

# Welcome to Shared Learning Groups



Bridging I/DD and Mental Health Systems

Shared Learning Groups

October 2023

Funded by the Administration for Community Living

# About Shared Learning Groups

- We will be hosting four meetings for: Direct Support Professionals (DSPs), Clinical Professionals, Individuals, and Families.
- We have kept the content consistent but will change the discussion for each audience.
- This content is a collaboration among The Link Center partners, including people with lived experience, people who are researchers and people who work on policy issues.
- We will record and transcribe today's meeting. The materials will be sent to you after the meeting through an email — we encourage you to share.



**Monica Wafford**  
The Link Center Steering  
Committee



## Sharing Lived Experience

This meeting will be talking about crisis and strategies people use to address crises. Take care of yourself and allow silence to be a safe space and feel empowered to do what's necessary for your comfort and care.

A young woman with curly hair is looking out a window at a building. The background is slightly blurred, showing a modern building with a glass facade. The overall tone is bright and hopeful.

**988**

**SUICIDE  
& CRISIS  
LIFELINE**





# Crisis Planning & Supports

One size DOES NOT fit all





## Sharing Lived Experience

We celebrate our individuality, our diverse culture, and our singularity while we celebrate the discoveries realized in our collective humanity.

*We know that we are each unique with our own experiences in the world.*



## Sharing Lived Experience

We empathize with experienced traumas that hinder our resilience.

*Some people have experienced trauma that makes it hard to recover and move forward.*





## Sharing Lived Experience

We listen with open minds and compassion, without judgment or blame.



# Sharing Lived Experience

We reject failure and embrace  
hope.



## Today's Agenda

- Introductions: Put your name and any group, association, or membership you may have in the chat.
- What is The Link Center?
- Why are we talking about “**Supporting Someone in Crisis**”?
  - What resources, trainings, and information are available to support someone before, during, and after a crisis?
- Group Exercise: What are some challenges and solutions to supporting people in crisis — this will focus on audience participation and ideas.



## **What are your go-to resources, trainings, websites, and places to get information about crisis planning?**

(Think about this...we will ask you again at the  
end of today's session)



# What is The Link Center?

# The Link Center Partner Organizations

## LEADING PARTNERS

- NASDDDS
- NADD
- NASMHPD

## DIVERSITY, EQUITY, INCLUSION

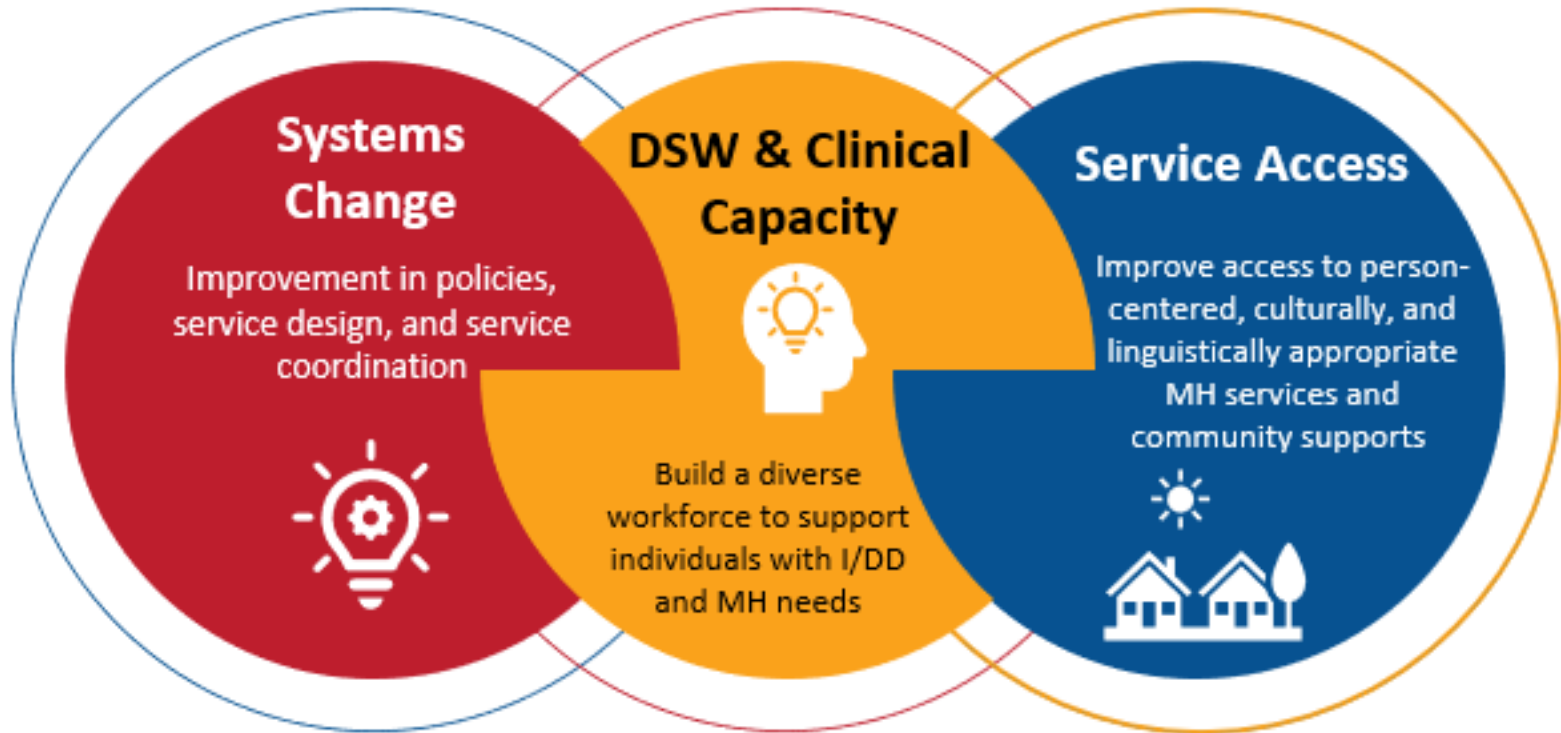
- Green Mountain Self Advocates
- Autistic Self Advocacy Network
- National Association of State Head Injury Administrators
- CommunicationFIRST

## CONTINUOUS QUALITY

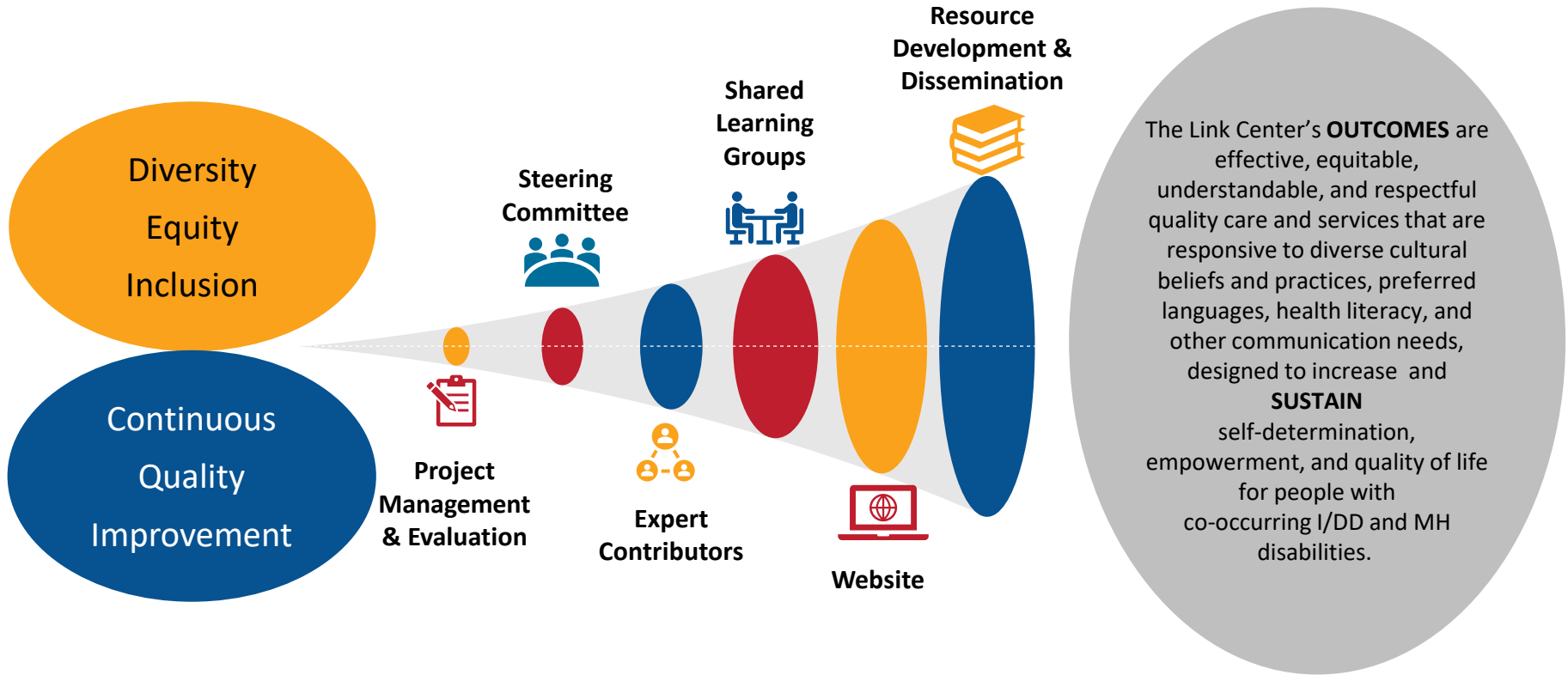
- National Center for START Services
- Sonoran Center at ASU
- Nisonger Center at OSU



# Key Goals of The Link Center



# The Link Center's Key Activities





# Today's Shared Learning Group



## Goals & Outcomes of the Shared Learning Group:

- We will share what we are doing at The Link Center related to **Supporting Someone in Crisis**
  - You will be able to identify the importance of crisis support and planning for people with I/DD and MH for The Link Center.
  - You will know where to find resources related to **Supporting Someone in Crisis**.
- We will get your input related to **Supporting Someone in Crisis**
  - The group will help identify needed resources and information that The Link Center can gather or work with partners to develop.
  - You will help identify potential solutions to targeted challenges presented in the group exercise.



# **Stacy Nonnemacher, Ph.D.**

## NASDDDS



Bridging I/DD and Mental Health Systems

## **Why are we talking about Supporting Someone in Crisis?**

What is one word  
that would describe  
what crisis looks like  
for you as you  
support a person in  
your role as a family  
member?

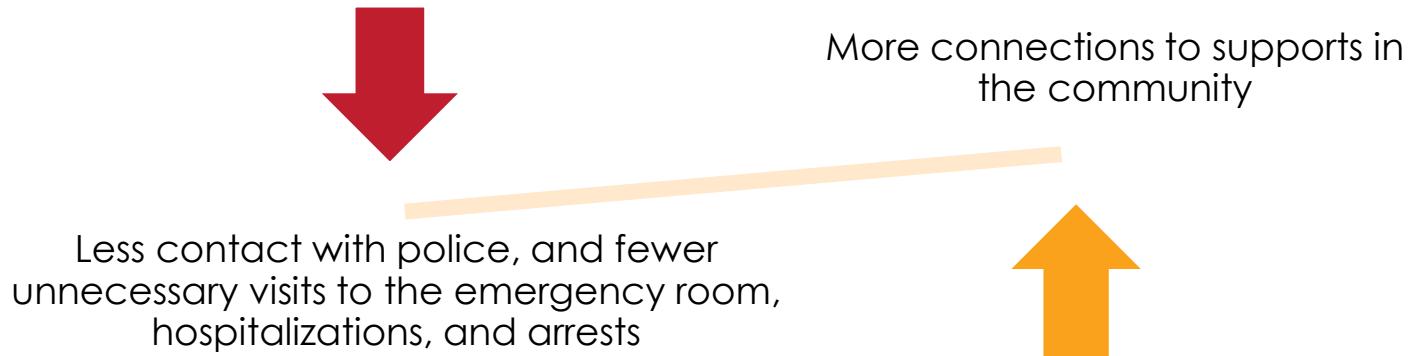




**Debra A. Pinals, M.D.**  
NASDDDS Consultant

# What is the issue/need?

- We need options for people with I/DD and MH support needs to get support-at every stage of crisis.
- We need trained people supporting someone in crisis.





Bridging I/DD and Mental Health Systems

## What does research tell us?

- Need to come together and support and educate people who work at hospitals to better understand and get more comfortable talking to and caring for people with I/DD (Lunsky, et al. 2014; Spassiani, et al. 2020).
- People who help people in crisis need to learn the best ways to offer person-centered support. Every person is different, and crisis care can reflect that (Pinals and Edwards 2020).



Bridging I/DD and Mental Health Systems

**What does  
research tell  
us?**

Some things can make people more likely to end up in the hospital for mental health crises, like:

- How their disability affects them;
- Whether they live in the community or a group home;
- Whether they've been to the hospital for a mental health crisis before; and/or
- Whether police have been involved.

Other things can make it easier to stay out of the hospital during a mental health crisis, like:

- Having a family doctor and/or
- Having a crisis plan.

(Lunsky, et al. 2012)



# Crisis Models

Successful models: START, Certified Community Behavioral Health Clinics (CCBHCs), and others

Pieces for success:

1. System connections
2. Inclusion of physical health
3. Many available services
4. Trauma informed supports
5. Evaluation – does it work? If not, make changes



Bridging I/DD and Mental Health Systems

## What does this mean for families?

- At times, when looking for support for their family member, families may experience a clinician who doesn't have knowledge about or experience with I/DD.
- Families can offer information to clinicians in a crisis that can help meet the needs of their family member (with the person's permission whenever possible).
- Families can be an important support to people because they know the person and what is important to them and for them.



# **Ren Koloni**


## CommunicationFIRST



## Resource:

*What To Do When I Don't Feel Okay*

# Resource: Making a Plan for When I Don't Feel Okay



**LINKCENTER**  
Bridging I/DD and Mental Health Systems

## What To Do When I Don't Feel Okay:

A Crisis Plan Developed for People with I/DD and Mental Health Support Needs

### About this guide

This guide was written by Ren Koloni, an autistic self-advocate with mental health support needs who has experienced crisis.

Ren is a part of the team at [CommunicationFIRST](#), a partner of The Link Center.


To write this guide, Ren combined their lived experience with existing resources for crisis support. That means this guide isn't the result of research and shouldn't be taken as medical or legal advice.

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For more information on resources for people with I/DD and mental health support needs, connect with The Link Center via email at [thelinkcenter@nasdds.org](mailto:thelinkcenter@nasdds.org).

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## Step by Step

### How do we know I'm not okay?

<b>Stage One:</b> I don't feel great...  I feel stressed out.  I feel upset.  I'm having feelings and I need to get them out.	<b>Warning signs that I'm not feeling well:</b>	<b>Who can support me now:</b>	<b>Here is how I communicate best:</b> <i>Let me talk</i> <i>Let me use my AAC:</i> <i>Yes/no questions</i> <i>Give me choices</i> <i>Tell me what to do</i> <i>Something else:</i>
<b>Stage Two:</b> Distressed and dysregulated  I feel like something's about to happen.  I'm in my "rumble stage."  Something's definitely wrong and I need help.	<b>Signs that I'm distressed or about to have a crisis:</b>	<b>Who can support me now:</b>	<b>Here is how I communicate best:</b> <i>Let me talk</i> <i>Let me use my AAC:</i> <i>Yes/no questions</i> <i>Give me choices</i> <i>Tell me what to do</i> <i>Something else:</i>



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# Resource: What to Do When I Don't Feel Okay

 Bridging I/DD and Mental Health Systems

## What To Do When I Don't Feel Okay: Big Ideas

This guide was written by Ren Koloni, an autistic self-advocate with mental health support needs who has experienced crisis.

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For more information on resources for people with I/DD and mental health support needs, connect with The Link Center at [theLinkcenter@nasddds.org](mailto:theLinkcenter@nasddds.org).

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**This guide explains some big ideas about crisis and crisis plans, like:**

- [What is a crisis?](#)
- [Why does a crisis happen?](#)
- [What is a crisis plan?](#)
- [What should I think about when I make my crisis plan?](#)
- [Who can help me?](#)
- [What do I do if I don't know anyone who can help me?](#)
- [Other words to know](#)

This guide is made for people who have I/DD **and** mental health support needs.

This guide can help you learn how to stay safe during a crisis.

At the end of the guide, you can look at some [different versions of crisis plans](#).

You can choose a crisis plan that works best for you.


NOTE: We intend to update this resource with new information and resources – please know that this is not an exhaustive list of resources or information.

 Bridging I/DD and Mental Health Systems

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 **CommunicationFIRST**  
Reduce communication as a human right.

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## A Sample Short Crisis Plan for People with I/DD:

I'm having a crisis right now. What do I do?

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My name is: \_\_\_\_\_ I live in: \_\_\_\_\_

Here's how I describe my disabilities:

\_\_\_\_\_

My supporters are: (Name, how to reach them, and who they are in your life)

\_\_\_\_\_

Where can I find my full crisis plan?


\_\_\_\_\_

Things that help me feel safe:


\_\_\_\_\_

Things that bring me joy and make life worth living:

\_\_\_\_\_

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# Sample Crisis Support Plans

- [My Safety Plan](#)
- SAMHSA's one-page "[Safety Plans Work](#)"
- Mental Health America's [Crisis Plan Worksheet](#)



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## **Group Exercise**





Ronny is a 16-year-old son and has destroyed the family home twice during arguments. Ronny has two younger siblings living at home. Child Protective Services warned that they would remove the younger children or Ronny from the home after he broke the wrist of the youngest sibling when he was angry. Ronny has been told that he has to stay on his medication because it is the only thing that has helped. Ronny refuses to take the medication because he says it makes him feel like a zombie. He told you that he smokes weed and it makes him feel better. Fearing the loss of the younger kids, Ronny is given an ultimatum to take the medicine or leave home. Ronny runs away and is gone for days until the police arrest him for selling drugs. What should I do?



**What are your go-to resources,  
trainings, websites, and places  
to get information about crisis  
planning?**

(Put in the chat)

An orange starburst graphic with a black outline, containing the text 'Website Coming Soon!'.

Website  
Coming  
Soon!

Until the website is available, you can reach us by  
email at:

[thelinkcenter@nasdds.org](mailto:thelinkcenter@nasdds.org)

# Upcoming Shared Learning Groups: Year One

(all group meetings listed are Eastern Time)

**OCT 24, 2023**

- DSP 1-2:30 PM
- Clinical 3-4:30 PM



SUPPORTING SOMEONE  
IN CRISIS

**JAN 23, 2024**

- DSP 1-2:30 PM
- Clinical 3-4:30 PM



SUPPORTS FOR TRAUMA

**APR 23, 2024**

- DSP 1-2:30 PM
- Clinical 3-4:30 PM



SUPPORTING  
SOMEONE THROUGH  
A TRANSITION

**AUG 20, 2024**

- DSP 1-2:30 PM
- Clinical 3-4:30 PM



SUPPORTING THE  
WHOLE PERSON

**OCT 25, 2023**

- Families 1-2:30 PM
- Individuals 3-4:30 PM

**JAN 24, 2024**

- Families 1-2:30 PM
- Individuals 3-4:30 PM

**APR 24, 2024**

- Families 1-2:30 PM
- Individuals 3-4:30 PM

**AUG 21, 2024**

- Families 1-2:30 PM
- Individuals 3-4:30 PM

**COMBINED SHARED LEARNING GROUP MEETING: TBD**

# Resources

- Lunsky, Y., Balogh, R., & Cairney, J. (2012). Predictors of Emergency Department Visits by Persons With Intellectual Disability Experiencing a Psychiatric Crisis. *Psychiatric Services*, 63(3), 287–290. <https://doi.org/10.1176/appi.ps.201100124>
- Lunsky, Y., Lake, J. K., Durbin, J., Perry, A., Bullock, H., Morris, S., & Lee, J. S. (2014). Chapter One — Understanding and Improving Care for Individuals with Intellectual and Developmental Disabilities in the Emergency Department. In R. M. Hodapp (Ed.), *International Review of Research in Developmental Disabilities* (Vol. 47, pp. 1–37). Academic Press.
- Pinals, D. A., Edwards M. L. (2020). Crisis Services: Addressing Unique Needs of Diverse Populations. Technical Assistance Collaborative Paper No. 8. Alexandria, VA: National Association of State Mental Health Program Directors.
- Spassiani, N. A., Abou Chacra, M. S., Selick, A., Durbin, J., & Lunsky, Y. (2020). Emergency department nurses' knowledge, skills, and comfort related to caring for patients with intellectual disabilities. *International Emergency Nursing*, 50, 100851. <https://doi.org/10.1016/j.ienj.2020.100851>.

# Acknowledgements

- **Monica Wafford**, The Link Center Steering Committee
- **Emily Brown**, The Link Center Steering Committee
- **Ren Koloni**, CommunicationFIRST
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