THE LINKCENTER

Live Caption Transcript
Shared Learning Group for DSPs
October 24, 2023
Supporting Someone in Crisis

OPENING

STEPHANIE MOTE: Hello, everybody. Thank you so much for being here, for joining The Link Center for this Shared Learning Group focusing on supporting someone in crisis. I'm going to go over a few housekeeping items while we get started today, and then I'll hand it off to our first speaker.
We do have live captioning, and ASL interpreters present today. This session will be recorded and the recording and the transcripts will be shared with all attendees. The PowerPoint and documents that we review today will also be shared with everyone via email. And we welcome you to revisit the content yourself and share it with your colleagues.

Attendees cannot see the names of other attendees and all attendees are muted. You can see the hosts and panelists on video. We can unmute as we need. Please use the chat function in Zoom to communicate with all attendees and your hosts during the webinar. You can use the chat function by clicking on chat at the bottom of your screen. And please be aware your name will appear in the chat if you make a comment but you can change your display name by clicking on the three dots by your name and selecting rename. We will have representatives from The Link Center watching the chat and responding throughout the session today. If you'd like to submit a question or comment privately to the host and panelists you can do that by using the Q&A function which is also at the bottom of your screen next to chat.
Following this webinar, you will receive an email in the coming days with all the material that we review today, the recording and transcript as well as an evaluation that will ask that you complete in response to today's shared learning group.

At this time I'm going to hand it over to Mary Sowers, who's going to start today's presentation.

INTRODUCTION and WHAT IS THE LINK CENTER

MARY SOWERS: Thank you so much, Stephanie. And welcome, everyone, to The Link Center. For those of you that don't know, The Link Center is a technical assistance and resource center funded by the administration for community living.

And the National Association of State DD Directors in partnership with the National Association for Dual Diagnoses and National Association for State Mental Health Program Directors along with many important partners are really honored to be able to bring to you the first of our shared learning group series this week.

A moment to talk about the Shared Learning Groups. We will be hosting four meetings today and tomorrow aimed at different audiences, the direct support professionals, welcome to all of you who are joining us today, interested in that topic. Clinical professionals, individuals, and families.
We have kept the content of these meetings consistent, but will change the discussion for each audience to make sure that it's usable in your day-to-day experience and work. This content, the content contained for this meeting is really a collaboration among many of the link partners, including people with lived experience, people who are researchers and people who work on policy issues.

And I'd like to give a very special thanks to several of our partners who you'll hear from a little later today who are members of our Steering Committee, The Link Center is governed by a Steering Committee of people with lived experience which we'll talk about. And of course as Stephanie mentioned, we will record and transcribe today's meetings and the materials will be sent to you after through an email.
We encourage you to share that and revisit it and really use it as a source for your own interactions day-to-day.

I'm really honored to introduce my colleague, Monica Wafford. Monica is a member of our

Steering Committee. As I mentioned, The Link Center Steering Committee is a committee comprised of people expressly with lived experience and importantly, it's made up of people from across the United States and it is really serving as a key guide for all the work that The Link Center will do.

We've just completed our first year, and the Steering Committee has already made important contributions to how we think about teeing up the resources and information that are going to be most helpful as we really strive to bridge the gap between mental health systems and supports for individuals with cognitive disabilities.

So I'm really honored to be able to introduce Monica Wafford. Monica serves as a community advocate for victims of violent crime with central counsel and Indian tribes in Alaska. She serves as coordinator for state of Alaska senior vocational services. She has been a certified peer specialist since 2007. I'm honored to hand over the speaking to Monica. And I'll join you back in a little bit. Monica.

MONICA WAFFORD: Hi, everybody. I am now retired. So I just want to make it clear that I am not in those capacities, although they have enriched my life so much. I wanted to say that the shared living experience that we're talking about in this meeting is about crisis and strategies people use to address crises.

So, we need you to take care of yourself and allow silence to be a safe space. Feel empowered to do what's necessary for your comfort and your care.

We like to offer that the 988 suicide crisis line is available now. It's nationwide. If you want to give out this resource, it's like the most available to clients or anyone who's experiencing crisis.

So we're going to talk about crisis planning and supports. And I really like for people to think outside the box when you talk about planning and supports. You can think of things like do you even know your organization's plan in case there is an emergency or crisis. Things like that are important for the safety of your team, yourself.

So just think one size does not fit all. It could be outside the box.

We celebrate our individuality, our diverse culture, and our singularity. So everybody's an individual and should be respected and treated as such. This is why we celebrate the discoveries realized in our collective humanity. We know that we are each unique with our own experiences in the world.
We empathize with experienced traumas that hinder our resilience. Some people have experienced trauma that makes it harder to move forward and to recover. This is especially I wanted to point out that's especially something for people with lived experience when we often practice with the people we serve, we sometimes forget that since we have lived experience, we could be struggling with the trauma of reliving that trauma, seeing it through other people, empathizing.

So we just want to honor that. We listen with our open minds, compassion, and without judgment or blame. And lastly, we reject failure, and we embrace hope.

You can put your name if you feel comfortable in the chat bar, any group you're affiliated with, association or membership you may have, you're welcome to add that to the chat. If you're looking for work, we're direct support professionals. Hey, I use LinkedIn, you know, use it to say, hey, I'm looking for work. That's fine.

We're going to talk about what is The Link Center. We're going to talk about why we support people in crisis, what resources, trainings, information are available to support someone before, during, and after crisis.

We're going to have a group exercise, and we're going to talk about challenges and solutions to supporting people in crisis. This will focus our audience participation and ideas. And I did forget to describe myself at the beginning. And I'd like to do that for people who are visually-impaired.

I am a light brown-skinned woman, I'm 65 years old. And yes, it true what you heard, I do look young. But other than that, I have on a gray dress, and I smile a lot. I'd also like to tell you a little bit about myself if that's okay.

So, as a person with lived experience I'm one of those people who has had suicide attempts that often comes with a diagnoses. Two of those attempts sent me to a psych ward, and I had two without any clinical intervention. So the two that I handled myself were my motivation for coming up with my own treatment plan, which I called prescription positivity.

This plan is an ongoing process of finding value in life, finding what gives life worth is like discovering a new currency for me. It's the value I place in being with my family, things like having them near me, the option I have as an American to decide what my personal space and my environment is going to look like and feel comfortable for me.

These are the things that I treasure and they give me strength and reason and purpose. When I felt I couldn't go on with life, when I had those attempts, I determined that the reason I couldn't go through with my plan to end it was because I valued these treasures in my life more than I did 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 make my life worth living gave me the strength I needed to live my life. I felt a familiar hopelessness that sent me into crisis mode. When that happened I remembered those things that give my life value.

I became a certified peer support specialist when I learned I had the ability to empathize while others around me were just sympathizing. I realized by being a peer support that I could share tools that worked for me.

In my insight gave me the ability to calculate the tools available for my clients' use and then to contribute to my or my team's efforts of helping that person see the worth in their own lives. I became focused early on in understanding resources within reach of a client. Customer service for me has always been priority. As I developed work ethics, it was important to know the benefits of everything a person has to offer and finding those treasures that each individual can offer is finding value. As a practicing peer for me it has always been a delicate balance between professionalism and self-care. Sometimes my empathy will trigger by own crisis. So my environment can be crushing or it can support me spiritually and physiologically. That's why shared learning to me is like nourishment for my brain and my Spirit.

MARY SOWERS: Monica, thank you so much for kicking us off today, both with your observations and grounding for the conversation we're going to have today but most importantly for sharing your experiences and how it's impacted how you bring yourself to the Steering Committee of The Link Center and we're really grateful for all the contributions you continue to make. So thank you, thank you.

As Monica went over, we will cover several of the things noted in the agenda slide you're seeing here. We'll talk about The Link Center as well as move into the discussion on supporting someone in crisis. And before we jumped into the content, I wanted to thank all of you for being here, being a direct support professional is one of the most important roles to help individuals really have good lives in the community, supported by people that care about them so they can build relationships and thrive.

The work you do in day in and day out is so important to that. So we're grateful for you to join this conversation today. And we'll wrap up the conversation with a group exercise really identifying some of the challenges and solutions around supporting people in crisis and really thinking about how to bring in the audience participation there.

As you're listening today and preparing for the group discussion, we'd very much like you to think about what are your go-to resources. Are there trainings that have been especially helpful to you? Are there websites, places to get information about crisis planning?

If you could have that in your mind's eye as we go through the conversation today, that will be especially helpful. We'll be bringing this question up again toward the end of the session. But I think you'll see as we talk about the role of The Link Center, why we think it is so important to really get information about what you as direct support professionals really find useful in supporting individuals with different support needs as they arise.

So, what is The Link Center? At The Link Center, we are extraordinarily grateful for the leadership of the Administration for Community Living for funding The Link Center. It's, as I mentioned at the top of the conversation, a technical assistance and resource center really aiming to bridge the gap between mental health services and supports and individuals who experience cognitive or developmental disabilities or who have communication differences.

And you'll see here The Link Center is truly fueled by partnership. As I mentioned earlier, NASDDDS, NADD and NASMHPD lead the group. But we have other partners. Green Mountain Self Advocates, the Autistic Self Advocacy Network, the National Association of State Head Injury Administrators, CommunicationFIRST, the National Center for Start Services, the Sonoran Center of Excellence and OSU the Ohio State University Nisonger center. All come together to bring pieces and expertise to this work so that we can really have an impact on several areas.

The goals of The Link Center are threefold. Our hope is to identify improvements in policies, service design, and service coordination in an effort to make systems change.

We know as a practical matter that sometimes people with intellectual and developmental disabilities or other cognitive disabilities have trouble accessing good solid mental health clinical services and supports. And we want to make sure that we have in our mind's eye improvements we can make to the systems both at the state and federal level, possibly the local level that can help individuals have meaningful access to the supports and services they need.

We're also hoping to identify resources that can help direct support professionals have the tools they need to be successful in their work as they're supporting individuals in the community. And we're also hoping to expand the access of clinical professionals who are able to support people who might communicate differently or require different time or accommodations to be able to engage in important mental health treatment.

And then finally, certainly not least, is to make sure that people just have access to the services that they need in a person-centered culturally appropriate way. So our goals are lofty. It's a five-year project. Hopefully we'll be able to make a lot of resources available during that time.

And the shared learning groups play an important role in that.

So our key activities are really rooted in ensuring that we've got an eye and lens on diversity, equity and inclusion in all that we're doing. And we're also, thanks to both our partners at the nice center at

OSU and all of our partners really trying to make sure that we're in a constant learning mode so that we are really engaging in a continuous quality improvement approach. And that holds true for the shared learning groups that we're starting today.

We're really hoping that this format works for folks but we're also really interested in your feedback so that we can continually improve how we're both sharing information and getting information from all of you to make sure that we have a really important -- a really impactful approach to the supports and services, the supports and resources that we're offering.

And you've met one of our Steering Committee members, although the Steering Committee is made up of 12 individuals. And it really is forming the guidepost for all the work of The Link Center. So we're really grateful for the participation of our Steering Committee. We also have a bevy of expert contributors.

Of course we'll have these Shared Learning Groups that will happen on a quarterly basis. We will have a website, that's coming soon. And through that website and other mechanisms, we'll be able to identify existing resources and hopefully lift up the good research that's out there but also identify places where additional research might be necessary or that there are other resources that can be provided. So our aim is to really try to make sure that information is available to as many people as possible to help individuals gain and maintain good lives in the community, getting the mental health and long-term supports and services they need.

Our hopes for the Shared Learning Group is we will share some of what we're doing at The Link Center related to supporting someone in crisis. And our hope will be that you'll be able to identify the importance of crisis support and planning for people with IDD and mental health for The Link Center and that you'll know where to find resources related to supporting people in crisis.

We hope to get your input related to supporting someone in crisis, including those resources that you might need that might not be readily available or those resources that you have found especially helpful that you think would help many other people.

In addition, through the group learning exercise, we're hoping to pose a challenge and have a groupthink on how to solve or make -- identify solutions to the targeted challenges through that group exercise. Next slide. And it's my great honor to introduce my colleague, Dr. Stacy Nonnemacher. Dr. Stacy Nonnemacher is the NASDDDS Director of Cross System Strategies and leads a lot of the work that has gone into the Shared Learning Group. So Stacy, thank you for your efforts and I'll hand it over to you.

DR STACY NONNEMACHER: Thanks so much, Mary. And thank you, everyone, for being a part of the inaugural shared learning group for direct support professionals.

I am a white middle-aged woman. I'm sitting in front of a white background. I have brown straight shoulder length hair and I'm wearing per usual for me a black shirt.

So, let's just kick off the conversation around why we're talking about supporting someone in crisis, particularly as it relates to people with cognitive limitations and mental health support needs.
So we know that people have different experiences, history with crisis and perspectives. And to really kick this off, this is the part of our time today, one of the parts, where we really want to ask you and turn it to you all using the chat and say what is one word that would describe what crisis looks like for you as you support a person in your role as a direct support professional?

I think Monica did an amazing job describing both her personal relationship to crisis as well as her professional relationship to crisis. And yet that's just Monica's experience. So just take a minute or so, again, using the chat if you would, and just think about what would be one word, maybe we'll give you one or two words that would describe what crisis looks like for you in your role as a DSP.

Thanks for kicking us off, Sarah. So Sarah says suicidality. First episode psychosis. Heightened state. Homeless. Big feelings. These are all great. Keep them coming. Hopelessness. Overstimulation. Dealing with loss. Loss of interest in usual activities.

So you can keep adding to the chat as you're thinking through this and how you would define crisis or your relationship to crisis in your role as a DSP. But really the point that we're making here is while a crisis can simply be defined as a time when things are not okay, what it looks like, how it's experienced, is individual, and it's based on a great number of things, including the role that you play.

We thought it was really important to do some level setting there as we go through the rest of our conversation today and as you'll see in the chat, just in the handful of people who have responded, crisis looks very different. Right? Again, based upon a great number of things.

I get to turn it over here to Dr. Debra Pinals, forensic psychiatrist and consultant to this grant. She is the senior medical and forensic advisor for the National Association for State Mental Health Program Directors and has a great deal of experience in supporting people with IDD and mental health needs and working in the public system. Deb, you're on next.

DR DEBRA PINALS: Great. Thank you so much, Stacy. It is really a pleasure for me to be here. Let me start by describing myself as well. I am a white female, middle-aged, with dark short hair. I wear glasses. And I am wearing a dark sweater and a pearl necklace, pearl-shaped necklace. And I try to smile a lot as well, although I know when we talk about crisis there's some pretty serious things and significant things that come up for people.

So, what I'm going to do is try and focus us a little bit on the science, the science and research on crisis services. We can go to the next slide. What we really need to understand is how do we find appropriate options for people with IDD and mental health support needs so that they can get support at every stage of a crisis. We need trained people supporting someone in crisis as well.

We know, and I certainly see very often, especially with my forensic background where I work with justice-involved individuals, that all too often, when there is a crisis that involves behavior that may be a challenge to other people to support, calls to police can be involved, and we see people with IDD and mental health overly involved with police because of that.

And we are working nationally to build out better crisis responses, including having non-police responses as much as possible when that's safe. We also want to make sure that people get the help they need in the right place. We know that emergency departments have been the default place where people go, and the emergency room is not necessarily the right place to manage an emotional crisis.

Emergency rooms are really good places when people need that type of emergency medical and psychiatric support. Hospitalizations also are really important when people need that level of care. But all too often we see that people wouldn't need that level of care, and then it becomes like a square peg in a round hole, you're getting the wrong care in the wrong place.

So what we really want to do is have a conversation to build out the right responses for people with unique needs. We all have unique needs. And limit inappropriate emergency department usage, hospitalizations, and of course police contacts and arrests.

And that means that we need more connections to proper supports in the community. It is the balancing test that really needs to be built up on the proper support side so that we can reduce those negative consequences.

And that will require a lot of conversation and understanding, and I'm hoping that through the shared learning group we will have more opportunity to build out better supports. We can go to the next slide. So again, focusing on the science, what does research tell us? Well, first of all, in looking at the literature, we know we need a lot more research to tell us what we need to know. There is a very important need for more information about how to care for people with IDD. But there are some interesting studies out there and some papers that are out there that give us some clues.
For example, we know that we need to do better at supporting and educating people who work in hospitals and to help them better understand and get more comfortable talking to and caring for people with IDD.

I work in an emergency department, and I have worked in emergency psychiatric care for a long time in my career. And all too often when somebody comes in with those unique needs, the staff may not have the education or experience to manage them.

And so the research and studies actually confirm this. We also know that people who help people in crisis need to learn the best ways to offer person-centered support and really need to understand what person-centered support is all about.

We know that every person is different and crisis care can reflect that. And my colleague, Dr. Matthew Edwards and I, wrote a paper on this for the National Association of State Mental Health Program Directors, and the federal government Substance Abuse and Mental Health Services Administration, which is partnering with us on this ACL grant.

We also know from other studies that there are some things that can make people more likely to end up in the hospital for a mental health crisis. And these are the kinds of things that if we understand them, we may be able to avoid the hospital level of care and avoid the crisis to begin with. For example, how somebody's disability affects them, whether they live in a community or group living environment, whether they've been to the hospital for a mental health crisis before, and/or whether police have been involved.

This is from a study published in 2012. Other things can make it easier to stay out of the hospital during a mental health crisis, like having a family doctor who understands the support needs and having a crisis plan in advance. And we're going to be talking a lot about that throughout the rest of this shared learning group. Next slide.

There are successful models that are out there for crisis services, the start program, certified community behavioral health clinics are becoming more and more numerous throughout the United States, and they are required to have an element of crisis services in them and to serve anyone who comes to them.
And there are other models as well. We know that some of the elements of success from these models that have been tested and true are having connections across systems. Making sure that physical health and behavioral health are working hand in hand so that needs can be met uniformly.

Making sure that there are many available services because it is not a one-size-fits-all approach. And of course making sure that services and supports are informed through the understanding that many people in crisis, if not all people in crisis, have some type of trauma in their background. So we need to be trauma-informed. And also looking at evaluations. How are we approaching our evaluations for somebody who's in crisis? Does our approach work? And if not, we know that for successful response, we need to make changes in how we approach our evaluations.

So what does this mean for direct support professionals? Well, just looking at my experience in working again in the emergency room and working with direct support professionals, I would, and looking at what the literature and science show, I would say perhaps direct support professionals should get the needed support to understand crisis plans for people they support, how they work, how does a crisis plan work, and where does it fit into the person's overall support plan?

Also if the person wants them to do so, a direct support professional could be supported and empowered to share important information, if the DSP is with someone at an appointment with the clinician. Often as a psychiatrist if somebody comes in with a DSP, if I wasn't working in this space, I might not know whether I can ask them questions and the DSP might not know whether they can share information. So that can be worked out with the person being spored.

This may help the clinician understand more about what is happening with the person. The DSPs have a unique role in offering information to others in a crisis that can help meet the needs of the person. And they can be a very helpful piece of the equation as we try and support sort through how to help a person in crisis.

I'm curious what you think in terms of the role of DSPs. Are there other ideas of what you think would be useful and that we might have missed in terms of what the research says for you and what you think the role of the DSP could be? Please feel free to chime in in the chat.

Great. Somebody says that they're trained in WRAP, Wellness Recovery Action Plan and ALGE, Assess, Listen, and Give Encouragement. That's great. Anybody else?

As you think of these ideas and as we go through the learning group, just know that 988 is that three-digit number that is rolling out nationwide, and for people in any type of behavioral health crisis, whether it's mental health, emotional or substance use related, and more and more mobile responses are going to be rolling out as well.

And these will require further research as we go, and we look forward to learning again from you in these shared learning groups. I now want to turn this over to my colleague Ren Koloni. Ren Koloni and I have gotten to work together along with Stacy and others, and they are a program associate with CommunicationFIRST, one of The Link Center's partners.

They developed a guide for people with IDD to learn more about crisis plans, using knowledge they've gained from their own lived experience. And now, Ren, I'll turn it over.

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

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

Not all people with 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. While we're still on the thank yous, I just want to say to both you and Monica, thank you so much for being involved with The Link Center generally and in particular with these shared learning groups. I've learned so much from you and Monica, and hopefully those of you who are in the audience as direct support professionals really gained some practical recommendations to consider as we support people to plan for crisis back to what Dr. Pinal said about the need for continuum.

The need to be really mindful about the process of planning for a crisis. As Ren mentioned about the toolkit that they developed, we will put it both resources, so there's two resources that Ren developed that make up this toolkit, we're putting it right now in the chat for you all to have. But really there's two restores here, and we're just giving you a taste of them on the slide.

But the first one is what to do when I don't feel okay. And this is the full crisis plan that Ren mentioned that they designed, keeping in mind what things are important to someone, what things are important to be in place, how can others be supportive, if and when somebody experienced crisis and to Ren's point, filling out something like this, thinking through this, when you feel okay.

So that's already in the chat for you all. And then the second resource that's part of the toolkit that Ren developed for The Link Center is what to do when I don't feel okay. And these are the big ideas. So really looking at this robust resource as a guidance if you will to talk about what is crisis, why does it happen, what is a crisis plan, why do I need a crisis plan. And as part of this particular resource is an abridged, a shortened version, if you will, of the crisis plan from the previous slide. So those are the two resources. They're in the chat. And again, a hardy thanks to Ren for really thinking through this and developing these resources that I think will be such an amazing contribution to the work that you all do in supporting people through crisis.

And certainly I'll echo what Mary said in the beginning. Today through these Shared Learning Groups is also an opportunity to really get your feedback. So in looking at these crisis plans and thinking about them as part of the work that you do in supporting someone, getting your feedback will be really, really important.

Ren also mentioned that they took a look at what really was out there in terms of existing templates or sample crisis plans, if you will. We're sharing three of them here. You'll have them in the PowerPoint when we share the PowerPoint with you all in the follow-up email.

We have also identified additional crisis plans and additional information that we will be disseminating as well as part of The Link Center's website and resources that we're putting together and disseminating. This also includes a crisis plan that was created by Dr. Joni Beasly who is the founder of START Services. And she'll be doing a training for us on that crisis plan next month. So keep your eyes open for that as well.

Okay. So, we're pivoting to the last part of our time together today, and this is really where we're going to call on you all to engage with us and whether or not you're going to volunteer to be part of this exercise or if you're going to be witness and we welcome you to engage in the chat so we would love to have you react to the exercise in the chat. Again, if you're not volunteering. But we're going to do a group exercise.

ACTIVITY: CAPSULE EXERCISE

It's called a capsule exercise. So it's a structured conversation that we're going to facilitate. And it's going to center around a relevant, hopefully relatable challenge or issue for direct support professionals. And we're going to present that challenge or issue. And Monica is going to help do that. Monica is going to play the role as a direct support professional, and what we're going to need from you all, by way of volunteers, we're going to need three to five people who want to volunteer as what we're calling the reactors.

So these are the people who are going to listen to this challenge or this issue with their direct support professional hat on, and really talk through different ways to come to a solution, different ways to generate some ideas around how we can get to a better place in supporting this person in the situation that we'll present to you all.

during this process, we invite others to write ideas and solutions in the chat. We want you all to be engaged and we want to get as much good thinking and brainstorming during this exercise as possible. If you'd like to jump in with us and volunteer to be a reactor, please raise your hand or ask to come off mute. And we'll ask Stephanie to choose a random three, four, five people who we can spotlight. And you can come off video or not. But again, as a volunteer, we're just asking you to listen to this challenge or this issue that Monica is going to present, and just in realtime, talk through it, offer some ideas, brainstorm with the other volunteers, offer some solutions.

So, anybody willing to come auto and hang out with us and volunteer to be part of this? I promise we'll be kind and gentle with you all. I think this is a great opportunity to open our lens and hear from other people, from you all who are doing the work.

I think what might be helpful here to get some people to think about whether or not they'd be interested, and we already have one person raising their hand, but Monica, how about we go ahead and read the situation so people know what they're getting into. We do have two people who are willing to volunteer right now. But why don't we go ahead and read the challenge or the issue, and if anyone else would like to volunteer, we'll bring you up and then we'll have some conversation around solutions and ideas on how to address this. So Monica, over to you.

MONICA WAFFORD: As the direct support professional, I just started working with someone who lives with their family. I have noted in their person-centered plan that there have been instances in which they talk about wanting to kill themselves.

The plan does not talk about what to do in those situations, and I am not sure what has been done in the past. I know this is a sensitive topic to discuss with the family, but I am not sure I will know what to do if or when they talk to me about any thoughts of suicide. Think about what you would do.

DR STACY NONNEMACHER: Thank you, Monica. And hopefully there's other people that are out there that are willing to share. I'm sure you're churning some ideas, thinking about some solutions. I'm hoping that this is a relatable challenge or issue for you as a direct support professional. I also, while you're thinking about whether or not you want to jump up with us, take care of yourself, just I know we said that earlier.

Please do what you need to do to take care of you, regulate, calm, we are talking about crisis and we know that it can be difficult for some of you and triggering for some as well.

Thank you. We have two folks. How about one more? Can we get one more person who would be willing to -- again, you don't have to come on video. There we go. All right. Kimberly. Great. So, in the design of the capsule exercise, this is where Monica and I were quiet, we'll go off screen, and we'll let the three of you go ahead and talk through if this were you as a direct support professional, what are some things that you would consider?

How would you support this person? What are some other ideas that you may have that others may not think about? So, thank you again for volunteering. And I will go off and leave it to the three of you.

>> I would say first to contact their parents, and then the hotline, the crisis hotline, and then go from there and follow directives from them.

>> I would say contact the team. We could have a team meeting to discuss him thinking about killing himself. And we could also -- I have been training in the system where it helps you to on a crisis deescalate situations like this. And you want to support them and positive things that they are doing. And that's what I would do. Have a team meeting to discuss.

>> Right. I would do the same thing. And also check the documentation, see if there's been any indication in their behavior, changes in medication, possible instances that have occurred that might trigger a pattern if they've done this in the past, are there any specific things that have triggered this response. Is it something that happens that makes this person threaten to kill themselves?
So is it a pattern? Does it happen because of a certain occurrence, that kind of thing.

>> And I'll ask them why do you want to kill yourself? What makes you feel this way? Just ask open-ended questions. I'm thinking of if I'm saying it right. Engage with them, talk to them. Talk with them, not at them. That's what I would do. And also what Kim says, reach out to the suicide hotline as well.

>> Always seek professional help. We're trained to help them and make sure that they get the right help, but it's up to professionals to find out if they actually need medication or what kind of help they need.

>> Also speaking of medication, have they had a change in medication that might have some kind of effect on them? That's always a possibility.

>> I like what they said, to listen to them, just listen.

>> Right. Maybe they need a therapist, they need someone to talk to.

>> I would also remove any objects that they may use, like any sharp objects, anything like that. Keep them in a safe space with you.

>> And definitely be sure to follow up that they got the appropriate help that they needed and that

they felt better even when they returned to work.

>> And always document. Keep documentation.

>> Yep.

DR NONNEMACHER: I know for the sake of this exercise, I'm supposed to stay off mute and not respond or react, but I just want to say to the three of you, keep going. These are amazing ideas. I'm listening with bated breath. And I think everyone else is as well. So if you're not paying attention, you're really churning some conversation in the chat. So feel free to take a look at the chat as well.
But I'll go on mute again and let you keep going. But I just wanted to let you know, we hear you, and these are amazing ideas. Thank you.

>> Yeah. And I agree in the chat, it says do not leave them alone. I agree with that. But also to bring them away from everybody to where you two are alone and everybody else isn't seeing them upset, because that might upset them even more.

>> And also seeing in the chat somebody put down self-care for the DSP. Yes. You would definitely need that afterwards. That can also affect you and traumatize you as well.

>> One of the things I'm looking at says I noted in their person-centered plan, there have been instances. How often has this happened? Is it kind of on a regular basis that they talk about wanting to kill themselves?

>> It also said the plan does not talk about what to do in those situations. And I'm wondering why. If it's the emphasis, why haven't they discussed it in the plan or what to do, why that hasn't been brought up?

>> Right. What about a plan, making a plan?

>> I agree. Because it not the first time in person has thought about killing themselves.

>> If they actually do have a plan, that's when it becomes more serious.

>> What if you're a new staff and you're not familiar with this person, and they saying they want to kill themselves, and you looking in their plan to see what you are supposed to do but it's nothing in there.

MONICA WAFFORD: And this is Monica. I just want to jump in and say that is so important, because a lot of times documentation may not be so informative or somebody may have forgotten to document something. So, knowing and looking at documentation is super important.

>> Right. And the last speaker was Ren, saying about having a plan. You know, and also it says I'm not sure I'll know -- it's a sensitive topic to discuss with the family, obviously. Because they're going to be on the defensive, I would think.

>> Yes.

>> Maybe find a way to talk to the family separate from the person, from your client. And see if maybe you can ferret out any issues that there might be between your client and the family. Maybe some family members and then maybe have them come together as a group, you know, speak to them separately, and then together. That's a possibility. But I really like the idea of keeping all the dangerous objects away from your person as well.

>> Lake sure that they're okay with letting everybody know too.
I see in the comments somebody brought up HIPPA.
If they're okay with letting their person know and it's not their guardian then we can't tell them. The only thing we can do is report it to the crisis hotline.

>> Right. They may not want them to know. You have to be very sensitive about that, about confidentiality.

>> Mental health first-aid course is a great resource as well. That's what someone said. That would be a great resource for DSP workers to start taking for their clients so that we know what to do in these kind of situations. Because if we're panicked that makes them more panicked, we have to stay calm and know what to do. So if we know what to do and we stay calm, then they'll most likely calm down too.
But if we're upset and don't know what to do and we're all over the place trying to figure it out, that's how they're going to feel.

>> You're absolutely right. I'm getting nervous just talking about it.

>> Me too.

>> I just want to say, sometimes it gets in the way of privacy, but health and safety first. And we don't know what that person's situation is at home.

>> Right.

>> So we can communicate this with them if they don't want us to, we can communicate this to the parents if the client doesn't want us to?

>> I think you could, because it's safety, mental health.

>> Yeah, I think that's why they have the crisis line though so you can tell them. Yeah, if they're their legal guardian, we can, but if it's not their legal guardian and they just live with them, then we can't just tell them.

>> Well, wait a minute, what if it's a situation where the reason they want to kill themselves is because there's some sort of abuse?

>> That's why I go right back to my first suggestion, and it's always best to get that crisis hotline on there and trained professionals to know what they're doing. To help guide us through each step. A lot of times the crisis hotline will also come out.

>> Having a great team is really an asset. But they're not always available. So it's a good thing to think these things out when you need someone.

>> It says in their person-centered plan, there's been instances when they talk about wanting to kill themselves. That's in their plan.

>> They don't talk about what to do in those situations, which is ironic because it should include that.

>> Sometimes it's in their plan, and sometimes it's not. When everybody sits down to make up their plan, they're just people, and there could be more stuff at hand that they talked about than even bringing

that up, so it might not even have been put in there. Everybody makes mistakes. And when it comes to documentation, if everything isn't documented, and documented properly, then we -- communication is the key when it comes to this.
And a lot of times communication, there's a lack of it.

DR NONNEMACHER: All right. We're going to wrap this up, this exercise up. And thank you so, so much, Marianne, Alima, Kimberly. Thank you for being brave and jumping up and volunteering and talking through this. So many great ideas.

And also thank you to those of you in the chat. A lot of great brainstorming happening. And I'm hearing some themes, themes around making sure the right people are at the table, including the person.
Making sure that there's a focus on planning that we have a better understanding of what this means for the person when they say they want to kill themselves, any changes that have happened, certainly that's an important part to this person's story.

And I heard this more than once, what are the positive things in this person's life, how can we capitalize on those things, and what's worked in the past. One thing that I like to say when I worked with teams is if I gave you a million dollars, what would you need to do to support somebody so they had the best day ever and so they wouldn't talk about wanting to kill themselves in this situation.

So just another strategy, something to think about. And again, thank you to everybody. I think -- you know, I have written down a lot of things that I think are going to be fodder for some conversations that we're going to have at the Link Center, but really the intent of an exercise like this is to open our lens and to recognize that coming to solutions is sometimes hard and requires multiple perspectives.
And sometimes it means that we need to get out of our own way. Because sometimes we're so myopic or focused on our own solutions that we can't get out of our own way. Hopefully for you direct support professionals, hopefully something resonated for you throughout that activity. And thank you again. I can't thank you enough.

This really turned out wonderfully for our first foray into a capsule exercise. Okay. So we're going to be wrapping up now. We're getting to the end of our time together. Mary at the outset or the introduction of today's time together had said we're going to ask you again later, and now's the time. Our question to you all is what are your go-to resources, trainings, website, and places to get information about crisis planning and crisis support?

CLOSING

We really we want to take the feedback today and as The Link Center we want to elevate what exists and take other pieces for action and consideration for all audiences. So, really the information that we shared today, the resources that Ren has created, the resources and research that Dr. Pinals mentioned here, and we have so many others that we're identifying and vetting will all be available soon for you and other audiences on our website.

Until that website is available, you can reach any of us and just The Link Center generally by emailing us at thelinkcenter@nasddds.org. And I'm seeing some really great ideas and go-to resources and information coming in the chat. Thank you so much, again. These are all things that we'll be taking a look at, things that we'll look to elevate around crisis planning and crisis support and resources for folks.
So, just to let you know, we have some additional shared learning groups planned through 2024. So we have a shared learning group around supports for trauma, planned for January. And again, we're doing it by audience. In April we have shared learning groups planned for supporting someone through a transition. What we mean by that is transition across the life span, across settings.

And then in August of 2024 we have scheduled some shared learning groups, really around the topic of supporting the whole person. So what I heard today was the importance of teaming, the importance of the right people being at the table to support someone. And that's really what we mean by supporting the whole person.

So, just to give you a quick glance, write these dates down. We'd really love for you all to join us. And you'll also have these resources that Dr. Pinal's referenced when talking about what research is out there and what research is saying around crisis planning and crisis support. You'll have that in your PowerPoint.

And lastly, just a big thank you again to Monica and Ren for their amazing contributions to today and generally to The Link Center and the work that we're doing with The Link Center. Also Emily Brown is also part of the Steering Committee and has been really critical in developing today's content, and they play such a significant role with the Steering Committee. But they were unable to join these meetings. But we wanted to recognize Emily as well as recognizing all of the partners at The Link Center for contributing to the preparation of and to the content for today's meeting.

I just want to thank everyone again for joining us, really truly, the work that you do is valued, and we thank you for doing what you do. It's so important.

I want to echo what was said earlier, that take care of you. Self-care is really critical in the work that you do. So know that we thank you, and we appreciate you finding the time to be here today.
Hopefully throughout the meeting something jumped out for you that you can take to the work that you do tomorrow in supporting someone. And I'll just leave you with one last piece of housekeeping. Stephanie mentioned in the introduction that you will be receiving an email and that email will have all the resources that we offered today, as well as the PowerPoint and a recording and transcript of today's meeting.

And I'll also mention that there will be an evaluation there. And we acknowledge that these Shared Learning Groups may evolve over time, because what we want to do is we want to meet your needs as much as we're pulling from you for The Link Center, we also want to be sure that you're getting what you need coming and spending time with us and taking time out of your valuable day.
Please take a few minutes to complete that evaluation when it comes through so we can take a look at that and ensure that these meetings are meeting your needs as well.

I just want to say thank you again for joining us. It really has been a pleasure being with you and spending time with you all today. And hope to see you all on the shared learning groups in the future in January. Take care and have a wonderful day.