The Hidden Trauma of IDD Families in Crisis

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Objective:

To equip professionals with strategies to recognize and address the psychological stress experienced by families supporting individuals with IDD during crises.

But also…

To look *beyond* the crisis, hear the voice behind the call and to respond with understanding, hope, and compassion.

What we'll explore…

- Common Psychological Stress Patterns
- System Factors
- Trauma Informed Communication Strategies
- Indicators of Effective Crisis De-escalation/Prevention

The voices behind the calls…

“I never thought I’d be seeking alternative placement for my own child, but I can’t do this anymore.”

“His tantrum has gone on for hours! He’s smearing feces everywhere! Please help me.”

“I have no one. I can’t keep doing this.”

“I have to lock myself in my room for hours a day until my husband comes home to help me. I’m not safe alone with her. My own child.”

“My son is bigger than me now, I can’t protect myself anymore.”

“Right before she passed, I promised our mother I would care for him, but it’s too much for me to manage and I am so sorry.”

“I had to quit my job to stay home and take care of her because we have no one else. Now I’m struggling to pay the bills and I can’t afford her adaptive aids.”

“The school sends him home on a nearly daily basis. I’ve already lost my job. I can’t keep doing this.”

“Their mother left us and now I’m here trying to figure this out myself.”

“He goes days without sleeping. I am falling apart.”

…The voices behind the calls

A “crisis" is not just a behavioral event.

It can be a parent hiding in a bedroom,
A caregiver losing a job,
A sibling being overlooked,
A spouse becoming overwhelmed,
And a family considering placement despite never wanting to.

These are not just calls for services. They are often calls for help, safety, connection, and hope.

Identifying the Crisis

The Crisis We See…

- Behavioral health crises
- ER Visits
- Repeated calls to 911 or emergency services
- Severe Behaviors
- Hospitalization
- Self-Injury/Aggression
- Medication Challenges
- Lack of appropriate respite or support
- Fear of institutionalization or out-of-home placement

…VS The Crisis We Don’t see

- Caregiver burnout and exhaustion
- Fear of losing housing
- Financial strain and unexpected expenses
- Family conflict and relationship strain
- Siblings' needs being overshadowed
- Social isolation and loss of support networks
- Feeling blamed or judged by professionals
- Constantly having to "prove" the severity of the crisis

- Navigating fragmented systems and conflicting information
- Being told to "wait" when the family is already at a breaking point
- Fear of losing the ability to safely care for their loved one at home
- Disruption to employment or career
- Missing work or losing income to manage crises
- Sleep deprivation and chronic stress
- Grief over the loss of the future the family imagined
- Feeling alone, unheard, or invisible

Straight from the families:

https://www.youtube.com/watch?v=BJu19LgEH_M

https://www.youtube.com/watch?v=is0yt_HszS8


N.J.'s Autism
Therapy Crisis,
Part 1


CityNews

Common Psychological Stress Patterns

- **Guilt/shame cycles**: Seeking alternative placement, Institutionalization, Feeling responsible for not being able to “fix” the situation or “handle” ones own loved one
- **Isolation from supports**
- **Impact of repeated crises on family functioning:** Mental and emotional well-being decline, Divorce, Effect on siblings

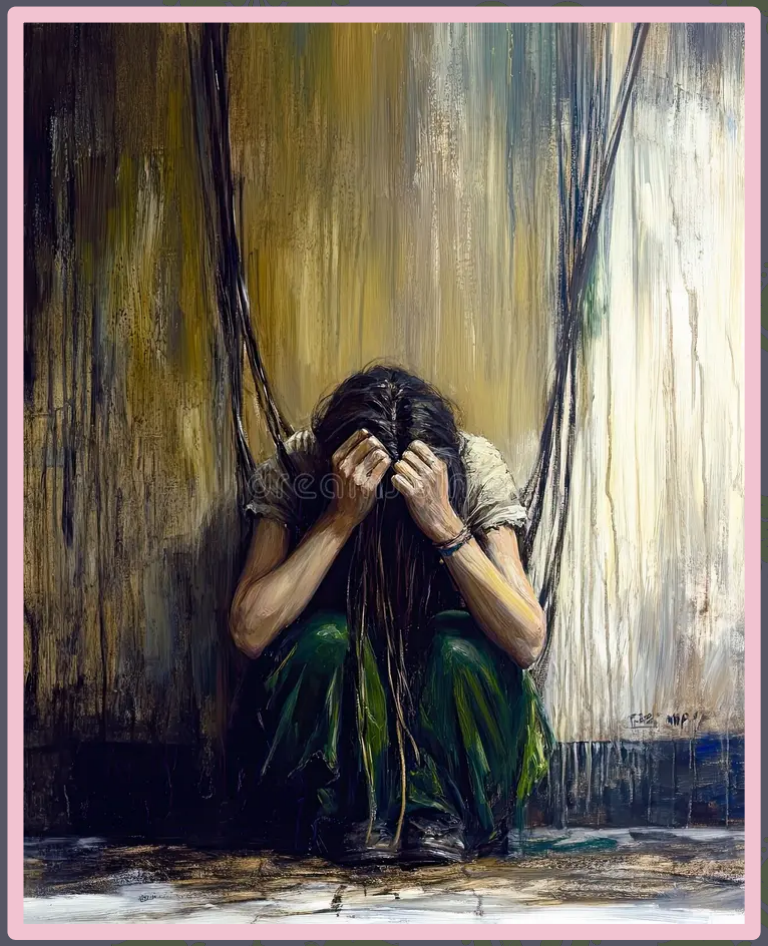
- **Anticipatory Anxiety**: Living in fear of the next crisis
- **Loss of identity**: Caregiver becomes the only role that sounds possible.
- **Moral distress**: being forced to make choices that conflict with personal values or expectation
- **Ambiguous loss**: Families may grieve the life they imagined, the future they expected, or the relationship they hoped to have- while simultaneously loving the person in front of them deeply.

System Factors That Contribute to Caregiver Burnout

The Revolving Door

Crisis→ Emergency Response → Short-term stabilization→ Discharge →Return Home→ Services Unavailable or delayed →Crisis

- Fragmentation between IDD, mental health, and medical systems
- Delays in eligibility, waiver services interest list, crisis diversion access
- Communication breakdown between providers, local authorities, and families
- Short-term stabilization without long-term follow up
- Understanding programs and all of their components
- Lack of coordination between systems
- Families repeatedly telling their stories
- Services that begin only after a crisis becomes severe
- Long waits for appropriate placement or supports
- Waiting on eligibility determination before addressing the immediate need



The First and Most Important Step….

ALLOW THEM TO FEEL HEARD

Trauma Informed Communication Strategies

Core trauma informed principles in crisis settings:

- Creating emotional and physical security for families in crisis.
- Building trust through honesty, clarity, and consistency.
- Partnering with families as experts in their own experiences.
- Restoring choice, voice, and hope during difficult circumstances.

Lead with empathy before problem-solving

“I can hear how overwhelming this has been.”

“You have been carrying a lot.”

“It makes sense that you're feeling frustrated.”

Acknowledge the family's experience before immediately moving into solutions

Assume there is more to the story.

Families in crisis may appear angry, demanding, disengaged, or resistant. Consider what may be underneath the behavior—fear, exhaustion, grief, uncertainty, or previous negative experiences with systems.

Slow down the conversation

Crisis can impair attention, memory, and decision-making. Use simple language, pause frequently, and avoid overwhelming families with too much information at once.

Be transparent about what you can and cannot do

Avoid making promises you cannot keep. Explain the process, limitations, timelines, and next steps clearly. Predictability builds trust.

Validate without reinforcing escalation

You can acknowledge someone's emotions without agreeing with every statement or demand.

“I understand why you're upset. I want to work with you to figure out what we can do next.”

Ask before assuming

Don't assume what a family needs, understands, or is capable of managing. Ask:

“What feels most urgent to you right now?”

“What has worked in the past?”

“What are you most worried will happen?”

“What would make this plan feel manageable?”

Recognize caregiver trauma and compassion fatigue

Families may be making decisions while emotionally depleted. Acknowledge that the caregiver's capacity may be limited, especially after prolonged periods of crisis.

Preserve dignity during difficult conversations

Never reduce a family to a crisis, a diagnosis, or a "difficult case."

Remember that families may already feel judged, blamed, or misunderstood by multiple systems.

End with clarity and reassurance

Before ending the conversation, summarize the plan in plain language:

What happens next?

Who is responsible for each step?

When will the next contact occur?

Who should the family contact if the situation changes?

The difference between a family feeling dismissed and a family feeling supported can be as simple as *how* we communicate what happens next.

Trauma-informed communication is not about having the perfect words. It is about creating an interaction where families feel seen, heard, respected, and safe enough to participate in the solution.

WALK WITH THEM

Let’s process together…

Indicators of Effective Crisis De-escalation/Prevention

System/Behavioral Outcomes

- Reduced ER visits
- Fewer law enforcement calls
- Fewer psychiatric hospitalizations
- Increased service stability
- Decreased severity of behaviors

Family Outcomes

- Reduced caregiver stress and burnout
- Increased caregiver confidence
- Improved family stability
- Fewer disruptions to daily life
- Increased access to respite
- Families feel supported and know who to call *before a crisis occurs*

"Effective crisis prevention is not just the absence of a crisis. It is the presence of stability, support, and hope."

Before the crisis ends…

There is a mother who hasn't slept,

a father who is afraid to go home,

a sibling who has learned to stay quiet,

a caregiver who is grieving a life they never expected to lose,

a family who has been told to wait, to call someone else, to try again tomorrow.

And somewhere in the middle of all of that, there is a family asking the same question:

Does anyone see us?

Our job is not only to respond to the person in crisis

Our job is to see the people standing beside them,

To *listen* before we fix,

To *understand* before we judge,

To *support* before the breaking point.

Because when we care for the family, we strengthen the person.

The crisis may belong to a single person, but the trauma is often carried by the whole family.

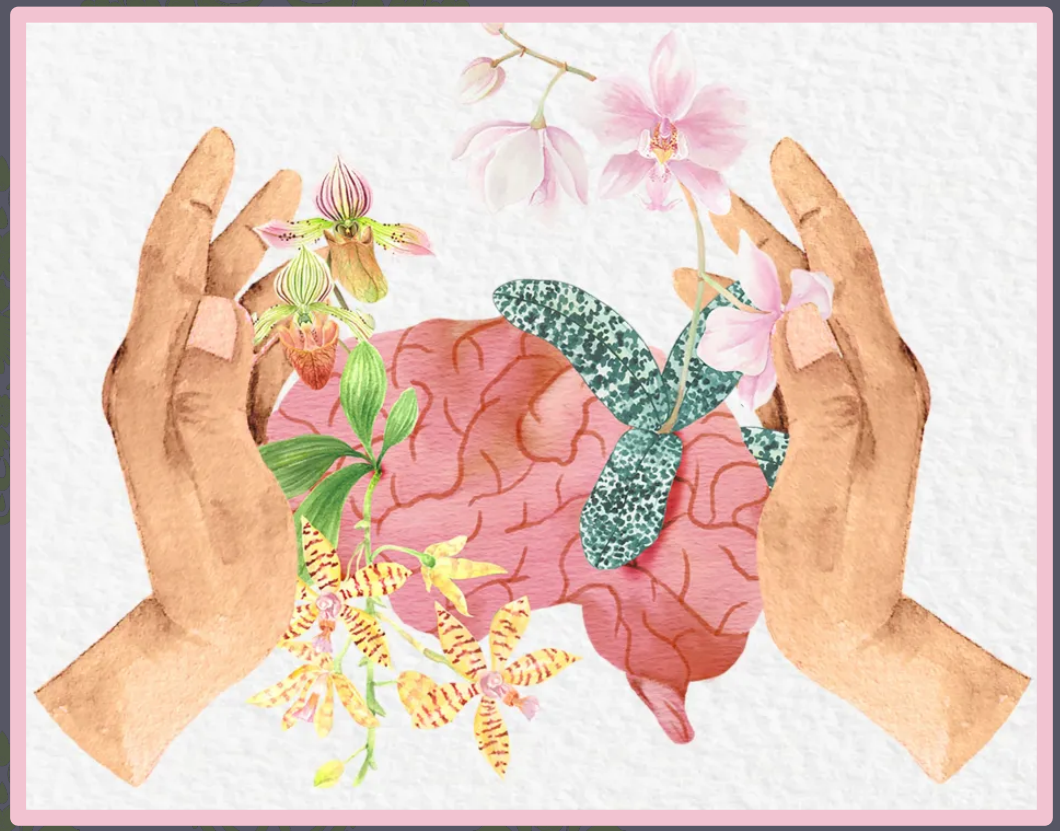
Our response should care for both.

Our response can **become** the intervention, even when we cannot change the outcome. The family may leave without the answer they wanted, but they should never leave feeling like their voice didn't matter.

Sometimes, we simply do not have the answer.

But we always have a choice in *how we respond*.

Sometimes, being heard is the first place that
hope begins.



Thank you

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