Crisis Planning and Community Resources for Individuals with Neurodevelopmental and Behavioral Dual Diagnoses

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Disclosures

• I have no real or perceived conflicts of interest to disclose
“Dual Diagnosis”

- Individuals diagnosed with an intellectual or developmental disability who also have a co-occurring psychiatric or behavioral disorder.
A Complex Situation...

- Individuals with an intellectual disability have a higher prevalence of psychiatric disorders

- Under diagnosis and misdiagnosis are common

- Families are affected
  - Unmet medical needs
  - Financial concerns - inability to pay for mental health care or prescriptions
  - Aggravation with the medical system
Gap Analysis in Colorado

- 2013
  - 143 families of children with DD in Colorado
  - Majority had visited the ED in crisis 2+ in the past 3 years
  - Medication management issues was a common trigger
  - Only 21% felt that the ED met their child’s need completely
  - Only 48% of families had a crisis plan
  - Many of the families did not feel like they had the tools to create a good crisis plan
Barriers To Care

• Limited access to behavioral treatment and follow-up
• Poorly coordinated services for medical and mental health
• Few out-of-home options
• Inconsistent crisis intervention training (CIT) for first responders, clinicians, and families
• Clinician training
• Billing/reimbursement
• ETC.
• **Caregiver Quote:** “We felt like we just got passed around. No one was willing to sit down and really figure out the problem. When we finally had a diagnosis, no one would take him as a patient because he was too far out of their comfort zone. I don't know if this was a policy issue, insurance issue, or what. It was an extremely frustrating and scary time.”

• **Provider quote:** “Colorado does not have options for in-home supports to help prevent patients from going to the Emergency Department when out of control behaviorally. CCBs and mental health centers are not equipped to manage high needs children. NSC [Children’s Hospital CO] is only inpatient unit for this population in the whole state with only 4 beds. When families are in crisis, their only option is the ED. We do not have adequate outpatient, in-home, day treatment, or residential placement options for people with developmental disabilities.”
Financial and Family Impact Analysis

• 2014
• Families found their own best ways of coping
• Parents expressed a need for crisis training
• Parents who did have a crisis plan felt that it helped them:
  1) Control the crisis better
  2) De-escalate the situation more often
  3) Communicate their needs better to providers
Crisis Plan and Resource Guide Creation
Crisis Plans

• Individuals **without** a crisis plan were more than 2x as likely to visit an ED

• Individuals with a crisis plan have a decreased rate of compulsory admission and fewer days of inpatient care

• Individuals with a crisis plan felt more involved in their care, more in control of their mental health, and more likely to continue with their treatment
Crisis Plans

- Identify triggers
- Identify best de-escalation methods
- Often during a crisis, the patient needs a safe space to be alone calm down— but this is hard to find/not available
Crisis Plans

• Specific rules for the individual about unacceptable behaviors and consequences
• Clearly define the specific role or duty for a limited number of trustworthy people involved
• Initiate the plan early in a crisis situation
• Work with a trusted professional
• Write the plan down on paper!
Is a crisis plan useful for individuals with a dual diagnosis and their families?
• Complete in a time of calm
• Include other family members and if possible, a professional who knows your son or daughter well
• Use to identify
  • Triggers
  • De-escalation techniques
  • Crisis events specific to your son or daughter and family

## Planning

Describe what a crisis looks like and feels like to you.

<table>
<thead>
<tr>
<th>Triggers</th>
<th>Behavior During a Crisis</th>
<th>What I did:</th>
<th>Was it helpful?</th>
</tr>
</thead>
<tbody>
<tr>
<td>He yells, hits, scratches, and has difficulty</td>
<td>run away</td>
<td></td>
<td></td>
</tr>
<tr>
<td>listening and following directions. He sometimes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>runs away.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How does your son or daughter’s behavior differ from other times in his or her life? How do you respond? Does it help?

<table>
<thead>
<tr>
<th>Trigger for Behavior (if known):</th>
<th>Behavior During a Crisis:</th>
<th>What I did:</th>
<th>Was it helpful?</th>
</tr>
</thead>
<tbody>
<tr>
<td>I took away the iPad</td>
<td>John repeats himself over and over again</td>
<td>I ask him to take deep breaths or go to his room</td>
<td>Usually</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I told him to go to his room</td>
<td>John makes really repetitive movements</td>
<td>I ask him if he is upset and wants to talk</td>
<td>Sometimes, but other times I don’t know if he can hear me.</td>
</tr>
</tbody>
</table>
Crisis Plan

Keep this plan in a visible place that can be quickly referenced in a crisis!

Fill this out with your entire family to prepare you for the possibility of a crisis. If possible, it may also be helpful to have someone on your child’s care team (Primary Care Provider, Counselor, Psychiatrist, Mental Health Professional, etc.) review your completed plan.

<table>
<thead>
<tr>
<th>Stage of Individual’s Behavior</th>
<th>Recommended Parent Response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 1: Prevention</strong></td>
<td><strong>Remain calm and work to de-escalate.</strong></td>
</tr>
<tr>
<td>Early warning signs that individual is becoming increasingly distressed.</td>
<td></td>
</tr>
<tr>
<td>Warning Signs:</td>
<td>De-escalation techniques:</td>
</tr>
<tr>
<td>• Repetitive hand flapping.</td>
<td>• Remind son or daughter to perform coping strategies listed above — safe hands, deep breaths, go to room.</td>
</tr>
<tr>
<td>• Persistence on a certain topic, or repetitively asking questions.</td>
<td>• Try to compromise</td>
</tr>
<tr>
<td>• Persistent, escalating refusal of requests</td>
<td>• Use picture schedule to communicate requests.</td>
</tr>
<tr>
<td>Consider if proper medications have been given or can be given now.</td>
<td>Medication: Methylibenadate and Fluoxetine</td>
</tr>
</tbody>
</table>

| **Stage 2: Escalation**       | **Speak calmly and directly.** |
| Signs that individual is progressing towards a behavioral crisis. |
| Warning Signs:                | Continue De-escalation Techniques. |
| • Yelling/raised voice        | Consider calling therapist or Crisis Hotline for help. |
| • Larger, repetitive movements (stomping/pounding ground) | • Crisis Hotline: 1-844-493-TALK (8255) |
| If able, transport to Crisis Center: | Health Care Provider: [person's name] |
| Nearest Crisis Center:        | Phone: 303-555-5555 |
| Aurora Walk-In Crisis Center 2206 Victor St. | Aurora, CO 80045 |

**Individual:**
Son or daughter in crisis: John
Siblings: Justin (brother)
Parent 1: Jackie (mother)
Parent 2: Jared (father)

**Safety Plan:**
Use code word to identify to everyone that you are in a crisis. Go to room and turn off lights to give yourself a calming atmosphere.
Get dog and go to neighbor’s house to wait.
Continue to model calm behavior.
Remove all dangerous or important items from the area. Retrieve a phone in case someone needs to be called. If necessary, he should restrain John from hurting himself.

**Stage 3: Crisis**
Situation has escalated to the point that safety of individual, others, or environment is at risk.

Warning Signs:
• Individual is harming self or others
• Hitting self or others
• Throwing and/or destroying property

Continue to ensure safety.
Call 911 for Help:
• Ask for a Crisis Intervention Trained (CIT) officer
• Provide the first responder with the information in the quick hand off form to assist them in communicating with your son or daughter

If able, transport to Nearest Emergency Room.
Nearest ED:
• Children’s Hospital
• Take crisis kit.

**Emergency Contacts:**
<table>
<thead>
<tr>
<th>Emergency Contact Name</th>
<th>Relationship</th>
<th>Contact Info</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jackie Smith</td>
<td>Mother</td>
<td>303-555-5555</td>
</tr>
<tr>
<td>Jared Smith</td>
<td>Father</td>
<td>303-555-5555</td>
</tr>
<tr>
<td>Elizabeth Jones</td>
<td>Next Door Neighbor</td>
<td>303-555-5555</td>
</tr>
</tbody>
</table>

**Provider List:** (include physicians, therapists, or anyone who provides services for you)
<table>
<thead>
<tr>
<th>Name:</th>
<th>Role:</th>
<th>Contact Info:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Luke Rodriguez</td>
<td>Psychiatrist</td>
<td>303-555-5555</td>
</tr>
<tr>
<td>Dr. Julie Hunter</td>
<td>Primary care provider</td>
<td>303-555-5555</td>
</tr>
</tbody>
</table>
Have a Crisis Plan Ready

Here is an example of how to best utilize your resources! Place this, or your own plan, in a place that is visible and easy to reference.

Crisis Begins:
No Outside Help Necessary

De-escalation techniques at Home

De-escalation techniques are NOT working

Escalation:
Family Needs Outside Help

IF child is physically violent

IF Child is safe to transport AND removing individual from the situation would be helpful

Drive to Nearest Walk-In Crisis Center

IF Child is not safe to transport OR no Crisis Center is nearby

Call Crisis Hotline
1-844-493-TALK (8255)

If situation escalates, they may help you call 911.

Contact Emergency Services

Emergency:
Individual is Combative and Inflicting Harm on Self or Others

IF Child is safe to transport

Drive to the Nearest Emergency Department

IF Child is not safe to transport

Call 911
Ask for a CIT Officer
Can be given to anyone who may interact with your son or daughter in a crisis.
- First responders
- Teachers
- Babysitters
- Hospital/clinic staff

Provide in advance, if possible

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**Quick Hand-Off Form: About Us**

<table>
<thead>
<tr>
<th>Name of son or daughter:</th>
<th>Date of Birth:</th>
<th>Gender:</th>
</tr>
</thead>
<tbody>
<tr>
<td>John Smith</td>
<td>04/21/2002</td>
<td>Male</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address:</th>
<th>Phone Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1234 Smith St., Denver, CO 80220</td>
<td>303-123-4567 (Mom’s cell)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mental Health/Behavioral Diagnoses:</th>
<th>Current Medications and Dosage:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>Methylphenidate sustained release, 30 mg, 1x/day</td>
</tr>
<tr>
<td>ADHD</td>
<td>Fluoxetine 10 mg, 1x/day</td>
</tr>
<tr>
<td>Depression/Anxiety</td>
<td>During a Crisis, these medications help my son or daughter:</td>
</tr>
<tr>
<td></td>
<td>Valium</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other Medical Problems:</th>
<th>Allergies:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Celiac disease</td>
<td>Penicillin</td>
</tr>
</tbody>
</table>

**Interacting with My Son or Daughter:**
Because of John’s diagnoses, he/she will act and respond differently than others. Please use these tips when interacting with my son or daughter:

**My son or daughter is verbal/non-verbal. Please communicate with my son or daughter by:**
- Speak slowly in short sentences
- Use “First...Then” language (Ex: First stop hitting, then you can sit with your mom.)
- Use picture charts

**Please avoid doing/saying this:**
- Use a calm, low voice
- Move slowly
- Say what you are going to do before you do it

**Things that help calm my son or daughter:**
- Watching a cartoon
- Holding a yellow blanket
- Sitting alone in a dark, quiet room

**Things that will upset my son or daughter:**
- Too much noise/stimulation
- Moving too quickly
- Being touched without warning

**Typical behaviors of my son or daughter while they are in crisis:**
- Hitting and scratching
- Throwing items
- Running away

Other things to know or expect about my son or daughter when they are in a crisis:
- Risk of elopement
Important Documents:
• Identification (IDs)
• Copy of insurance card
• Copy of Crisis Plan and Quick Hand-off Form
• List of Medications

*If you are not the legal guardian, bring Consent to Treat form signed by Legal Guardian.

De-escalation/Coping Tools:
• Book, toy, or music
• Sensory or Mindfulness Tools

Basic Supplies for Trip Out of the House:
• Change of clothing
• Snacks
• Basic hygiene supplies
• Complete after the crisis has subsided

• Change the planning document as needed

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**Reflection**

A few days after the crisis has resolved, please take some time to reflect on what happened.

Do you know what triggered this crisis (consider change in routine, illness, lack of sleep, etc.)?

Justin took the dog for a walk without John. When John found out, he got mad. He continuously shouted that he was left out and became violent. When asked to go to his room, he refused and it was necessary to call 911 to ensure everyone’s safety.

What did you try? What worked or did not work?

- We followed the Crisis Plan and used the hand-off form.
- The charts helped John understand that the first responders were there to help him and not to hurt him.
- His brother was unable to go to his usual place because he did not know that the crisis was taking place.

What happened? Who was called (police, ambulance)? What was the end result?

- The CIT officer arrived at the house. They spoke calmly to John and were able to convince him to come with them to the hospital.

What could be done differently next time? (For example, does your environment need to be altered to make it safer for your son/daughter or the rest of your family?)

- Request that John go to his room and calm down before he becomes violent.
- Say “first go to your room, then calm down, then the dog can come and sit with you.”
- Remove unnecessary breakables from family areas and John’s room.
- Ensure that his brother has a way of knowing that the crisis is beginning if he is not immediately aware that it is happening.

Do you think your son or daughter’s current medications and treatments (including therapies and services provided) are still helping?

- Yes, but we probably should schedule an appointment with Dr. Nguyen to follow-up after this crisis.

If necessary, try to go back to review and alter your original Crisis Plan based on your reflections.
• Remember, no crisis is too small, and every family has unique circumstances that make their crises look different.

• If you are feeling overwhelmed, get the help you need.

• These resources are not just for your son or daughter.

Wyoming 24 Hour Crisis Lines
Resource Centers vary by county
• Wyoming 211 for list of centers
• https://211wyoming.communityos.org/zf/profile/service/id/1378722

Colorado Crisis Hotline
Call: 1-844-493-TALK (8255)
Text: Text ‘Talk’ to 38255
Online Chat: coloradocrisisservices.org

The Colorado Crisis Hotline is a way to get in immediate contact with trained professionals during a behavioral health crisis.

It is free.

Anyone can contact the hotline, including family members or others that need support during the crisis.

Personnel are trained to provide support, help with de-escalation techniques, and identify helpful resources for your family.

Call, text, or chat online.
Call or text available 24 hours a day, every day of the year.
Online Chat only available 4pm-12pm, 7 days a week.

Translation services are available for the call option ONLY.

What kinds of questions will they ask?
Although you may remain anonymous, they will ask you:
  ➢ Your Name
  ➢ Your Phone Number
  ➢ Your Zip Code
  ➢ About thoughts of suicide

The person answering will also want to know specifics of the situation. This information will be saved, so if you need to call again, they will have a better understanding of how to help you.

When do I call/text/chat the Crisis Support Hotline?
If calling someone for support would be helpful,
OR if there is no Walk-In Center nearby,
OR if it is unsafe to bring your son or daughter to another location.
Crisis Walk-In Centers

Why is this sometimes better than going to the Emergency Department?
- It is less expensive.
- They are well trained in mental health crises.
- They can help with de-escalation techniques.

When do I go to a Crisis Center?
When your de-escalation techniques are not working,
AND it is safe for you to transport your son or daughter in a car,
AND you believe that removing him/her from the situation would be helpful.

Walk-In Centers are not appropriate if:
- Your child is physically violent
- There is a medical emergency
- Your child needs medication
- You think your child needs to be admitted to the hospital
Smart 911

- Medical Conditions
- Allergies
- Disabilities and Equipment
- Medications
- Crisis Plans!

https://safety.smart911.com/advocate
Suggested Next Steps for Families:

1. Create Your Crisis Plan
2. Create Crisis Kit
3. Call Crisis Hotline to discuss your Crisis Plan
4. Visit your nearest Crisis Walk-In Center to get acquainted with the building and staff
5. Set Up your Smart 911 Account and/or Special Needs Registry Account
Acknowledgements

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• Patrick Romani, PhD
• Mary Hoefler, Office of Behavioral Health, Manager of Crisis Services
• Many other key stakeholders!
“A mental health crisis is as important to address as any health crisis. It is difficult to predict when a crisis will happen. While there are triggers and signs, a crisis can occur without warning. It can occur even when a person has followed their treatment or crisis prevention plan and used techniques they learned from mental health professionals. We all do the best we can with the information and resources we have. Some days we can handle more than other days; this is normal and to be expected, especially for those living with a mental illness. You or your loved one may need help when you have exhausted all your tools for coping with a crisis.”

Questions?

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