OPENING

STEPHANIE MOTE: Welcome, thank you for joining The Link Center for this shared learning group focused on supporting someone in crisis. I will go over some housekeeping items while they get started today.

We do have live captioning and ASL interpreters present today. The session will be recorded and the recording will be shared with attendees. We welcome you to revisit the content and share with your colleagues.

Attendees cannot see the names of other attendees but you can see all the hosts and panelists and all attendees are muted. Please feel free to use the chat function in Zoom to communicate with other attendees or the hosts of the webinar. You can use the chat by clicking on the chat at the bottom of your screen, be aware your name will appear in the chat if you make a comment but you can change your display name if you want to by clicking on the little three dots next to your name and selecting "rename".

We will have representatives from The Link Center watching the chat and responding throughout the session today. And if you would prefer to submit a question or comment anonymously, you can do that to the Houston palace by clicking on the Q&A function at the bottom of your screen.

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

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

INTRODUCTION and WHAT IS THE LINK CENTER

MARY SOWERS: Thank you so much, Stephanie, and welcome everyone to The Link Center's shared learning group on supporting individuals in crisis. We will talk about today about The Link Center but we are really aimed at elevating good practices to help bridge mental health systems, to ensure strong clinical support and community-based services for individuals with I/DD and TBI and other cognitive disabilities.

Especially we are thrilled to have all of you today. Wearing a clinician hat and we really hope to be able to make this as useful for all of you as possible.

We are especially grateful for the Administration for Community Living's leadership in this work. And the shared learning group is just one component of The Link Center. We will go through some of the other activities of The Link Center in a bit.

Today we will be hosting, today and tomorrow we will host four meetings of the shared learning groups and some key elements of The Link Center aim at identifying strong resources for four primary groups of folks. Direct Support Professionals, clinical professionals, individuals with lived experiences and families.

You will note that we have kept the content consistent across the audiences for these groups but we are changing the discussion to really tailor it to your day-to-day work and to make it applicable in how you think about supporting individuals with cognitive disabilities in the mental health space.

This content is really a reflection of a strong collaboration among The Link Center partners. Many of whom you will meet today in the presentation. It includes individuals with the experience, individuals who are researchers, and individuals who work on policy issues and so you will again come through this conversation today, you'll get to meet some key partners.

We will be transcribing and recording today's meeting and the materials will be sent after the meeting through an email and we hope that you will use that to reflect on the time together today but also perhaps to share with other colleagues who were not able to make it and we will be making these resources more widely available as well.

To kick us off today, we have a member of our steering committee, Monica Wafford by joining us and I will talk about the steering committee more later in the presentation but The Link Center is covered by the steering committee made up entirely of people with lived experience from across the country from lots of different backgrounds but individuals who identify as having cognitive or developmental disability or communication difference and mental health support needs.

And the steering committee has already made tremendous contributions to The Link Center and the direction that The Link Center will go over the course of the five year work of the center. So we are especially grateful for Monica and another colleague who helped truly develop the work today for joining us today.

Monica Wafford brings a lot of wonderful experiences you will see in a moment. Monica served as the community advocate for victims of violent crime. With the Central Council and Indian tribes in Alaska and served as coordinator for state Alaska senior vocational services. She has been a certified peer specialist since 2007 and it is my tremendous honor to handover the speaking to Monica. Monica, please.

MONICA WAFFORD: Hi! I'm going to describe myself. I am a 65-year-old, brown skinned lady. Who smiles a lot. At this meeting, we will be talking about crisis and strategies people used to address crises. We need you to take care of yourself because some of this can be triggering. Allow silence to be your safe space. And feel empowered to do what is necessary for your comfort and care. Next slide.

I want to introduce and talk about the 988 Suicide and Crisis Lifeline. That is nationwide. This is a great resource for turning to if you find people who have come to that point where they are thinking of suicide as an option. Next slide.

So we are going to talk a lot about crisis planning and supports. I want you to think about where you work or people that you have dealt with in your practice. How those supports came about, how individualized are those supports? One size does not fit all.

We celebrate individuality. Our diverse culture, and our singularity while we celebrate the discoveries realized in our collective humanity. We know that we each have unique experiences in this world. We empathize with experienced traumas that enter 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. Because what place do either of those have in our treatment of people who need us? Lastly, we reject failure and we embrace hope.

So, in the group I like to just say a little bit about me for a second so you know kind of where I'm coming from. I am a person with lived experience. I'm a certified peer, like Mary said, since 2007. I am retired now.

I personally have had four attempts at suicide. Two of those attempts sent me to the psych ward, and two of those attempts were without clinical intervention. So to overcome the two that handled myself, were my motivation for coming up with my own treatment plan which I carry throughout. And it is called prescription positivity.

This plan is an ongoing process of finding value in life. Finding what gives life worth is like discovering new currency for me. It is the value I place in being here for my family and having them near me. The value I place in the option to make my personal space in my environment what feels comfortable to me. Those things are what hold dear. They are valued treasures that give me strength, reason and purpose.

When I felt that I could not go on with my life, I determined that the reason I couldn't go through with my plan to end it was because those things that I valued, those treasures in my life, meant more to me than the prospect of death.

My prescription for finding positivity saved me from sinking into that hopelessness that comes with suicidal ideation. Finding the value of things that made my life worth living gave me the strength I needed to live my life.

If I felt the familiar hopelessness that sent me into a crisis mode I remembered those things that gave my life value. I became a peer support specialist when I learned I had the ability to empathize while others around me were only sympathizing.

I realized by being a peer support that I could share the tools that worked for me. My insight gave me the ability to calculate the tools available for my client's use. And then to contribute to my or my team's efforts of helping that person see the worth in their lives.

I became focused early on in understanding resources, within reach of my client. Those little things like insurances and funding. Customer service for me has always been a priority.

And as I develop work ethics, those -- it was important to me to know the benefits of everything a person has to offer. Clinical, patient, what have you. And finding those treasures for each individual can offer is finding value.

As a practicing peer for me it has always been a delicate balance between rationalism and self-care. -- Professionalism. Sometimes my empathy will trigger my own crisis. My environment can be crushing because of my disability. Or it can support me spiritually and physiologically.

That is why shared learning to me is a nourishment for both my brain and spirit. That is about me. And then the group, I want you guys to know that we are going to talk about what The Link Center is.

We are going to talk about supporting someone in crisis. What resources, training and information are available to support someone before, during and after a crisis. We are going to do a group exercise at the end. And we hope that people will participate.

What challenges, solutions, to supporting people in crisis, this will focus on audience participation and ideas. Shared learning. Thank you.

MARY SOWERS:

Thank you so much Monica, both for grounding us in the principles that we'll hope will enter the conversation today but also most importantly for sharing your own journey and the expenses that have led you to really help shape this conversation today and a lot of the work of The Link Center, so thank you again, Monica for all of your work.

As we begin the conversation today, we would love for all of you to have in your mind's eye what your go to resources are, what trainings, websites and where do you go to get information about crisis planning. Just to be thinking about this, we will ask again at the end of the session but as you will see, as I go through a brief description of The Link Center and our hopes for elevating good practices, identifying strategies to better support individuals with cognitive or communication differences and to ensure strong mental health treatment, we want to ensure we are trying to identify the best resources available and making those as widely available as possible and most important, accessible as possible so that people with left experience and their families can really partner with Direct Support Professionals and clinicians to work together in supporting individuals to have a good life in the community.

What is The Link Center? The Link Center was funded last year in 2022 by the Administration for Community Living, and we are eternally grateful for their leadership on this issue. Recognizing that individuals with intellectual developmental disabilities, brain injury, other cognitive disabilities, and folks who communicate atypically, often have difficulty accessing strong mental health treatment and there are lots of barriers and contributing factors to that. We hope that The Link Center can help to overcome those during our time together.

We also recognize that the work of the center can't be done by one organization alone. The National Association of State DD Directors who I worked for has partnered with the National Association of Dually Diagnosis and the National Association of Mental Health Program Directors to lead the efforts of The Link Center. We are in strong varnish up with several other key partners, some of whom you will meet in some detail today.

We are especially grateful to the leadership of The National Association of State Head Injury Administrators, CommunicationFIRST, the National Center for START Services, the Sonoran Center of Excellence and the Ohio State University's Nisonger Centre. Each of our partners brings important skill set to The Link Center and we are trying to elevate those elements that are going to be most successful in coming together around supporting individuals with cognitive or communication differences in being successful in mental health treatment.

Our key goals of the center are threefold. Our hope is to identify opportunities to improve policies, service design and service coordination to create systems change. We know in many states and across the country, individuals with intellectual and developmental disabilities and cognitive disabilities have difficulties accessing mental health treatment for a lot of systemic reasons.

Our hope is to identify those reasons and remove those barriers through systems change. We also know the important pivotal role that direct professionals and clinical professionals play in making sure that individuals have access to the things they need.

Our hope is to offer a wide array of resources to build a diverse workforce to support individuals with their mental health and community living, to really bring all of those elements together successfully.

At its basis we are hoping to identify strategies… We all know mental health services can be a hard thing to access and layering communication issues can make that exponential. We want to identify strong practices to help really make a dent in all three of those areas.

You will see in this slide a graphic illustrating some of the key components of The Link Center. Know that on the left-hand side of the slide, all of our work is rooted, in an effort toward keeping an eye toward the diversity equity and inclusion making sure individual supported and the individuals who support them have equal access to information and are able to engage meaningfully in ways that are culturally and linguistically appropriate.

We have a keen eye towards that. We also want continuous quality improvement approach. As we enter the share learning groups, and is a perfect example we are very much hoping to hear from folks on how we can improve and make things better to both share information but also gather information and ideas from the strong community of folks who are represented here today.

We are of course as I mentioned at the top, really leaning into being governed by our steering committee. Individuals with lived experiences. And while the steering committee has 12 members from across the country, from very diverse backgrounds we also have to reach out to other communities and understand from a broad array of voices all the different considerations that The Link Center needs to take into account. They are also leaning in with expert contributors and through the shared learning groups to get the perspectives on a wide array of individuals across the spectrum that we hope to impact.

We will have a website available soon. It is coming soon. And through that vehicle and others like this, our hope is to elevate some resources that exist today. We have tremendous research partners who have done a lot of work in this area and want to make sure all of it is accessible and readily available to the community.

We also want to make sure things are accessible in plain language and understandable by the widest array possible. We are also identifying places where there may be gaps and resources, with The Link Center can make some contributions.

To give you an idea, we are just beginning our second year. And so we are excited at the prospect of the impact The Link Center can have. But as you can see from this work, we are really interested in knowing sort of what your resources have been up to this point. What you have found most successful and where are the places you struggled to gain information that you feel will be especially useful in your day-to-day activities?

Our hope today is sharing what we are doing at The Link Center, especially supported to someone in crisis. Hopefully by the end of this conversation you will be able to identify the importance of crisis support in planning for people with I/DD, other cognitive disability, communication differences and mental health.

And you will know how to find resources to support someone in crisis.

We definitely want to get your input on this topic of supporting someone in crisis and through that we are hoping you can identify necessary resources that might not be readily available or other resources recommend strongly to your colleagues.

We will also have a conversation and Monica described this a bit. We are going to have a group exercise, putting a challenge out there targeted towards clinical professionals like yourselves. Really hoping to gain some input on potential solutions in the hope we can collectively learn from another and brainstorm about interacting with individuals.

It is my great honour to turn the mantle over to my colleague... She has done a tremendous amount of leadership on pulling a shared learning group and other aspects of The Link Center to gather. It is my honour to turn this speaking over to Stacy.

STACY NONNEMACHER: Thank you so much Mary and hello and welcome. Good afternoon, may be good morning for some of you. Thank you for joining us for our inaugural share learning groups.

I am a middle-aged, white woman with brown straight shoulder length hair. I am in front of a white background with my usual blacktop on. I am wearing glasses today.

We are going to really just kick off what we were talking about today with our shared learning group around supporting someone in crisis. Why we think it is really important to be talking about crisis planning and crisis support as it relates to people with cognitive limitations and mental health support needs.

We know and we have identified crisis planning and support is a critical topic with The Link Center. We know that people come to this conversation with different experiences, different histories with crisis and different perspectives.

As clinical professionals who are here with us today, recognizing that although you will have perhaps similar roles, there are really differences. When we talk about your relationship to crisis. I think that in the introduction Monica did such an amazing job talking about both her personal and her professional relationship with crisis. To dive a little bit deeper into these differences and how crisis can be very individualized and how we define it and what it looks like for us. I am going to ask you to engage a little bit with us in the chat.

First of all, I do want to say thank you so much. I see you already putting some really good resources and information in the chat. Keep it coming.

Really to focus on this concept of crisis, we are asking you in the chat what is the one word, maybe two words that would really describe for you in your role as a clinical professional what crisis looks like as you support someone?

Take a moment to think about that and pop in the track. What is the first thing that bubbles up for you? –

Be calm and not make the situation worse.

Noticing a theme here already. Keeping calm, compassion, concerning, Carol, understand the situation, validate feelings, patients, listen, empathy. A lot of listening a lot of being calm. Compassion.

Every crisis is unique, agreed.

Validate feelings and follow-through.

Be thinking that supports and resources that can be connected to. Person centered, joining. These are so great. Trauma informed listening for the needy. I am already thinking about, we held a shared learning group earlier today with Direct Support Professionals. What an interesting comparison to the things they said when we asked this question of them.

As these are coming in, the point here again is while crisis can in its simplest definition be defined as a time when things are not alright, what crisis looks like, how it is experienced, what your role is in it is truly - as you are pointing out here - individualized and based on a great number of things.

Again including the role that you play. I am making some comparisons here and really excited to dive in tomorrow with individuals with lived experiences and families and see how they define and describe what crisis looks like.

Thank you so much. Just a great way to really be kicking off and again pointing out that the way we define crisis is informed by what we bring to the table.

Now we are going to pivot and talk about the research and the science that is out there. I am going to turn over to Doctor Deborah Pinals who is of psychiatrist and consultant.

Doctor Pinals is a senior medical and forensic advisor with the National Association for State Mental Health Program Directors and has extensive, amazing experience supporting people and also supporting people in public systems.

Doctor Pinals, I will turn it over to you.

DEBRA A PINALS: It is a pleasure to be here. For those of you who may be visually impaired, I am a white woman with dark brown hair, short. Wearing a sweater and a necklace today, a black sweater and a pearl shaped necklace. I wear glasses to help me see what I am supposed to be saying.

Let me frame some of the things from my clinical perspective as a psychiatrist who spends time in emergency services and working on crisis services and a lot of different venues. Really what we want to start with is defining what is the issue and the need that we are trying to build upon and solve for?

First of all, we can see already from a chat that we need options for people with IDD and mental health support needs who can get support at every stage of a crisis. A crisis can come in many forms. We want to be able to prevent crisis, address crisis and help people in the post crisis stabilization and intervention period.

We also need trained people supporting someone in crisis. And that is part of the point of this Shared Learning Group, to hear from you what you know so that we can continue to learn as we build out the resources and The Link Center.

We know that there are negative outcomes happening right now that we want to reduce. For example, all too often people with I/DD and mental health illness are in crisis encountering police where they are at risk of all sorts of negative outcomes. Including arrest, incarceration and even overuse of lethal force. We know that we have people in emergency departments waiting for placement and that people with I/DD and mental health and complex needs are disproportionately stuck in emergency departments unnecessarily. Now, emergency departments are important places in our continuum of care so we want to get the right people in those bright places at the right time for the right reason.

Similarly, psychiatric hospitalization is important when people need it but we want to avoid hospitalizations that are not necessary. And so we need to improve our crisis continuum so we can get those proper responses.

Counterbalancing the negative impacts of fewer appropriate crisis resources are that we need more connection to proper supports in the community. That is again one of the things we are trying to build out with these conversations and building our resources, to help people make those connections to both avoid crisis and manage crises in all the forms that they come in.

We know that 988, the national three digit number for mental health and substance use crisis is rolling out. We are doing a lot of work on that. In this grant we are working with SAMHSA and the Administration for Community Living to try to help figure out how to best address the need for people who call 988 who also have IDD and mental health.

With 988 is coming a lot of mobile crisis responses to try and reduce the contact with police when it is not necessary or appropriate. There is a lot of work to do and we are sort of building the bridge as we walk on it.

We need to be informed by the science that exists although I saw in the chat people asking questions and wanting more research in certain areas.

What does the research tell us? There is not a lot of research on how to serve people with an IDD in a crisis setting. Certainly because our crisis system is in a seachange we are going to need more research as new services unfold. There are some published studies that support some evidence in the literature that I think is important to anchor ourselves in.

For example a series of studies showed that there is a need to come together and support and educate people work in hospitals and again this was hospital-based crisis services because that is what has existed historically, to better understand and get more comfortable talking to and caring for people with I/DD. As a psychiatric emergency room physician, in my career, I've seen over and over again we need more information and education of staff working in these settings to best support people who come in crisis with these backgrounds.

We also know from a paper I wrote with one of my colleagues, Doctor Edwards and a review of the literature, the people who help people in crisis need to know the best ways to offer person centered support and not everybody is familiar with the concept of person centered support so that is something we also have to provide a lot of education about and refreshes and reminders.

Every person is different and crisis care can reflect that. We will hear later about the unique aspects of one individual's crisis support plan. Next slide, please.

Additionally, from another study, we see from the research that some things can make people more likely to end up in the hospital for a mental health crisis, for example how their disability affects them if it does lead to those difficulties in emotional crises or if they are having challenges getting their needs met.

Whether somebody lives in the community or in a group home setting may impact whether they are more or less likely to go into the hospital for a mental health crisis. A history of mental health hospitalization or going to a hospital for a mental health crisis will protect more likelihood of returns.

So we want to think about people who are in that cycle of going back and forth to the hospital. And also whether police have been involved can be another driver of being more likely to end up in the hospital for mental health crisis and frankly also what makes them more likely to be arrested for mental health crisis or have a police contact.

Other things can make it easier to stay out of the hospital during the mental health crisis, like having a family doctor who supports a very well integrated plan and or having a crisis plan. So the individual can preplan how to best respond and how to look at what a crisis looks like for them as an individual.

There are crisis models that are out there and that are emerging even more. For example, the -- start model, CCBHCs which have standards and one of the standards are they must include crisis services and must serve anybody who comes to their door for an assessment. And other models that are emerging.

And we know there are pieces we can take from emerging models that help them establish more success in responding to crises. One is having system connections. People come into crisis with all sorts of needs. It could be that they have housing needs or food sustenance needs or they could have I/DD needs and mental health needs and we need those systems to be connected. We are seeing a lot of that with youth in schools, for example the inclusion of physical health. There's lots of discussion, and we working at the National Association of State Mental Program Directors to think about what are the medical services that are needed to help people in behavioral health crises. They will also need the success will be determined by having many available surfaces because different people will have different needs and we need to make services available to meet the unique needs of anyone who comes in for a crisis response.

We also need trauma informed response. We can say that the number of people who are struggling with mental health and IDD issues who have histories of trauma either and are they develop until years or as adults are enormous if not everyone has some degree. But because it is so common we need to make sure the supports that are offered have a sensitivity and are informed by the literature on how to address trauma in those moments and how to be trauma informed. And how to refer people to trauma specific therapies that are appropriate to their unique needs.

And also, we need to look at evaluations. Successful evaluations will help drive the next step in care planning for people. Does the evaluation work? Is the evaluation geared for somebody with these complex needs in this population? And if not, what changes do we need to make to ensure that our evaluations drive the conversation forward in a way that will be impactful and positive for the individual who is coming in for crisis services or being seen for crisis services in their own environment.

What does this literature mean for clinicians? Really, as a clinician, trying to think of some things that might mean but as I'm talking would really love to see in the chat: what have I missed? What have we missed? What more can you think of? What can you tell us that you need and what the literature tells you, what does it mean for you?

Some of the things we thought about are that clinicians do need to gain additional knowledge and training about I/DD and mental illness and what they look like when they cooccur. And what they look like even separately. It will help, getting that additional knowledge without conditions do better supporting people. We also need to realize that Clinicians may need guidance on persons and practices as I said. Many clinicians in the mental health field or working in settings where crisis is be responded to might not understand person centered practices.

Also, clinicians can ask people whether they have a crisis plan since we know having a crisis plan can help that person drive their own care in a person centered way when they are in crisis.

And clinicians should ask people about their living arrangement to better understand stressors and experiences because remember, that one piece of data that showed people living in group home environment or communities may have other, different stresses and that can help inform the clinician who is trying to figure out how best to support that individual.

I see some people putting in the chat, would love to hear more, from people, to put in the chat what does the literature show you as a clinician serving people with I/DD and mental health and crisis and what more do you feel like you need to best serve people?

Alright, as you are thinking about that, I want to turn it over to my colleague, Ren Koloni who worked with us very carefully and did a fantastic job helping to develop a crisis plan and show us what their experience is. Let me describe Ren.

Ren Koloni is a program associate with CommunicationFIRST, one of The Link Center's partners. They developed a guide for people with I/DD to learn more about crisis plans using knowledge they have gained from their own lived experience. I'm really excited now to turn this over to Ren Koloni.

REN KOLONI: Hello everyone! My name is Ren Koloni and I use they/them pronouns. I'm a fat, white, non-binary person with rectangular glasses and soft dark hair, half of it shave half of it in a long braid. I'm rocking gently back and forth.

I came into this conversation as a program associate with CommunicationFIRST, 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 IDD have speech disabilities, and not all people with speech disabilities have IDD. But across these communities, we have many things in common.

The ways we live, think, move, and communicate are so often met with communication, discomfort, fear, or abuse. And 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 weather the suffering or heal from it. The Link Center is doing work that I believe will start to change that. As an autistic person with complex post-traumatic stress disorder, dissociative conditions and a handful of other psych disabilities I know firsthand the importance of this work.

In many ways, I've been lucky. I have never been hospitalized or institutionalized for my psych disabilities. Though I am a part-time AAC user, I have never had my voice taken away from me because it was deemed a safety risk but I 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, don't have that support system. So, I count myself lucky, but I've always lost months of time to dissociative episodes, months where I could not care for myself or take part in the world.

I've had breakdowns in bathrooms and bus stops, bedrooms and ballrooms. I've hidden common household objects from myself so I wouldn't 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 didn't have the money for the copay or a psychiatrist told me he didn't know what to say and that I didn't need to come back. Or a therapist looked uncomfortable and changed the subject.

All my care has ultimately come from me and a small circle of loved ones. I have survived but going through it so alone has been dangerous, painful, isolating, and exhausting.

Despite all of this, I still have enormous faith in the power of mental health care. I spent most of my time in college learning how well it works when we do it right.

And I've met so many professionals who really truly get it. It's impossible for me not to believe in that potential. But I also believe in the tremendous power and importance of sharing lived experience. When people with IDD who have been through crisis and suffering come together to pool our knowledge, we can create incredible change for each other and the peers we haven't met, too.

A few months ago, folks from NASDDDS's communication asked for our communication on supporting people with a crisis. I had a lot to say. I pointed out when we're in crisis the way we communicate often changes. 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 and even then, my words may be slow or difficult to understand for people who don't know me. Other people I know, no matter how they communicate, when they're 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're communicating. That means they also need to know how to respond when I do things they aren't expecting. For example, my rocking, flapping, and slapping helps me stay present in my body. We should never be viewed with fear or disgust for regulating during stress.

And we definitely shouldn't be restrained, isolated or assaulted. But for many of us mistreatment of all kinds is a looming threat never far from our minds. We can't afford to forget about it.

Here's an example. I wouldn't feel totally safe calling 988 just because of the chance 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 chance of police involvement as small as possible. Early data suggests 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 it can be inaccessible and hostile to people with IDD. I feel strongly that one of the best things we can do is put as many tools as possible directly in our hands.

For example, having a crisis plan doesn't fix crisis but it can make it so much 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 adapted them into a toolkit focusing on crisis plans.

The toolkit starts by explaining basic ideas about crisis in plain language. It offers tips on what people with IDD may want to include in their crisis plans 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 work well, along with a short version of one I drafted on my own.

When I'm in crisis, I need to know exactly what to do. I don't have the energy or brain power 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 I do and don't want and lays a foundation for some of the decisions I would make if I were in the right head space to make them. It also puts everything that other people need to know about me and my disabilities in one place. I also feel strongly that crisis plans should be adaptable for many different kinds of crisis.

To me crisis is stress that is unmanageable, overwhelming and all-consuming and that also puts me or others in danger in some kind of harm. The results that have stress are different spend depending on many factors.

My crisis isn't always about wanting to die. Sometimes, like with my dissociation, it's about not noticing I'm 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 isn't based on research, and it shouldn't be taken as medical or legal advice. Instead, it's 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 in 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 IDD 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 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 too. I think that people with IDD 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 doesn't have all the tools we need to heal, but I hope it's a good start. I'd like to thank The Link Center for including communication first as a partner. If you'd like to learn more about our organization and our work, visit our website at communicationfirst.org.

And I'd also like to thank The Link Center Steering Committee for the knowledge they're sharing. This is vital work, and I'm grateful to be a part of it. One last thing, to everyone listening who has experienced crisis, I want to thank you too. I say that The Link Center's 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 this beautiful world of ours. Thank you. I'm glad we're here.

STACY NONNEMACHER: Thank you so much, Ren. I have learned so much from you and from Monica hearing your story, particularly around potentially difficult topics. I once again want to thank you for being here and for showing up. I hope the rest of you have pulled some practical recommendations to consider as we support someone, as we plan for crises. And the two resources that Ren mentioned we will pop those in the chat for you all. It is two resources that make up the toolkit. I am going to show you. Two screenshots. First resource, Making a Plan for When I Do Not Feel Okay is really a robust crisis plan that Ren has put together as a result of their research. And looking at what is out there.

I think it is such a beautiful contribution to what is already out there. It is something that I definitely think you should all take a look at. The second resource that makes up this toolkit that Ren was talking about is what to do when I do not feel ok.

These are some big ideas -- for people who can use and potentially benefit from crises plan and those of us who support them. This guide looks at starting at the beginning, what is a crisis? Why do I need a crisis plan? Who can help me and what should people know about me and how to support me?

Again, we drop those into the chat. This is the place that Mary mentioned earlier and I know Deb and others have said, this is shared learning groups. Certainly we are looking for you all for feedback on the things that Ren has developed, taking a look at the things Ren has developed and what is out there and letting us know as The Link Center, what are some things you are identifying that are not out there? That would be so helpful to your role as a clinical practitioner, clinician who is supporting somebody, helping them plan for potential crisis helping them through a crisis.

That really would be a way that you all could be engaging with us at The Link Center so that we can be elevating things that are out there, like the psych sample crisis support plans and templates that are out there that Ren mentioned. That are also contained within the resources that we put in the chat.

Where are some gaps that you are seeing? We can elevate some things and see if there are some ways for us to really take some of that feedback that you all have for action

Speaking of action this is where we are going to bring all of you into the conversation and pave it to a group exercise for the last half hour or so that we are together.

ACTIVITY: CAPSULE EXERCISE

What we are looking at, this is called a capsule exercise. Simply put it is a structured conversation that we are going to facilitate with you. Thank you, Monica for coming up. Monica is going to help me introduce this exercise as well.

It is really going to center around what we consider to be a relevant, relatable challenge issue that I am sure and I am also hearing through some of the chat and some of the Q&A that you have already been thinking about this particular situation that we will share with you in just a moment.

We will present this challenge, we will present this issue with a focus on, having a few volunteers, three at the least maybe five at the most, who would be what we are calling "reactors." These are people who will take this issue on as if it is their own and start brainstorming amongst one another about what some ideas are, what we can do here. Brainstorming solutions. Because where there is a challenge, where there is an issue, where there is a barrier we should also be seeking solutions. Hopefully, those of you who are willing to come up and do this exercise with us will be modelling that problem-solving approach, bringing ideas, getting the wheels turning around how we could address these problems?

I will also say the rest of you will be witnessing this. For those of you who do not volunteer, I am sure you are going to have some ideas or go to strategies and solutions if this is something you can relate to.

We are asking you to put that into the chat. We want to have some conversation and engagement with you all that are in the chat. Those of you who are volunteering, pay attention to the chat as well. No pressure. Earlier today the Direct Support Professionals really stepped up and we had an amazing conversation around their issue and to challenge!

Before we ask you to either raise your hand or ask to come off mute, I am going to ask Monica to read the challenge or issue that we develop for you all and that may spur some interest in those of you who will be willing to step up and be a volunteer.

Monica let me pull it up. I will turn over to you Monica.

MONICA: This is the exercise and feel free to answer, to ask questions.

As a mental health practitioner, I have very little experience supporting someone with an intellectual disability. Recently a person from Rose's group home brought her to my office because she has recently been diagnosed with depression and anxiety by her PCP.

The staff person seemed to think it was important to be in the room and while I would normally engage someone who is struggling with depression and anxiety in cognitive behavioral therapy, or CBT Rose does not like to talk to people they do not know and I am not sure CBT would make sense for them. What should I do?

STACY NONNEMACHER: Thank you, Monica. As a reminder, if we could get 3 to 5 people who would volunteer. You can stay off video and open your mic but please go ahead and raise your hand. Or asked to come off mute and we will bring you up as a reactor.

OK, thank you, Erica. Wendy.

SPEAKER:

I was going to suggest that the clinician might want to talk to the staff. Who is with Rose. Usually the direct staff know people pretty well the stop just to see what her coping skills have been, what she usually communicates with folks, if she is involved with any kind of counselor, what coping skills the team has supported her with in the past. I would just be asking a lot of questions at this point to find out what resources this person has.

STACY NONNEMACHER:

Thank you for jumping in, Erica. I'm going to go off mute, I know Erica and Wendy were reactors. I think I saw third person raise their hand. OK. Maybe one more person interested in brainstorming here with Erica and Wendy? Thank you, Debbi. Alright, great.

I'm going to go on mute so that Erica, Debbi and Wendy, you can have a conversation and I don't want to lose what Erica sat around talking with staff and getting more information, particularly around coping skills, communication, etc. So I promise to go off and you know and Shonda, also. Thank you.

SPEAKER:

I was going to say let's talk to the person. Let's talk to Rose and explain it to her and get some feedback and maybe not assume because she doesn't like to talk to people she doesn't know that she would be interested or willing to engage with you. In that way.

SPEAKER:

Absolutely. And also asking Rose how she sees, what are her ideas so she can participate in the discussion and the treatment and the plan. Moving forward. It would be difficult to go into a conversation with somebody you don't know that had just been diagnosed with depression, anxiety, and trying to muddle through those feelings with somebody you don't know. She has a safe person she could identify and that person could be part of those meetings or discussions or sessions or whatever.

SPEAKER:

Making time to get to know each other before jumping into therapy. A little self-disclosure and allowing some bits about who I am as a person and to build a relationship.

SPEAKER:

I'm not a clinician who would be administering CPT but, this clinician says "I don't know if it's right for her."

What other resources or other therapies could be tried? There's a million different therapies. (Laughs) That maybe could be utilized to be more suitable for Rose.

SPEAKER:

Yeah. Somebody else said in the comments "take time to create a trusting relationship and then ask." Some consensus. Other people were part of the conversation. I don't know…

SPEAKER:

I would. I agree, talking to the staff if they know a lot about everything. I also agree about talking to Rose. I don't think it is an either or. I think it's a conversation. You are both in there. And asking, what changes have happened lately? If we have recently started engaging with struggling with depression and anxiety, what changes have happened recently that might have triggered this? Is it something socially that has happened?

Did her best friend move out of the group home and we just assumed that didn't affect her? Maybe she's not feeling well physically which is now manifesting itself in this way.

I know sometimes when I get physically ill, it makes me feel or anxious. I think there is physical things that could also be or medical things that can also be triggering this as well. Definitely the conversation with the both of them, it is not a one undone and, it is ongoing.

There's lots of therapies out there, not just CBT, but don't just assume she wouldn't be able to make sense of CBT because she has an intellectual disability.

SPEAKER:

The other thing you noticed is the staff person thought it was important to be in the room, but does Rose agree it is important for the staff person to be there? She want them to be there? Because they have a relationship, is it a safe relationship from Rose's perspective?

Find a way to get to that also, I think that would be important.

SPEAKER:

Right. Maybe Rosemont the different staff member with her, not this particular staff because just like we have favorite people, I know the people I've worked with in the past have theater people as well unfortunately, I'm not the favorite all the time!

SPEAKER:

Absolutely.

SPEAKER:

She might just want the intimacy which she does not want anybody there so that is good that you pointed that out because a lot of times when we support individuals with intellectual disabilities, we always assume we need to be there 24/7.

Not really allowing the person that intimacy in the one on one because that is like with any of us, we are going to have a conversation and you might have family member sitting there providing their two cents so just being there makes things awkward.

And I also agree about the whole medical thing. Following up to address that first. Because someone had mentioned, if she's going through something medically, like you mentioned it can manifest where now we are more anxious. Now we are more depressed.

So definitely rule out the medical. And I know I'm kind of tying in towards the end but also just letting her know who I am giving her reassurance that this is a safe space and just kind of seeing what her needs and priorities are and like before, asking if she felt comfortable with the staff present, but then also checking out with the staff afterwards just giving them the clinical insight.

But also letting the individual know that whatever is disclosed is going to be between us.

SPEAKER:

Absolutely. Trying to help build a safe spot for her.

STACY NONNEMACHER: Just wanted to point out to our reactors is a lot of chatter in the chat if you wanted to take a second look at the ideas and solutions that people are offering there that you might want to react to as well.

SPEAKER:

I did look at a lot of that it was coming in and there's a lot of things, I think most have been discussed but not all.

SPEAKER:

I see Aut Play. Never heard of this.

SPEAKER:

One of the comments was that it is great for kids and the other one was make sure to use nonverbal as well as verbal communication. Don't rely just on talk therapy. I'm not familiar with that either.

SPEAKER:

I am on their website. It says it's a framework for implementing Play Therapy. Mental health needs and neurodivergent children, looks like it's mostly for individuals 3 to 18.

SPEAKER:

The chat says specifically for neurodivergent children. Does this say how old Rose is? I guess she is in a group home so that gives us some idea.

SPEAKER:

The other thing I think we all alluded to but didn't actually say is that we always need to keep in mind that individual, the individualized thinking. What rose wants as well as what she needs. We need to come up with a plan or help rose figure out what she wants to do and how she wants to proceed. In everything that we do.

Everything is highly individualized. There is great generalized things but in the end we need to come up with something that is individual for her to help her get past her depression and anxiety.

SPEAKER:

I think somebody else said they were not a clinician who would do CBT and I'm also not trained to do CBT, but is it a practice that could be modified for rooms in some way? -- Modified for her in some way? I think most can be modified to accommodate a person's needs. Somebody says yes?

SPEAKER:

Brandy says yes.

SPEAKER:

For adults to help them communicate. That could be an interesting… (indiscernible)

SPEAKER:

If you can share the link that would be awesome.

SPEAKER:

Above that it says more time for the appointment. That I think is definitely true because of a possible communication delay. It is going to take longer to get to the root so allowing more time for those appointments.

SPEAKER:

That's a good idea. I never would've thought of that.

SPEAKER:

It's interesting, as we talk you wonder how much time we as clinicians really sit and think about that because we are also pressed for time and it feels like, I think that is one of our biggest issues, especially with the workforce shortages we don't take the time to individualize our approach and think through all of these things.

Things don't come in the nice, succinct paragraph I don't know that we always give ourselves, it is not a luxury but the time to really think this through. That might just be something to think about when you think about resources for The Link Center is how do we, are there tools to think through that process?

The short questionnaire you can go through to kind of challenge yourself on, other accommodations I can make? Are the people that should or should not be present in the room? Have I explored the person's preferences for communication or needs for communications, preference for treatment? Do something like that exist?

I see there are several people in the chat. I don't know if anybody addressed that.

SPEAKER:

I think there are many different tools out there. That have all of that available. I don't know if it is all one package or kind of a build your own as you are going. Peace and parcel from this and that to make what you need specifically for you and your clients in therapy.

SPEAKER:

Mary said the resource Andrea that you shared has many such considerations.

SPEAKER:

I look forward to diving into some of these more when we are done here.

SPEAKER:

I see Amanda said nontraditional activities. Sometimes if you go for a walk, walking and talking. The walking facilitates the talking.

SPEAKER:

I do not know if any of you have had a client participate music therapy. I got to witness that earlier,. Last year actually. The client may be did not put the specific scenario but in the 30 minute session I saw her open up so much. My jaw dropped I think and I got teary eyed (Laughs).

I feel like you mentioned nontraditional activities, I feel like there is a lot of that out there that could be beneficial. Some people don't have something meaningful going on in their lives so to help facilitate what is meaningful to them, and certainly help in this situation.

SPEAKER:

Music therapy is powerful and it can reach people in a way that nothing else can. A that very early in my career. Huge proponent, huge believer in it.

SPEAKER:

When it comes to music therapy do you send the person to a music therapist or is that something you can add on to your credential by doing resources and finding literature?

SPEAKER:

The one we worked with was a certified music therapist.

SPEAKER:

I have seen a used and a lot less structured way, music being able to bring people together or to engage in a way that would not otherwise. To call it music therapy you really have to have a therapist but there are ways you can incorporate music into a lot of different group sessions especially.

SPEAKER:

I wanted to piggyback what Ren put in on the track. I have worked with three people who use the communication device. The first person I ever worked with I was actually direct care. I do remember going with her two appointments as her direct care staff.

I would have to advocate for people because they would look to me to answer as she is trying to answer. I would have to say, "she is working on it you just have to give her a minute."

The importance of if somebody is using the communication device, sitting and waiting patiently for them to gather their thoughts and put it out. It is not easy to get that information on the board to get it to talk. As therapists we need to be quiet a little bit longer than we are used to probably.

SPEAKER:

Just to tie into that, I noticed that a lot where if someone has a direct support staff present instead of addressing the individual directly they will go to the staff member and disregard getting the feedback from individuals. Even if they are verbal or nonverbal, I still recommend talking to the person first and then talking to the staff as opposed to talking directly to the staff (Laughs)

SPEAKER:

. Exactly.

STACY NONNEMACHER: Amazing conversation and ideas and resources being thrown out there. That I know we are all going to be adding to our toolkit.

One more minute, and the last thoughts? Anything you want to rise up from the -- chat

Only to say there is so much good stuff in the chat and I am sure we are all capturing it.

STACY NONNEMACHER:

Thanks for asking Wendy. And thank you to the rest of the reactors for being brave enough to come up and volunteer. For those who were engaging in the chat, I think we heard a lot of really amazing ideas and resources, things that we can be thinking about.

We heard some strong themes here around the importance of building report and including the person, being individualized in our approach. Focusing on modifying mental health practices for people with ADD.

There is a lot of resources in the chat for that as well. Good ideas that were put out there are around communication, modalities, more time for appointments, have the therapy happen somewhere else.

I love the conversation around other meaningful activities and therapies and how that can be woven in as a complement to the therapy at hand.

Thank you so much for everyone. That was beautifully capturing the need for multiple perspectives when we are facing things that may be challenging us as clinical practitioners and clinicians. This really intent was to show how if we open the lens, we do not know the background of all the reactors or people in the chat but it really does help us get out of our own way, frankly." Our assumptions and biases to the side so that we can really look at all the solutions that are out there and think outside of the box, if you will to support someone.

Thanks everyone for joining in around that. Hopefully you got a couple of extra resources and ideas for yourself for going back to do the work that you do.

We are going to wrap up our time together today. I know that you all have been amazing with doing this throughout our time together, but here is another prompt and an opportunity for you to get your go to resources, training's website any information or places you go when you are thinking about supporting someone.

Whether it is crisis planning or crisis support. That full continuum, that Deb talked about earlier.

The crisis research we mentioned here and others, we are tagging them for all audiences and to have that up on our website, which will be coming soon we promise.

CLOSING

We are going to take today, all of this really great feedback and sit with it and elevate what exists that we have not already identified. We are going to take other pieces for action. Again, as we said in the introduction and we will say it again at the outset; we are really interested in taking the feedback from the people who participate in these shared learning groups and diving into them.

As The Link Center and really identifying, embedding things and taking into account the things that you have identified in your role that there may be gaps or needs for you to do your work.

Until that website is available, you can reach us by emailing us at thelinkcenter@nasddds.org

We have quarterly shared learning groups now, starting with this one. We are really excited to have so many people up here and so much engagement in the chat and in the exercise today. I have learned so much and just creating this content for you all but also from this conversation today and in January we will be talking about. The importance of supports for trauma in April we will take a look at supporting someone through transition when we say transition we mean across settings.

In August we will meet again to talk about supporting in person. Thinking about integrated care, multiple perspectives like we just practiced in the exercise, teaming.

We would love to have you join us with these additional shared learning group opportunities.

Because you will be getting the PowerPoint, here are the resources that Doctor Pinals used in talking about the research around crisis planning and support.

Again, cannot state it enough we are so very grateful to the contributions of Monica and Ren in developing the content for today and being here during these meetings. Emily Brown is also part of the steering committee and although they were not able to be with us today, they have a very critical and in the development of this content and the focus of crisis support and planning. Certainly all of the partners in The Link Center. Mary went through them and there are many people to be thinking for contributing to all of this content and preparing to talk with you at -- thinking

Last housekeeping before I let you go. Just to remind you as Stephanie mentioned, we will be sending an email with all of the resources including the PowerPoint, including what we put in the chat.

We will send you the recording and the transcript and an evaluation. We really acknowledge that this is our first foray into shared learning groups and we acknowledge that they could be evolving because we really want to make sure that these are meeting your needs. And that we are really in tune with what the different audiences need from DSP, clinical practitioners and clinicians to individuals with lived experience and families.

Long and short of it is, please take a moment. You have already given so much of your time to be with us today and be engaged and participate but we are asking you for a little bit more of your time. When that email comes through, take a second and go through the evaluation. We will take a really good look at that.

Thank you so much to everyone for all that you do and for finding the time away from the important work that you do and being with us today. It has been an incredible and informative time. Have a great rest of your day and thanks again.