

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 by clicking on the Q&A function at the bottom of your screen.

Following the webinar today, you will receive an email with the material we 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, I'm 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 Ren, 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.

PRESENTATIONS

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 lived 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 partnership 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 honor 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 honor to turn this speaking over to Stacy.

DR. 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'm going to describe myself, I'm a middle-aged white woman with brown straight hair, goes about to my shoulders. I am wearing glasses, and I am wearing a multicolored shirt, greens and blues, and in front of a white background.

So we are going to shift the conversation now and really get into the topic that we wanted to bring to you all today, which is supporting someone in crisis.

So why are we talking about supporting someone in crisis as it relates to people with I/DD and mental health support needs?

Well, we know that, and Monica did an amazing job of pointing out that crisis looks different for different people. We bring our experiences, our histories, our perspectives to the table and really that is our relationship and that is how we talk about crisis. How we think about crisis.

And again, Monica pointed out her relationship to crisis both personally and professionally.

And so, to kick us off, and we are going to use the chat so hopefully if you are comfortable using the chat, if not you can ask to come off mute. But to kick us off, we really want to ask you: what is one word, or maybe two or three words, that you would use to describe what crisis looks like for you? As someone with a lived experience.

So again use the chat, think about that. Ask to come off you'd -- to come off mute. What is one or a few words that would describe how you define crisis or what it looks like for you?

Overwhelming, frightening, complied to incoherence. Overwhelming. Melt down or shut down. Crisis to me means loss of control. Thank you.

So I want you artist -- you want to keep thinking about this, where you put it in the chat or not. You see some common words, you see some differences, but we really wanted to set the stage if you will, again the point B -- the point here being that walkways is considerably be defined as a time when things are not OK, what it looks like for you is how it is experienced and it is very individual, and it is based on a great number of things including the roles that you play, including the relationships that you have to crisis.

So as we move through this topic I want to just give you a reminder to take care of yourself, regulate, calm as you need, and we will repeat that as just a reminder just to be kind to yourself throughout today and as we talk about crisis.

I am going to turn it over now to Doctor Debra Pinals. She is a demand to the links that are, as well as a senior medical and forensic advisor to the national Association for State mental health directors and has a great deal of experience supporting people with co-occurring conditions and working with public systems. Doctor Pinals, I will turn it over to you.

DR. 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 certified behavioural health clinics which are coming out more and more across the United States and have a unique funding mechanism. But also have a mandate to serve anyone who walks in to be able to do that initial assessment. They also have a mandate to supply crisis services and include mobile crisis services and network with community systems like schools and police and others to help incomes for individuals.

What we know from these different models is that there are elements of success that can be very helpful that we should think about as we build out our crisis services. One is that we know what works for system connections. As I said, having connections to schools, to local hospitals, to the local crisis centres. Those are all going to be very important because when an individual shows up with a crisis or in crisis. though systems might need to be leveraged to get that person what they need.

Inclusion of physical health so that we are looking at things from a biosocial perspective which... If someone is struggling with asthma or diabetes and at the same time feeling very stressed emotionally we can look holistically at that individual to give them the best services we can provide.

We also recognize we have to have in the pieces of success, many available services. Somebody might need transportation, and my need housing support or food support in addition to taking care of the mental health crisis. Having all of those services at the ready to help support that individual to help lift them up is going to be important.

Another piece for success seen in these emerging models is trauma informed support. We know that people with I/DD and mental health needs often have trauma histories. The supports that are put in place to recognize that, honour that and be trauma informed and how they deliver services.

Another piece for success is the role of the evaluation. When somebody walks in the door, in crisis if I am doing an evaluation or clinical assessment of their needs, if I am not doing it right or asking the right questions or tailoring my evaluation to address the I/DD and mental health needs of the individual, it may not work. We may not get to a good plan.

I need to look at what changes might need to be made and how I approach a valuation. We are hoping to get more resources out to help the field improve and use these pieces of success to build up the crisis response continuum.

Next slide?

What does this mean for people with lived experience?

As I am speaking it would be great to see in the chat if you have other ideas. For what all this research means to you. Put in the chat any of the ideas that you have, or raise your hand and we can have you be called upon.

One of the things we thought about is for people with lived experience it is important to have information about how best to communicate and feel supported. That can help others around them be more helpful. If you show up in my crisis service and you provide me with information about how best to communicate with you and how best to support you, it will help me and guide me to be more person centred and how I approach support.

Also crisis planning and the support of DSPs in clinical staff can all work hand-in-hand as people learned to support the person in need. -- We all need to know that we have to work hand-in-hand. That is what the literature shows. We need to offer more education and support to the supporters so we can all work together.

My last thought we had, certainly not the least is that sharing important information like one's living situation to understand the context, how the person feels most supported and any information about their history if they were in prior mental health crises or please contact would be helpful as we address that support in response to helping improve future outcomes as well.

Is there anything that we have missed here? Is there anything that rings true to you or things that you would like to add relating to how the research feels to you and what other things you might think about?

I will give a few moments for people to respond. If they choose.

It is a lot of information to take in and we certainly can hear your feedback throughout the presentation so no pressure on responding immediately. But think about as you are listening if there is any information you think is helpful for people to understand what all this means for your lived experience? That would be fantastic.

Let me read some of the responses in chat. And acknowledge them. We heard people of lived experience welcome more specialized training to operate in a clinical setting as will support. That is a great comment.

Somebody else wrote, "I have a specific environment, my apartment that is evolved as a process of years of personal development crises and the living space nurtures and I can be alone, private and at best quite and productive."

I think that is so important to think about, how our own living space can be that nurturing environment that we need. That is an important element in crisis response, honoring and respecting what the elements are in our environment or people or other tools that you will hear a little bit about the Ren that can help support you in those crises. I will turn it over to you, Ren.

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 shaved 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.

DR STACY NONNEMACHER:

Thank you so much Ren. I appreciate you sharing all of that with us, and also sharing your experience and the time and energy that you put in to developing these resources for us. I know some of you have already asked to see the resources that Ren has developed, and we are going to put them in the chat for you.

I do want to just talk a little bit more about the resources Ren developed, and I think Ren talked about some things that you all can consider in planning for crisis that are captured in these resources.

The first resource, What to do When I don't Feel OK is really a large crisis plan, or I should say comprehensive or very thorough crisis plan.

Step-by-step, how do we know when I am not OK? How do we know what support I need and how I am going to communicate during this time?

So that is the first resource that Stephanie dropped into the chat. Go ahead and download that. Let us know if you have problems downloading it.

The second resource Ren created is called What to do When I don't Feel OK. And these are big ideas. Really it is a guide for you. Around crisis and crisis plans. Start at what is a crisis, why does it happen? What's a crisis plan? Why do I need one?

At the end of this resource, again that's the second one Stephanie put in the chart. There is a sample short version of a crisis plan. So something you may need in the moment real quick to give somebody, so you might choose to have a shorter version.

But really the intent here is for you to have resources and different types of plans to find one that works for you.

I want to repeat what Ren said. To really think through these things about what you would need if and when a crisis would happen, when you are feeling OK.

So here are three other crisis plans that Ren had identified that are out there. When we send you the PowerPoint you will be able to access these three crisis plans online. Or if you type any of these into Google now I am sure they will pop up for you.

We are going to continue to really keep our eye on what is out there by way of crisis plan, and additional information that we will be sending out and will be part of the website that Mary talked to you all about.

ACTIVITY: CAPSULE EXERCISE

OK, we are going to switch gears for a moment here. This is the group exercise that we talked about, and we think this will be a really good opportunity. This is the sharing part of Shared Learning Group's. This is the we are also learning from you, and in doing that we are going to center the conversation around a relevant, may be something you can relate to, situation.

We will present the situation to you all, and we are interested if anyone would want to volunteer, go off mute, come on camera. No pressure with any of that.

What we are going to do is present the situation and people who volunteer can help us really think through solutions, help us think through ideas and how to support this person who we are calling Joy. Joy is her name.

So you can volunteer, I will have Monica in just a moment read through the situation or issue that Joy is having.

If you don't want to volunteer, if you don't want to go off camera or go off mute, you can also use the chat and we would love to hear some thoughts and ideas and solutions you all may have from you or an experience, or just from thinking about the situation we are going to present to you.

So again, I'm going to remind you here. This may be something that relates, that you relate to. This may be something that is potentially triggering and hard to hear, but take care of yourself, regulate as you need, calm as you need. So just as a reminder to do that in this last piece of time that we are together.

Monica, you want to go ahead and read the story?

MONICA WAFFORD:

I see in the chart about getting in the way mandatory reporting. Mandatory reporting and HIP PA do both get in the way when you are seeking help for people with crisis.

I have had this experience many times and I would hope that the organizations would put together a plan for addressing or maybe you can become familiar with your agency or organization's plan for dealing with confidential information and privacy.

I also want to put into the chat of resource that I know about because I also saw in the chat there is someone here who is from a rural community and I am familiar with a lot of people who are homeless now who are quickly making up the homeless population with people with disabilities.

Everybody is not going to have a telephone is what I am hinting at. Am also going to put in the chat resource that I used in the past of learning how to work with the homeless. And that is the national care for working with the homeless organization.

DR STACY NONNEMACHER:

Sorry for interrupting and I am glad you tended to the comments in the chat, I appreciate that. What a wonderful point around mandated reporting, mandatory reporting, HIP PA and privacy... That is something that we are really going to take for action.

MONICA WAFFORD:

Joy has a history of reaching the crisis line 3 times a week. The crisis workers know she lives alone and is very lonely so may allow her to talk for 10 minutes. Joy's crisis plan includes calling the crisis line if she feels suicidal.

Today she is having suicidal thoughts and is trying to call the suicide prevention line but they think that she is just doing it for attention. What should Joy do?

DR STACY NONNEMACHER:

Thank you Monica.

Is anybody willing to come off mute? Come on to video so you can raise your hand as if Stephanie is saying in the chat? You can ask to unmute if you would like to volunteer and have a conversation with us about, if you were Joy what would you do?

Or if you are Joy's peer. What is some advice he would give Joy?

I am seeing some folks raising their hand.

Mike?

SPEAKER:

I live in Pennsylvania, Lancaster County and I will call the crisis prevention line in the nighttime. If being alone, sometimes feeling isolated what I do is get a good sense of how busy it is.

Sometimes it is staff with only two, three, sometimes only one individual. I feel a sense of checking in. Though three or five years ago there have been times, it is difficult because of boundaries. I do not really understand often...

I do not feel that I have a legacy of suicide I feel overwhelmed. I do at the moment actually, I really (indiscernible) here and I understand this scenario with Joy. I am trying to speak and understand how it has occurred.

Anyway, I am at home and I spent a lot of my day washing cloth and washing and getting an assignment done that I send off tomorrow. I am going to mute now.

DR STACY NONNEMACHER:

Thank you Mike.

I heard as a solution, as a strategy for you staying busy is helpful?

Do you want to respond to that?

SPEAKER:

What I want to say is as somebody who has to deal with depression for over 20 years, I have felt lonely and that I do not connect with people for years. When I am saying I want to harm myself I am expecting professionals to know that this is not a attention seeking.

If they identify that there is suicidal ideation, they need to take their roles and their position. You cannot say suicidal thoughts and just let it be this person is just asking for attention. Nobody that admitted to something as painful as being willing to take your own life, should be considered that you are seeking attention.

Especially from a team of people who are identified as crisis line. They should be able to identify that and take it seriously. If that person on that line does not do it, I would suggest joy to talk to another crisis support line.

That is very difficult. You do not tell people how you want to harm yourself, how do you have a plan? What are the steps you were going to take for somebody to consider you are just trying to get instead of your regular 10 minutes, a little bit more time. That is offensive to me.

I think once Joy handles or crisis she should do a formal report and say that was wrong. But handle herself first and come back to this violation of whatever code of ethics they have at this organization. Thanks.

DR STACY NONNEMACHER:

Thank you for that thoughtful response.

One of the things I want to point out and please correct me if I'm wrong, what is very important with lifeline workers is they are educated and trained.

There was a comment in the chat that I wanted to mention; everyone who calls a crisis line is "doing it for attention What is wrong with seeking attention or connection? It is a human need. "

Mike any reaction to that one?

SPEAKER:

I tried to be careful... If a crisis worker at three in the morning is having to other crisis experiences and he or she may have to parlay officers to an emergency scenario. I tried to make myself aware of that.

Attending to my life, I would rather do that myself. When other people do that, I feel imposed upon. At the same time, I check in.

I guess I need to admit, I have a reputation in Lancaster County at HMR. It is sad. I have not called for a while and to be honest with you I am concerned I will have a late night tonight because I have quite an assignment to do.

One of them is maintaining my home and I have been doing 80% of my time today. Anyway.

Announcement and attention, attending to and the making of announcements. (indiscernible)

Thank you.

DR STACY NONNEMACHER:

Thank you Mike.

I do not know if Lourdes or anybody wants to respond to Mike's point about relating to joys calling the crisis line, relating to how the lifeline workers are acknowledging joy and destroys situation. If you look we see joy situation is very lonely.

What are some things that perhaps joy or other people in joys life could support joy to do?

In the chat box related to that question, "are there services and supports available for joy to help her make community connections?"

SPEAKER:

I have two things.... Ineligible for the... Which may be helpful for Joy and it is one of my biggest pet peeves that the state of Maryland refuses to exist that people can be-- dual diagnosed.

We also in Maryland have an extensive network of wellness and recovery centres and those are open to anybody because they are not willing insurance.

At three in the morning that might not be the most helpful thing but I can tell you, half a dozen places within a half-hour drive of me that have either online or in person support groups. Right at the top of my head. But you need to know to look for it and if somebody is getting I/DD services, their whole support system is not aware of the other support structures. There is no cross to some education in this state. If you are not good at digging up the stuff yourself, how is your support system supposed to know?

DR STACY NONNEMACHER:

Thank you for that comment.

Another really good comment that we will be taking back to The Link Center for pieces of action on our end. I want to point out that the other comment related to my question about helping Joy make community connections, in the chat. Somebody said "this speaks to a lack of education on the part of the crisis line, an important part of their job should be knowing local resources that they can share with callers including places that can help support joys need for social support network. Why not refer her when she is calling in during a time that is not a crisis to local self advocacy groups for example?"

To your point about local resources and accessing local resources. Lourdes you have your hand up again, go ahead.

SPEAKER:

We live in California and we have the mental health aspect covered through generic resources like mental health providers. We have a very great team called wrapped around services. Those are for people who have been in and out of psychiatric hospitalization and they are going to need more follow-up.

They give you wraparound services.

We also have regional centres for the specific people with developmental disabilities. Regional centres only cover five different diagnostics which would be autism, cerebral palsy... I forgot the other ones I am sorry. I am not an expert.

What they do is and one thing that was done just recently, they allowed to cover for social recreation activities. We know that joy needs to be connected to her community. They could pay the local YMCA. She could go to the local support groups for doing something that she likes; -- art class, swimming class.

Whatever it may be that would help her feel connected, establish relationships and you could advocate to say "I need a personal assistant, a community integration support."

That is something that California is doing that I feel is making life-changing moments into everyone that is stepping into the (indiscernible) of services that are given by regional centres. That is something very unique to California.

DR STACY NONNEMACHER:

Thanks Lourdes, you bring up a point Cheryl brought up. That is being eligible for the services that are available. At the pace we can be looking at as part of our goal for system change with the link center. So thank you for sharing those services and supports that are available in California Lourdes.

I know in the chat someone said, and if someone gives a resource they should definitely follow-up to make sure the resource was available and helpful. I think that was a really great comment, especially if Lifeline workers, in this case if they are trained and knowledgeable about what local resources and community connections are available for Joy, may be following up with Joy. Seeing if she was able to access them, seeing if they were indeed helpful.

Cheryl, not sure if your hand is up or if this is a new hand for you. OK, thanks. I saw you took it down.

These are all really great ideas and comments around this particular situation. I know we have just a few minutes left.

You want to just open it up and see if anybody has anyone -- any general comments for consideration for The Link Center around the idea of crisis planning, crisis support, what is out there, what is not out there, things we should be thinking about, things we could be elevating or bringing up to others. You already gave us some really great ideas.

As we engage with Lifeline workers which is one of the things we are doing through The Link Center.

Listening to YouTube lectures within my specific interests and responsibility has been useful. Mike, I am assuming to really find ways to fill your time, meaningful ways to fill your time. I think that's a great idea.

Doesn't have to be in the community making connections, we can make some other connections. Virtually, right?

Any other thoughts or things... Something that hasn't been said that you are really wanting to put out there for us to hear.

Let's add a social recreation activities as part of everyone's plan. Lourdes says, remembering it is person-centered and individualized. What it looks like for one person may be different for another person.

WRAP wellness recovery action plan. Thank you.

The Native American healing center has great nontraditional methods without pharmaceuticals. Monica will share the website.

Cheryl, thank you for sharing the -- WRAP website.

Let's move away from clinical centered to self-centered -- to self-determined centered philosophies.

All really great thoughts, all great comments. We appreciate those of you who have been engaging, especially around the exercise that we created for you. And really the intent here...

Often times we get stuck when we are facing an issue or a problem like in this case Joy has, and it is so much better when we have other perspectives, other people's ideas and thoughts around it because sometimes, doesn't matter who you are. We sometimes have our own biases, we sometimes get in our own way and get stuck and cannot think outside the box. Or think of solutions. Ortega strategies to move forward.

So this exercise is to show we all collectively came up with some really amazing ideas. Things Joy can be thinking about. Things the crisis workers can be thinking about to support Joy.

So again, it is about widening our lens. It is about thinking bigger. Thinking outside of ourselves sometimes. And sometimes it is thinking -- it is bringing other people in so their eyes, and their thoughts and brains are also helping you think about that.

So I know all along and just here in the last few minutes you have been putting in some resources and information in the chat.

CLOSING

If there are any other resources, trainings, information that you go to for yourself when you think about crisis, crisis planning and crisis support, please continue to put that into the chat. We would like to take all of this information, we will take all this feedback, everything you said today and we are going to sit with it and take the resources and vet them and really elevate them and put them on the website if that makes sense.

And the other comments and information you bring up, those are pieces of information we are going to take for action as The Link Center.

Mary talked about the website where developing as The Link Center. We are so very excited for it, that is coming soon. Until it is available you concoct us here at thelinkcenter@nasdds.org. We welcome you reaching out to us. We want to hear your experiences. We want to get a resources information you want to share with us. So please feel free to email us there.

And we will have some more Shared Learning Group's. We will have another shared learning group in January, and we will talk about trauma and supports for trauma.

In April we will focus on transitions, so not just life transitions like moving from being a youth to one adult, but also settings transition. Perhaps moving from a hospital to a community placement.

And then in August we will talk about supporting the whole person. About how important it is to have all the right players at the table. How important it is to look at supporting someone holistically. That integrated care if you will.

So please, keep your eye out for the invitations. And please please join us for those shared learning groups.

Dr Pinals brought up a couple resources when she talked about the research. We put them in here for you as well.

And finally, just big thank you to Monica and Ren for sharing their stories and their experience and their thoughts around the importance of crisis planning, and some considerations for us all in supporting someone to navigate a crisis.

Also thank you to Emily Brown was also on the Steering Committee, was an important part of developing this content but unable to be with us today. And to all our partners to the link --at the Link Center for contributing to preparing for this meeting and all the other meetings that we have. Everyone has been amazing. I think across the board we have learned so much and it's been wonderful to hear from you all.

So just a last piece of housekeeping. There will be a follow-up email sent to you. It will have all the resources that were in the chat that we put there. So there were two resources there that we shared. We will also share the recording and the transcription, and the PowerPoint.

Now we already know you have given so much time to be here with us and talk with us about supports for crisis, but we will also be sending you an evaluation. And we acknowledge and we know the Shared Learning Group's will evolve, may change over time because what we want to do is we really want to meet your needs, we want to make sure this is a place where we can talk with the different communities in which The Link Center is going to be valuable for.

So please take the time to fill out the evaluation. We will be looking at these and it will inform our work moving forward.

Thank you all for taking time out of your day. Thank you for these wonderful thoughts and comments in the chat, as well as those of you who shared your comments and came off of mute. That was wonderful, thank you so much.

I hope you have a wonderful rest of your day. So very wonderful being with you. Take care!