So, with a team's effort or by myself, I could help other people see the worth in your lives. I became focused early on understanding about resources that were within reach of my clients. Customer service for me has always been a priority. And as I developed without kids, it was important for me to know the benefits of everything a person has to offer. And finding those treasure, -- work ethics. -- Give you the reason to go on.

As a practicing peer, when I became certified, it became a delicate balance for me between professionalism and self-care. A lot of times, I relived the traumas. Sometimes my empathy to would trigger my own crisis. My environment can be crushing or it could support me.

That is why this shared learning conference, this opportunity to talk to people about what is going on and how we can help bridge those -- those silos of services, then this for me is like nourishment to my brain and my spirit. Next slide, please.

We empathize with experience traumas that hinder our resilience. Some people have experienced trauma that makes it hard to recover and move forward. Next slide. We listen with open minds. We listen with compassion, and most certainly without judgment or blame. And lastly reject failure and we embrace hope.

So today's agenda, I'm going to read this, is to put your name and any group association or membership, or just like I said, why you are here. We will talk about what The Link Center is. I'm on the steering committee. Why are we talking about supporting someone in crisis? What are resources, trainings and information available to support someone, before, during and after a crisis. We will do a group exercise at the end. And we will talk about challenges, solutions, to supporting people in crisis. This will focus on audience participation and ideas.

So, what are your resources, trainings, websites, or places to get information about crisis and planning? Think about this, and we will ask you again at the end of today sessions.

MARY SOWERS:

Thank you so much for granting us in the meeting today, and most importantly for sharing your personal experiences that are really benefiting the work that we are doing because you're really able to share such great information and perspective. As Monica said, we are hoping that the session sort of prompt you to think about things that you need in your day-to-day life, or resources that you are using that have been especially helpful to you. We will come back to this later. Our hope with The Link Center in the shared learning groups, specifically, is that we can identify things that are available, and helpful to families as they support individuals with co-occurring I/DD and mental health conditions on or things that you need, so that we can identify gaps that need to be filled. Whether that is through research partners, or something that The Link Center can provide specifically, directly. Just thank you in advance for thinking about this, and as thoughts occur to you feel free to drop this in the chat. We will also have an opportunity to talk is a group of a little bit later on in the session.

What is The Link Center? The Link Center is a technical assistance and resource center, that was funded last year, it was our first year by the Administration for Community Living. It is really aimed at bridging the gap between mental health systems and systems that support individuals with I/DD or cognitive disabilities or brain injury, or folks who communicate differently. The very root of the challenge is that they do not have access to mental health services and supports even when they need them. Some of them -- that is rooted in payment policies that have gone on for a long time that make it difficult for people with those conditions to access mental health services.

Some of it is based in perception the individuals with those conditions cannot also experience mental health conditions, and so we know that there are lots of barriers that have come up in the lives of individuals to get them the needed support. As we were thinking about the project, we recognized that not one organization could do it by themselves. That partnership become so important in bridging these various systems. I am with NASDDDS, we are partnered with others to lead the work. We have many other partners that have been instrumental in helping us do the work of the grant and how it will take shape over the next several years.

Most importantly we have Green Mountain Self Advocates, the Autistic Self Advocacy Network, the National Association of State Head Injury Administrators, can occasion first met, the National Center for START Services, the Sonoran Center of Excellence, and OSU Nisonger Center.

Regardless of your background, you have access to the information and resources that you need. Next slide.

Our hopes for The Link Center are threefold. We hope that we are able to identify barriers in policy and service coordination systems change. At the state, federal and local levels. We are hoping to provide resources and tools that can help states in their partners increase direct support and clinical capacity to really build a workforce that can help individuals who are experiencing mental health, support needs, both in a clinical sense and also in those day-to-day interventions which we know that families in direct support professionals play such an important role in helping individuals thrive in their communities. We want to make sure that the professionals that help individuals really have a good life in the community and have the skills they need to serve individuals effectively.

An importantly, very basically, we want to improve service access. Like I said a moment ago, we know that sometimes individuals with I/DD or cognitive disabilities, or brain injury, or folks that communicate differently have a challenge in accessing services that they need. We hope that The Link Center can begin to chip away at those barriers to access. Next slide.

The character of these of The Link Center are rooted in two guiding principles. We are keeping it very intentional lens on diversity, equity and inclusion. We know that our systems are complex. And making sure that individuals regardless of their disability, their race, ethnicity, sexual orientation, other factors, everyone can have an equal shot at exiting supports and services will we are really taking a broad view in trying to reach lots of communities through the work of The Link Center.

But we are also really recognizing that we do not have all the answers. We are building in a continuous quality improving process so that we can learn and adjust the offerings of The Link Center to make sure that we are meeting the needs of the communities that we are hoping to reach, including families and individuals, especially those groups.

You've met Monica, she's a member of the steering committee, the work of the Link center is going to be guided by the steering committee. Made up of individuals from across the country with lots of different background, different disabilities, experiences, cultural and linguistic experiences, communication differences, and the steering committee has already and it short-term that it has been convened, has already come true did -- contribute mightily as we go through the work over the next several years. This is our first voyage with the shared learning groups. Our hope is to pull groups of individuals with the audiences that I talked about earlier, both to share information but also to get information that will be useful to you in your day-to-day activities and in the role that you play. In the lives of people with I/DD and mental health support needs.

But we are also, as I mentioned earlier, very interested in if this is working, should we tweak things, we are anxious to engage with all of you as we move forward today. Probably, at the most broadly based, where we will have a website that will have lots of resources aimed at different audiences. So, again, to reiterate our hope is to have information available to individuals themselves, their families, their supporters, people that are clinician supporting these individuals, and our hope is to have a broad base across that website.

We are really aiming to hopefully accomplish a lot in five years. But listen along the way to make sure that it's really hitting the mark for individuals and families especially.

So today, what we hope to get out of things is that we will share some of the work that we are doing at the link center. Especially as related to supporting someone in crisis. By the end of the time together we will be able to identify the importance of crisis support, and really planning ahead for people with mental health conditions and communicate in differences. And you will know where to find resources. We will be sharing some as we are together a bit more today, we also... If you've had tools that work for you and your family members, information in the past were we might locate those, that would be fabulous will stop or think that we might think about if there are gaps so that we can work with partners to develop things that might be useful.

We are going to have a group exercise where we will talk with several of you on potential solutions on targeted challenges. We are really trying to make this interactive, and hopefully get a lot of brainstorming going. We are pleased to say that in the meetings yesterday, during this group exercise, it will come at the tail end of the time together today, there was really some wonderful ideas generated. Just spark from a conversation around a particular challenge, that was really applicable to the audience that we were speaking with. Hopefully, you will think about participating in that, we will be asking for a few volunteers. So planting that seed now.

At this time it is my real pleasure to introduce my colleague, Doctor Stacy Nonnemacher. She is a key Link Center leader, Stacy, without further ado, thank you.

DR. NONNEMACHER:

Thank you, Mary. Good afternoon, or good morning to everyone who is joining us. We are so thrilled to have you here. As it says, be sure. I think that bears repeating over and over. Just by way of describing myself, I am a middle aged white woman, I am wearing glasses, I have Brown come straight here to about my shoulders, and I am wearing a multicolored shirt, blue and green, in front of a white background.

So, why are we talking about supporting someone in crisis? As it relates to The Link Center. And as it relates to people with intellectual developmental disabilities, brain injury, and co-occurring mental health support needs. So, we know that people have different experiences, people have different histories, and perspectives. Around the concept of crisis. And I think Monica did such a wonderful job of sharing her personal interprofessional relationship to crisis, and really made a case for the importance of talking about supporting someone in crisis.

So, this is where we are going to kick off the topic that is really centered in this meeting today. By asking you all, what does crisis look like for you in your role as a family member? If you had to pick one word, we will open that up to a couple words, what, how would you define crisis? How what does it look like for you? In your role as a family member. So hopefully getting you engaging in the chat, so that we are priming ourselves in getting ready for some engagement later on with our bigger exercise. I will be quiet for a moment and let you all sit on this. And see what you come up with, go ahead and drop it in the chat when you are ready.

Something needing immediate intervention. Great. When I don't have the resources at the moment to meet our family, thank you. Hopeless. Yes. Stress. Yeah, Deb, these are all really great. As you continue to think about what crisis looks like for you, how you would define crisis, you can keep putting them into the chat.

Really the point here, and I wanted to do some level setting, that while crisis can simply be defined as a time when things are not OK, what it looks like, how it is experienced, is individual. It's based on a great number of things. Including the role that you play. What you bring to the table. Right? So in just the four or five reactions that we had in the chat, we are seeing a variety of different ways that people experience crisis, people's relationship to crisis, how they define crisis. So, just take a look at those, even if you did not put anything into the chat, really think about that for yourself. And again, as we go through talking about crisis, really acknowledging the individuality of our relationship to crisis.

DR STACY NONNEMACHER:

Great. Just as a reminder as Stephanie mentioned in the beginning, if you want to send something just to the host, you can do that in the Q&A. You can be anonymous there. If you feel comfortable in the chat, that is fine as well. Raise your hand, and we can take you off mute as well. OK. We will keep going. Please raise your hand again if you want us to take you off mute. Thank you, Stephanie, for pointing that out.

Now, I get to turn it over to my colleague Doctor Debra Pinals. Who is a forensic psychiatrist and a consultant to this grant. Doctor finals also plays the role of a senior medical and forensic advisor for 1 of the grant partners, the national Association for State mental health program directors. Has extensive experience in supporting people with co-occurring conditions, as well as a consultant to public systems. Deb, I will turn it over to you.

DR DEBRA A PINALS:

Great. Thank you, Stacy. Really excited to be here and here the input that you all will be and have been providing. It is so important that in these Shared Learning Groups that we really do learn from each other, because we don't have all the answers. I am going to try and focus on some of the things that we know, and some of the things that we still need to learn. If we could go to the next slide.

Let me start by framing the issue. Again, I think Monica did a fabulous job as did Mary and Stacy. I want to talk about it in terms of thinking about how do we think about providing the right options for people with I/DD and mental health support needs, so that they can get supported at every stage of a crisis, for example, from prevention it to responding to the crisis, to then what to do after the crisis and stabilization services.

And really, we need a lot of trained people supporting individuals who are in crisis. This is across-the-board. Many of you may be aware that 988, that recently invoked 3 digit number for behavioral health crisis, went live, not just this past July, but the July before. And so, we are learning a lot about that 988 rollout. And also what it means when Mobile Crisis Teams respond to a scene. You will see more and more of that no doubt in your communities. We want to make sure that people with I/DD and mental health have the supports they need.

We know today there are too many bad outcomes that we want to erase. For example, inappropriate contact with police that can lead to very scary situations. We know that people end up in emergency rooms. When somebody needs an emergency room, that's a very important part of our care continuum. But it's not a place where people need to be when they don't need to be. And we know psychiatric hospitalization is also very important when people needed. And the right type of hospitalization. When people don't need it, we don't want them to be in places where they are not going to get the help they need.

We know that people with I/DD and mental health support needs are disproportionately held in emergency departments for longer time, try to access other levels of care. We really want to build more connections to support in the community, along this crisis continuum and beyond. That we really believe is the remedy for some of the challenges that we are having. Building out more adept, capable Mobile Crisis Teams for example who can come to the home, that don't need police involvement when there is not a real safety or criminal issue at play.

So, we want the better responses as much as possible. That is what we want to learn from you about in terms of your experience and needs. Next slide.

So, there is not a lot of research about how to best help the population that we are talking about. But there are some studies, and I want to go over a few of the highlights that we have seen from an extensive literature review. One series of studies talked about the importance of coming together and supporting and educating people who work at hospitals, if hospitals are the place where people will end up, to better understand and get comfortable talking to and caring for people with I/DD.

I work in a psychiatric emergency room setting, and this is a very true statement for my personal experience of people just not -- the staff not really having the education or experience they need to help people with I/DD all too often. A paper I wrote with my colleague, Doctor Matthew Edwards in 2020, looked at the literature and said, "We need to educate people and learn the best ways about person centered supports in a crisis settings. Recognizing that every person is different and has unique needs, crisis care needs to reflect how do we best support people with those unique needs."

Another study to highlight showed that some things can make people more likely to end up in the hospital for a mental health crisis. Things like how their disability affects them. If it does tilt them more towards an emotional crisis, especially if supports are changed in an instant, which is often a reason why somebody might have more demand on them than they are capable of handling and putting in a helpless, stressful, fearful situation, as we saw from the people putting in the chat how they see crisis.

Also whether they live in a community or group home setting may make them more likely to show up in a hospital. Whether they been to the hospital for a mental health crisis before, we know if you've been to the hospital once, you are more likely to go a 2nd time. And whether police have been involved. Very often, that is 1 of the ways that police have handled crisis for people with I/DD and mental health, is bringing them to a hospital or putting them in criminal custody, which is obviously another really problematic response if it is not appropriate.

Other things can make it easier to stay out of the hospital during a mental health crisis, like having a family doctor who really understands and can support the individual. And or having a crisis plan. We will hear more today about what a crisis plan can look like, and having that work in advance can be helpful to help keep people out of the hospital. They can predetermine how to best support them during a crisis. Next slide.

So, there are crisis models that we know are emerging and evolving. The START model is one. Certified behavioral health clinics is another and there are several others along the way. These are avenues to building out services, for example. Certified Community Behavioral Health Clinics Have a Unique Place with the funding mechanism that allows them to provide care for anyone who walks in the doors for an initial assessment. And to supply crisis services and partnerships with communities in the communities that they are serving.

We know it from the models and from the examination and evaluation of the models, that there are pieces that have shown some success. For example, having system connections. We know when someone is in crisis, multiple systems may be involved. If it's a youth, it may be the school system, plus the family system, plus a mental health system, plus the I/DD system.

We know that when we include behavioral health and physical health together, we can take care of the whole person from a biopsychosocial perspective. That physical health need might be really relevant. Somebody might be having asthma challenges while they are having emotional challenges. We wanted to address the whole person.

We also know a data to address a crisis having many available services is important. People might need food subsidies, transportation supports. Something beyond just a psychiatrist to talk to them or medications or therapy. We really need to think about all the available services that will help address that need for the families, and the person who is in crisis.

We need armor supports to be trauma-informed. We know that the rates of trauma amongst the populations sewing up with an emotional crisis or substance use crisis are very high. They are very high in the I/DD and mental health community. We want to be able to support people in a trauma-informed way.

We want to make sure that in a crisis setting when we do evaluations, that we are doing them right. That we are addressing the I/DD needs in a way that is accurate. If we are not, we want to make changes to how we do evaluations. These are just some tips and pieces of success that are being examined and built out as we go and as we work hard to better develop structures and supports that are not as a sideload as they have historically been, as Mary described. Next slide.

So, what is this research I have just reviewed me and for families? I would really love it if people could add it for the chat what this means for them, and whether we've missed anything. I will go over a few things that we digested from the look at the evidence. But I really think it is important for you as family members to speak up and tell us what you think all this research means for families, in your experience in managing crises that have come up.

One of the things we thought is at times when looking for support for the family member, families may experience a clinician who doesn't have the knowledge about or experience with I/DD. The family members and individual feels isolated and like they are not getting help that doesn't meet their needs.

Also, what we think the literature shows as families have an important role to play in offering information to clinicians when there is a crisis. And it's a help clinicians figure out to meet the needs of the family member. Of course with the person's permission whenever possible,

Families can be an important support because they know what's important for them! All of this is derived from the science we have seen. The role of family is key.

Hearing some of how we have digested that, is there anything else that comes to mind for people about what this means for you when you have had it to work with a crisis situation for your loved one? Feel free to chime in. Or speak if you would rather.

OK. We have someone saying, "It is also important that a crisis situation not only affects either or acutely or chronically the patient, but also the family system. Crisis typically affects multiple persons." That is a really excellent point. I think the support needs for everyone involved is really key. I think that is a really important point that we did not put on our side. I'm glad you added that. Anyone else have ideas?

Alright. I will let you still -- feel free to put anything in the chat at any time or raise your hand. I want to take this opportunity now to turn this over to my colleague, Ren Koloni, from communication 1st -- CommunicationFIRST. Ren is a communication associated with a CommunicationFIRST, 1 of The Link Center's partners. They develop a guide for for people with I/DD to learn more about crisis plans, music knowledge they have gained from their own lived experience. With that, Ren, I will turn it over to you.

REN KOLONI:

Hello, everyone. My name is Ren Koloni, and I use they/them pronouns. I am a fat, white, non-binary person with rectangular glasses and soft dark hair for stop half of it shaved and having a long braid was not I rocking gently back and forth.

I came into this conversation as a program associate with communication -- CommunicationFIRST, a partner of The Link Center. We are the nation's only nonprofit organization working for the civil rights of everyone in the United States who cannot rely on speech alone to be heard and understood.

Not all people with I/DD have speech disabilities, and not all people with speech disabilities have I/DD. Across these communities, we have many things in common. The ways we live, think, move and communicate are so often met with confusion, discomfort, fear or abuse. Our basic needs as well as our basic human rights are not always met and respected. As a result, we tend to carry a high burden of trauma and suffering.

Right now, our communities and our healthcare systems are not prepared to help us whether that suffering or heal from it. The Link Center is doing work that I believe will start to change that. As an artistic person with complex posttraumatic stress disorder, dissociated conditions, and a handful of other psychic disabilities, I know the first-hand importance of this work. In many ways, I have been lucky. I have never been hospitalized or institutionalized for my psych disabilities.

Though I am a part-time (unknown term) user, I have never had my voice taken away from me because it was deemed a safety risk, but I do know people who have had that happen to them. And I have a strong support system. Able and willing to help me when I can no longer help myself. Many of us, especially those of us who are unhoused, do not have that support system.

I count myself lucky, but I've also lost most of my time to dissociative episodes, months where I could not take care of myself or take part of the world. I have had breakdowns in many locations, bedrooms, bathrooms. I have hidden common household objects for myself so I would not end up in the hospital. And I did all of this more or less on my own.

Seeking care has never been a real option. Maybe I did not have the money for the co-pay. Or a psychiatrist told me that he did not know what to say and I did not need to come back. Or therapist looked uncomfortable, and changed the subject. All my care has ultimately come from me and from a small circle of loved ones. I have survived, but going through it so alone has been dangerous, people, isolating and exhausting.

Despite all of this, I still have a faith in the power of mental health care. I spend most of my time in college learning how well it works, when we do it right. And I have met so many professionals who really, truly get it. It is impossible for me not to believe in that potential.

But I also believe in the tremendous power and importance of sharing lived experiences. When people with I/DD who have been through crisis and suffering, come together to pool our knowledge we can create incredible change for each other and for the peers that we have not met as well. A few months ago, folks from NASDDDS asked for our thoughts on how to navigate strike his -- crisis. I found that I had a lot to say. Foreseeable, I pointed out when we are in crisis we often communicate differently. I usually have access to speech even if I prefer typing, but in an acute and overwhelming crisis I have no choice but to type.

Even then my words may be slow or difficult to understand for people who do not know me. Other people I know, no matter how they communicate when they are feeling well, rely on pictures, gestures or a person who knows them very well who can help translate. The people supporting us during crisis need to know how to interact with us, no matter how we are communicating. That means that they also need to know how to respond when I do things they are not expecting. For example my rocking, slapping help me feel present in my body. We should not be restrained isolated or assaulted.

But for many of us, mistreatment of all kinds is a looming threat, never too far from our minds. We cannot afford to forget about it. Here is an example, I would not feel totally safe calling 988 just because of the chance that they could call the police, a situation that would involve dire risks to my health, safety, and life as a multiply disabled person.

988 is doing a lot of fantastic work to make the chains of police involvement as small as possible, early data is that the chance is less than 2%, that is amazing. But I would still feel infinitely safer calling one of the few lifelines that refuses to contact police under any circumstances, like the trans lifeline. Even though it might be a lot less accessible due to a lack of funding.

Or, more likely, I might just decide not to reach out to a lifeline at all. In a mental health care system that can be inaccessible, and even hostile, to people with I/DD, I feel strongly that one of the best things we can do is put as many tools as possible directly into our hands. For example, having a crisis plan does not prevent or fix crisis all by itself, but it can make it easier, safer and smoother.

Working with my lived experience, as an autistic person who has been through and helped others through crisis as well as my academic experience with mental health and disability, I took a look at existing crisis plans and adopted them into a toolkit focusing on crisis plans. The toolkit starts by explaining basic ideas about crisis and plainly but, offers tips about what people with I/DD might want to include in their toolkit based on my experiences. It introduces 988 and defines words that we often hear surrounding mental health crisis. And I included three crisis plans that I think worked well, along with a short version of one that I drafted on my own.

When I am in crisis, I need to know exactly what to do. If I do not have the energy or brainpower to try to come up with a plan on the spot. For me, a good crisis plan tells me what steps I need to take and when to take them. It tells people about the kind of care that I do, and do not want, and lays a foundation for some of the decisions I would make if I were in the right headspace to make them. It also puts everything about what other people need to know about my disabilities in one place. I also feel strongly that crisis plans should be adaptable, for many different types of crisis.

To become a crisis is stress that is unmanageable, overwhelming, and all-consuming, and that also puts me or others in danger of some kind of harm. But the results of that stress are different, depending on many factors. My crisis is not always about wanting to die. Sometimes, like with my dissociation it is about not noticing that I am alive in the first place. And being unable to care for myself as a result.

Or, it might be a meltdown, a shutdown, autistic burnout, or a response to a trigger. None of these crisis situations is necessarily worse than the other, but a crisis plan can help me and the people around me to prepare for each one. This crisis plan is not based on research, and it should not be taken as medical or legal advice. Instead, it is based on my own experiences with crisis and my understanding of myself and my community.

But, of course, there is no single crisis plan for every person and every situation. Different people need and want different things as they navigate their mental health. So, I won't try to offer a one-size-fits-all solution. Instead, I hope this toolkit will guide and inspire people to think about what matters to them and their lives.

I hope that people with I/DD can feel empowered to talk to people who support them about their mental health and make a plan for the future together. And I hope that people who may not have a strong support network right now, will start to feel that they are not alone. Each day, organizations like 988 and local community crisis teams are learning how to support us in ways that honor and respect who we are. And others in the disability community are here for you as well.

I think that people with I/DD know ourselves best and that we gather wisdom each time we experience a crisis or go through intense suffering. When we have access to the right tools, we can make the most out of the knowledge we have gained, over a lifetime of living in our bodies and minds. And, we can begin to make sense of that knowledge to the people who want to help us. This guide certainly does not have all of the tools that we need to heal, but I hope it's a good start.

I would like to thank The Link Center for including CommunicationFIRST as a partner, if you'd like to learn more about our work visit our website. This is vital work and I'm grateful to be a part of it. One lesson, to everyone listening who has experienced crisis, I want to thank you as well for I say that The Link Center work of supporting us is vital and it is. But the most vital work of all is doing what you can to live and love is beautiful world of ours. Thank you. I'm glad we are here.

DR STACY NONNEMACHER:

And in the spirit of thanking everyone, Ren, I thank you as well for sharing with us. We are going to drop the resources into the chat now. I think between what Ren shared in these resources there is a lot of recommendations and resources for us, how do we support people, particularly how do we get a better understanding of the best way to support people when they are feeling OK, as Ren said, and the toolkit that they mention, we are giving you a quick look on the slide. In the chat, Stephanie is dropping in the resources so you can download them from there, if you're having problems please let us know.

This is made up of two resources, what to do when I do not feel OK, the full crisis plan if you well that was described, I think about as families and supporters, what a great resource and asset this could be to understanding what people feel they need, particularly if we talk about that and go through something like this crisis plan. When they are feeling OK. So that when they are not feeling OK, we know what our role is. Right? Sometimes that is something that we struggle with when we are supporting someone who was in the throes of crisis. Or could really use some support to de-escalate from crisis.

So take a look at this crisis plan. Again, it is in the chat. And the other piece that Ren created in a described really well was the resource of the toolkit, the piece of the toolkit, what to do when I do not feel OK. These are the big ideas. It is really breaking down for people what is a crisis? Why do I need a crisis plan? Who can help me? And that is all in here. At the very end of this particular resource, is a smaller, shorter crisis plan, if you will, for people. Something that is more at a glance. That can also be used. I think these are all really great and viable resources to check out. To consider. As was mentioned, they did a little bit of scoping and inventorying what really is out there, so there are some other templates that are out there that you will see on the screen now. And they are also contained in the resources. When you get the PowerPoint you will be able to click on these, they will take you to these other examples of crisis plans.

I think, really, really the intent here is to show you that there are lots of things out there, including the things that Ren developed, and really if you think about supporting someone as they navigate crisis, part of that is knowing what they need. What they need in the various stages of crisis. What your role is as a family member, as a supporter. We have additional The Link Center crisis plan, and additional information around supporting someone in crisis that we will be disseminating as well. As part of the website, that Mary mentioned. We are also going to be including a crisis plan that was created by Doctor Beasley, the founder of START services. Doctor Beasley will be doing a training session for us next month on that plan, keep your eyes open for that as well.

ACTIVITY: CAPSULE EXERCISE

We been alluding to this and mentioning that we will do a group exercise with you all, and we did it yesterday with the direct support professionals. In clinical professionals as well. We found it a really nice way for us, again, to be sort of sharing knowledge, to be bringing in multiple perspectives, and structuring our conversation so that again we understand on our end what your needs are, what things you're thinking about when you're thinking about supporting someone through crisis.

And so, what we are going to do is we are going to present, hopefully a relevant or at least a relatable challenge, problem, issue. And we are going to need a few volunteers who would be willing and able to really listen to this particular problem or issue. And take it on as their own. And think through.

If this for me is this person's parent, what are some of the resources I would tap into, what are some of the things I would be thinking through to support my loved one, really thinking about brainstorming and generating solutions. Hopefully we will get a few volunteers were interested to do that. You do not have to come up camera, but we invite you to if you are interested. If you're interested in volunteering you can raise your hand, you can ask to come off chat. But if you are just witnessing, and you are not necessarily volunteering or being as we call the reactor, you can feel free to listen to this issue, the situation and be putting things into the chat. Some ideas, some solutions. We really want to tap into you all who have the experience of supporting loved ones. And being supporters. So, no pressure, but we think it might be helpful for you all to hear the situation that we came up with. That we want you all to react and respond to. And so, I will turn it over to Monica, and Monica will read this particular issue and I will ask again for some volunteers.

MONICA WAFFORD:

I didn't introduce myself at the beginning, because I remember I have a lot of visually impaired friends who have said when I described myself, "Oh my gosh, Monica. That's exactly what I thought you looked like." Which I didn't understand, but look like. -- Anyway.

The exercise is Ronnie has a 16-year-old son and has destroyed the family home twice during arguments. Ronnie has 2 younger siblings living at his house. Child protective services warned that they would remove their younger children or Ronnie from the home after he broke the rest --wr= of the youngest sibling when he was angry. --wrist.

Ronnie has been told that he has to stay on his medication because it is the only thing that has helped. Ronnie refuses to take the medication because he says it makes him feel like a zombie. He told you that he smokes weed and it makes him feel better.

Fearing the loss of the younger kids, Ronnie is given an ultimatum to take the medicine or leave the home. Ronnie runs away and is gone for days until the police arrest him for selling drugs. What should I do?

DR STACY NONNEMACHER:

Thank you, Monica. Now that you've heard the issue, the challenge we are presenting before you all, is there anybody who is willing to come on up and have a conversation around what are some solutions? What are some things we should be thinking of to support Ronnie? Again, just raise your hand or asked to unmute. If you are interested in volunteering. Again, we have a small group, so it would be great if people are brave and willing to be part of this.

OK, I'm not seeing -- unless, Stephanie, am I missing anyone raising their hand or coming off? Oh, I see some -- so, Wendy. Thank you for raising your hand, Wendy. That is great. Anybody want to join Wendy?

DR STACY NONNEMACHER:

In the chat, someone is saying, "It's important to understand and support Ronnie's feelings about taking medication. Does he understand that the wife or the medication use? Does anyone listen to him when he says how the medication makes him feel?" Very important to have this conversation with Ronnie. I agree. Go ahead, Wendy.

WENDY MORRIS:

I was going to say that I think that's the 1st thing that needs to happen. Was he having side effects that were just things he could not contend with? Are there other options? Would he be willing to take medication if we could find one that didn't make him feel like a zombie or better addressed what he hoped to get out of treatment? Not just what the people around him think he needs.

Also, would there be other options to deal with some of his anger? I mean, he is 16, right? Sometimes some of those behaviors are part of that strive for independence. So, caution with attributing everything to illness or disability.

DR STACY NONNEMACHER:

Yes. And in the chat, going back to the point about talking with Ronnie, mentioning, "Did his person centered plan include what he wanted for himself?" I think engaging with Ronnie, talking with Ronnie, as folks are saying, is really important.

I think to the point of understanding the why related to medication use, or the resistance to using medications, even opening that lends a little wider when we think why. Just generally why is Ronnie -- Ronnie struggling? Not just why is he not wanting to take the medications. Why is he struggling? Are there some other things, to your point, Wendy, other treatment options? In order to know what treatment, what is really part of this story about how Ronnie is showing up, right? And understanding that. I think he is really important person that can be telling us, reporting back.

WENDY MORRIS:

I think as a parent, really need to explore some of those family dynamics. How old are these younger children? Sometimes younger siblings can be super up noxious. We've got 3 grandkids, and the 2 younger girls kind of torture their older brother when their parents aren't looking. He gets in a lot of trouble. I've had to intervene a couple times. Just say, "You didn't see what the girl just did when you stepped out of the room."

What's going on, and are there ways to provide him some prophecy or separation from younger siblings? -- Privacy. Maybe some coping strategies to allow him to take a self directed timeout or walk around the block. Or you know, have a safe space to be able to tell a parent what is happening. Just curious what those dynamics are.

DR STACY NONNEMACHER:

Clearly. And in the chat, just expanding the conversation around the why. What are the triggers for Ronnie to react and respond in such a way? And affirming what you said, Wendy, around the younger siblings.

There is another in the chat "Are there other supports that Ronnie receives to help them support him do things that he enjoys, in addition to clinical interventions?" I think that is really important. I think we minimize sometimes the power of relationships and how impactful they are to someone's recovery. The someone's -- just the way that they show up in the world. And how important it is for people to not just feel safe, but to trust others.

I sometimes think about -- and in my own experience, that I have had people in my life that would not take medication from clinicians and clinical practitioners who did they not trust. So, I love that concept around supporting him to do things that he enjoys. And how that can also be indirectly related to how Ronnie feels and how he shows up, right?

WENDY MORRIS:

Another thing I noticed in here is he says he smokes weed. And just devils advocate, as a reactor, as a parent, in many states now, there is medical marijuana. Maybe talk to his clinical practitioner about what are the properties of marijuana that might be helpful. Kind of explore why that might be helping and how does that compare and contrast to the medication, so on and so forth.

DR STACY NONNEMACHER:

Yes, that is great. So, blowing up in the chat right now. I'm trying to keep up. Question. "Is he receiving services available even at school? Does his primary care provider talk to him about medication and self-medication?" Great comment. "I wonder if he has tried some other medication since that would make him feel better." --bad maybe even showing him that people are willing to help him feel -- figure it out. If not this medication, is there something else we can try? I like that.

Maybe take a look at harm reduction strategies. If weed makes him feel better, why? In some states, (indiscernible) where it is safely dispensed. Are the admitted medications are activities that give him the safe -- same feelings of peace, relief, happiness or anything else that could substitute? Yes.

That being, again, understanding the why. The fully understanding why -- what does the weed do for him? and how to match that with replacement or alternative if necessary.

Another comment, if there are historical interactions and response similar to this, a crisis plan should be billed for future events. Amen. The crisis plan should also include law enforcement involvement was when to call, how to approach Ronnie, how to make the presence in the situation a helpful one, as opposed to a negative one.

I think that is a really great point. I think Ren did such a really nice job of illustrating that. And I know with the efforts through 988, and crisis response, really looking at a crisis continuum, and not law enforcement being the people who show up. Right?

So, having a plan. And thank you for really reinforcing that. That has been what we have been talking about today, is really critical. And perhaps something that Ronnie and his family and other supporters will want to sit down and work through.

Comment just came in. The ultimatum of leaving home. Was there an alternative plan for him if he left? Any supports to leave and be successful?

WENDY MORRIS:

I had that same thought. So, is it really that he's taking medication or other behaviors that we are hoping the medication is helping. If you can't stay here, let's work together to find a safe place for you to go. So that you know, running away doesn't have to be your only option.

Also concerning about selling drugs. So, we might need to find a bit more about his circle of friends. And what his his motivation for selling. Is it to get more drugs? Is it money for what purpose? Is it peer pressure? Again, because he ran away, and that was -- there's a lot to be explored there.

DR STACY NONNEMACHER:

I want to emphasize needing strategies to regulate and decompress. I think we all do that, right? When things get too difficult. When, you know, we just feel like we need to step away for a while. I think we all have our own coping strategies and that is such an important piece of crisis planning. Because, again, crisis planning is not just when the crisis happens, how do we react? Crisis planning is all of these pieces, what are good days? What things make you feel good? If I am feeling off or things are starting to feel not OK, what are some strategies that I have for myself, or ways that other people can support me? I think that is a really, really great point.

Any other thoughts before we wrap this up? This is great, thank you so much for the interaction in the chat. And thank you, Wendy, for jumping up here with me. I appreciate that.

WENDY MORRIS:

My pleasure.

DR STACY NONNEMACHER:

Great. OK, so really the intent here was to show you that sometimes if we open the lens and we include multiple perspectives, even though you all may play the role of family members, you all have different experiences and different histories, and different relationships and how you support someone and how you show up yourself. Sometimes we get in our own way, and we always -- we only see one solution, or sometimes, as Monica said, we are in this crisis with the person it is hard for us to see solutions or see a way out. Or perhaps we come to the situation with our own assumptions. Biases. And frankly, we get in our own way.

This was just a way to illustrate that there are more than one way to come to a solution and it's a really good exercise of having multiple perspectives at one table. And hopefully something resonated for you. Hopefully, you know, you took something away from this situation that perhaps you can use in supporting someone through crisis.

So, again, thank you to those of you who were engaging in the chat. Even if you were witnessing it, hopefully you really felt the power of the interaction, and again, I cannot state enough, the multiples protect -- multiple perspectives and how helpful that is to coming up with a solution and thinking out of the box and for problem solving. In using communities to do that.

CLOSING

OK, now we are going to wrap up our time together. And remind you all that if you have any resources, training, website, places that you go to to get information about crisis planning and support, please put that in the chat. Certainly, we are going to take any feedback, any ideas that you all shared today, we will elevate what exists, and the resources that you share with us, and really take back to our partners and the work of The Link Center. Other pieces that we can think about for action.

Again, to be as a robust resource, nationwide, to people and in this case, specific to crisis as well. So we are really, you know, hoping that the crisis research that we mentioned here and others that we have been targeting and identifying will all be up on our website that is coming soon. We are really looking at targeting resources and information for all audiences, for individuals, their families, and caregivers. For direct support professionals, clinical professionals, etc. While we are still working on getting the website up and running, please feel free to reach out to us at thelinkcenter@nasddds.org.

And we have some more shared learning groups coming up. We will be holding these quarterly. And there may be some modifications to them in terms of times and things like that, but right now what we are holding is in January, we will pull everyone together and talk more about trauma and supports for trauma. In April, we will talk about transition and supporting someone through transition, and we mean across the lifespan and across settings, because we know that can sometimes be a little sticky for some people. And then in August we are going to be pulling people together and share learning groups about supporting the whole person, really looking at integrating care and support, looking here at teaming and digging into multipurpose to -- multi perspectives and how important it is to support someone holistically. Keep your eyes open for those invitations. We are hoping to have January's out in a little bit.

And you will be getting this PowerPoint, these are the resources that Doctor Pinals had mentioned when we talked about the research that is out there. And finally, again, we just want to thank Monica Wafford, Ren Koloni for sharing your stories and giving us their time and energy. I again have learned so much from both of them. They have been informing the work of The Link Center along with Emily Brown, who really had been critical to developing this content, but was not able to be with us on the meeting today. And of course all of her other partners at The Link Center for contributing to these meetings in this work.

Just the last piece of housekeeping, as Stephanie mentioned during the introduction, we will have a follow-up email to you all with the resources that we share today, the PowerPoint, the recording and transcription, and also an evaluation. So here is our plea, please, you already gave us so much time just being up here with us today, but if you could take a little bit more time and complete the evaluation we really acknowledge that these shared learning groups are evolving based upon the needs of the communities. So, please, fill out the evaluation. We will take a really good look at those, and help us inform how these shared learning groups can be beneficial to all and meet your needs.

And, again, thank you for being here. Just a reminder that you need to also take care of you. And engage in self care as much as you can. We know that some days are harder than others. So, we appreciate what you do. We appreciate you taking the time to be here with us. So have a great rest of your day.