Meadows Mental Health Policy Institute

Supporting Youth with Developmental Disabilities in Mental Health Crisis

Why This Matters

Research shows that youth with developmental disabilities (DD)[1] experience traumatic and stressful events at higher rates than people without DD and are more likely to struggle with depression, anxiety, and suicidal ideation.[i,ii,iii] However, they often lack access to appropriate mental health care. Despite the higher need, training for mental health providers on working with youth with DD is extremely limited, and as such, providers often lack confidence to work with this population.[iv] Additionally, there are few evidence-based mental health screenings, assessments, and interventions that have been tailored for use with youth with DD. Due to the lack of training, support, and evidence-based interventions (among other things), this workforce is at risk of higher-than-usual rates of burnout and turnover. Ongoing staff shortages add more stress on staff which contributes to gaps in care for young people. These challenges may also lead to under- or misdiagnosis, nonexistent or inadequate treatment, and an over-reliance on behavioral management rather than addressing underlying mental distress in youth with DD.[v] Additionally, many mental health services have eligibility criteria that exclude individuals based on IQ scores or perceived functional abilities. When mental health needs go unrecognized or untreated, youth are more likely to experience escalating distress that can result in crisis situations.

Historically, crisis response for youth with DD has been left to systems that were not designed to meet their unique needs and that are unnecessarily restrictive. Law enforcement is often the default responder due to a limited supply of mental health crisis response resources, and law enforcement officers generally have limited specialized training in de-escalation strategies tailored to people with DD.[vi] In schools, teachers and staff are generally not given the training needed to understand and properly cope with mental health challenges for students with DD, often leading to the use of restrictive interventions like seclusion and restraint to manage resulting behaviors. Such practices result in further trauma and erode trust with families and youth.[vii] Finally, the lack of community-based supports gives families little choice but to go to hospital emergency departments (EDs) as a last resort for crisis support, yet EDs are typically ill-equipped to provide appropriate care for youth with DD. Leading to prolonged stays, unnecessary hospitalizations, or discharge without meaningful intervention and or plans.[viii,ix] Such experiences lead families and youth with DD feeling unsupported, unheard and unsure of where to turn.

[1] The term “developmental disabilities” refers to a group of conditions associated with an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person’s lifetime. Conditions include, but are not limited to, intellectual disabilities, autism spectrum disorder, attention deficit hyperactivity disorder, Down syndrome, fragile x syndrome, cerebral palsy, fetal alcohol syndrome, and epilepsy.

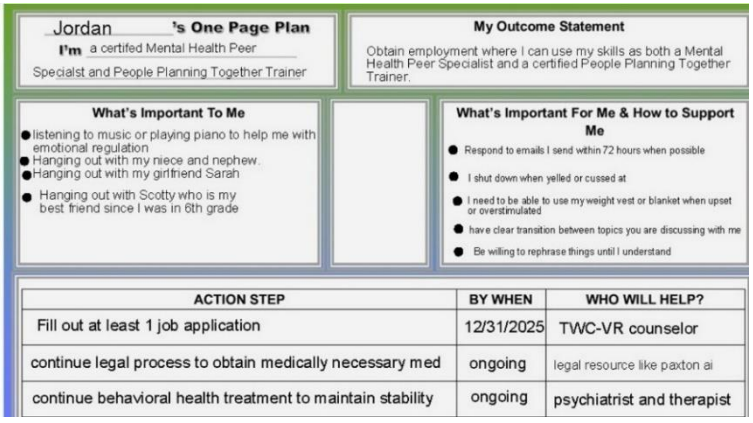
Purpose of this Resource

Youth with DD experiencing mental health crises can and should have access to supports in the least restrictive environments possible from providers who are trained and equipped to serve them. Better support for youth with DD in crisis requires a shift toward more flexible and person-centered crisis response systems. By recognizing the unique needs of youth with DD, training professionals to provide specialized care, and reducing reliance on restrictive interventions, we can create a more supportive, compassionate, and effective crisis response framework. Furthermore, this type of capacity can help reduce instances of crisis or crisis recurrence. **This resource includes best practice strategies for anyone responding to a young person in crisis who may have a DD.**

Best Practices for Supporting Youth with DD in Mental Health Crisis

Person-Centered Care

- Ensuring youth with DD have a voice in their care builds trust with providers and helps youth to feel empowered to make changes in their own lives. True person-centered care acknowledges and prioritizes providing an individual with choices and supports their decisions related to their care. This is especially important to remember for youth with DD as people often inaccurately assume individuals with DD cannot act in their own best interest. Click here to watch a video explaining person-centered planning.
- Person-centered care should include opportunities for people receiving services to explore their interests and talents. Click here to watch a video highlighting an example.
- A person-centered plan is developed in collaboration with the person and the provider. It focuses on an individual's strengths, their needs and preferences, and their personal goals. To the right is a sample person-centered plan developed by Jordan Smelley, Mental Health Peer Support Specialist and Certified People Planning Together Trainer. A person-centered plan can be helpful when things are going well and in times of crisis.



Jordan 's One Page Plan

I'm a certifed Mental Health Peer Specialist and People Planning Together Trainer

My Outcome Statement

Obtain employment where I can use my skills as both a Mental Health Peer Specialist and a certified People Planning Together Trainer.

What's Important To Me

- listening to music or playing piano to help me with emotional regulation
- Hanging out with my niece and nephew.
- Hanging out with my girlfriend Sarah
- Hanging out with Scotty who is my best friend since I was in 6th grade

What's Important For Me & How to Support Me

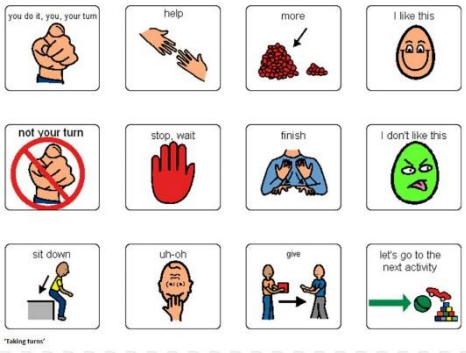
- Respond to emails I send within 72 hours when possible
- I shut down when yelled or cussed at
- I need to be able to use my weight vest or blanket when upset or overstimulated
- have clear transition between topics you are discussing with me
- Be willing to rephrase things until I understand

ACTION STEP	BY WHEN	WHO WILL HELP?
Fill out at least 1 job application	12/31/2025	TWC-VR counselor
continue legal process to obtain medically necessary med	ongoing	legal resource like paxton ai
continue behavioral health treatment to maintain stability	ongoing	psychiatrist and therapist

- Similar to a person-centered plan, many families develop a brief, often one page, summary for how to best support their child, specifically in a medical setting. Documenting what helps a person feel safe and sharing that with providers can be a helpful tool. Click here to see Parents Helping Parents - Introduction to One-Page Descriptions – A Person-Centered Tool as one example.

Engagement and Communication

- Building trust is essential before providing any intervention. In a crisis, it is often necessary to build trust quickly. Providing different ways for people to communicate their feelings, wants, and needs helps to build trust and engagement in care.
- It is important to be mindful of tone, body language, and distractions as this helps create a clearer, more supportive interaction. Some recommendations:
  - Tone: always try to use a calming and quiet tone.
  - Body language: limit eye contact, mirror the body language of the youth, avoid standing or hovering over the person in crisis.
  - Try to find a quiet place to meet and minimize environmental distractions to the extent possible.
- Remember to ask a youth about their communication preferences using plain language, yes/no questions, and visuals.
- Many youth with DD struggle with verbal communication, especially during a crisis, so using visual supports like the picture exchange communication system (PECS) to the right and social stories can be helpful.[x]



- Social stories are structured narratives that help individuals understand and navigate specific situations by setting clear expectations. Click here for a guide on how to write a social story. These narratives help reduce anxiety, build social skills, and improve coping mechanisms, especially for children or individuals with developmental differences.[xi]
- The Incredible 5-Point Scale to the right, developed by Kari Dunn Buron, MS, Autism Education Specialist, helps youth express emotions in structured way. Click here to watch a video that explains the scale in more detail.
- Remember to use plain language that is clear and easy to understand when helping someone in crisis. You can utilize "AI tools" like ChatGPT for suggestions on how to say something more clearly.

Assessments and Screening

- Most standard mental health screenings (including suicide risk assessments) have not been validated for use with youth with DD and often miss key signs of distress in this population. As such, it is recommended that in addition to standard screenings, providers be aware of:

  - Changes in functional skill level (daily living tasks, self-care, communication, and social interactions) and/or outward behaviors (an increase in frequency of repetitive behaviors, agitation, anger or irritability) which can be signs of deeper distress,
  - Factors that increase risk for suicide more significantly for youth with DD than other youth, such as loss of a family member, abuse, conflict, and loneliness, and
  - Factors that can increase dysregulation during a crisis event for young person with DD. These factors are often unique to the individual but may include sensitivity to noise, bright lights, feeling too hot or too cold.[xii,xiii]
- Effective screenings and assessments should consider biological factors like hunger and sleep, behavioral changes, and input from both the individual and caregivers to get a full picture of their needs. [xiv]
- Resources:
  - Please see an adapted safety plan you can use with youth on pages 6-11 of this document.
  - Safety Planning Intervention for Autistic Individuals - SPI-A – adapted from Stanley Brown - click here for presentation on using this tool.
  - Training for 988 National Suicide Lifeline Screeners: Suicide Screening for People with Autism Spectrum Disorder (ASD) and Intellectual and Developmental Disabilities (IDD) Mental Health
  - Texas Health and Human Services Commission (HHSC) Flyer – Suicide Prevention for Individuals with IDD
  - Click here to learn more about current research and efforts to develop an autism-specific suicide risk assessment tools and management strategies.
  - Understanding and Preventing Suicide in People with IDD: Experiences Learned from a Collaborative Research Project Webinar

De-Escalation Tools and Techniques

- De-escalation is used to reduce tension and prevent a crisis from escalating further. It involves using communication, body language, and structured techniques to help individuals regain a sense of control, reduce distress, and improve emotional regulation. Co-regulation, where responders model calm behavior, is key to guiding youth toward emotional stability.
- Grounding Exercises - Click here for examples of breathing exercises like “Belly Breathing” and physical movements like “Push Palms” or “Foot Press” are some examples of techniques. Click here for more grounding exercises.
- Bilateral Stimulation - "Butterfly Hug" or "Gorilla Taps" are common examples to use. Click here for more examples of bilateral stimulation.

Family Engagement

- Families are vital in deescalating a young person in crisis and often need support too. Partnering with caregivers and providing them with resources strengthens long-term stability. Some tips for working with family members include:
  - Engage families in safety and care planning for the youth. Ask for their concerns, feedback, and input while honoring the wants and needs of the youth.
  - Know that parents and family members are often also stressed and dysregulated during a crisis event with their child. Engage with them using some of the communication, engagement, and de-escalation strategies listed above.
  - Provide support, resources, and connection to ongoing services that are available for family members in their community.
  - Help family members explore and understand the crisis event (triggers and precipitating events, warning signs, things that escalate the crisis, etc.) and provide skills for de-escalation for them and their child.
- Family Partners—peers with similar experiences—can offer trust, relevant guidance, and advocacy. Think about how your agency might employ this critical role and engage them in crisis response activities.

Additional Resources

- Supporting Youth with Developmental Disabilities in Mental Health Crises webinar, Meadows Mental Health Policy Institute - Passcode: T7k8hM*x
- The Hub Learning Community, A project of Integral Care
- Psychiatric Difficulties and their Effect on Individuals with ID/D Webinar by Jean B. Mankowski, Ph.D.
- Mental Health and IDD Webinar by Tiana Anderson, Psy.D.
- National START Center Trainings
- Jordan Smelley, Mental Health Peer Specialist Worksheets
- Dr. Karyn Harvey's Website
- Supporting Access for Everyone (SAFE) care, developed by Developmental Behavioral Pediatric Research Network for emergency department staff
- Toolkit for Emergency Room Doctors and Personnel from The Arc of Massachusetts

For more information:

For more information on the Meadows Mental Health Policy Institute's work related to this topic please visit www.mmhpi.org and search "developmental disabilities" or contact Katie Mitten at kmitten@mmhpi.org

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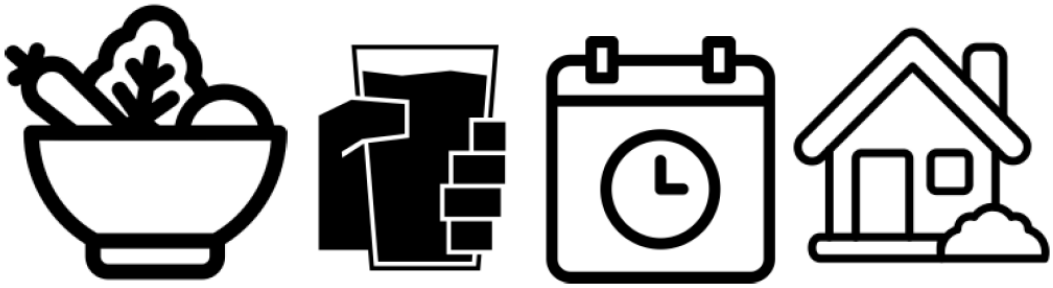
What makes my body feel alright?

Basics (Food, Sleep, Water, Regularity, Security)



Love (Friends, Family, Romantic)

Esteem

(Independence, Confidence, respect of others, respect by others)

Activities

(Little things and big things I like to do)

How do I know I'm not feeling OK?

Thoughts: 
Mood: 
Body feelings: 
Situations: 

What do I need when I might not feel OK?

By Myself:

Address –

Distract –

Check-in on Basic Needs

Places:

What if I'm REALLY upset?

T	I	P	P

Who can make me safer?

Others (support network):

How they can be helpful:

What is **NOT** helpful:

What can make my house safer?

Rules: 

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xiii Ludi, (2012). Suicide Risk in Youth with Intellectual Disabilities.
xiv Earixson, (2024). Adapting suicide safety plans for youth with intellectual and developmental disabilities.