Bridging the Gap:
Strategies for Integrated and Informed Emergency Response and Mental Health Evaluation for Individuals with Intellectual and Developmental Disability and Mental Health Needs

Felicia Bates, MPH
NCSS Project Facilitator

National Center for START Services™
University of New Hampshire Institute on Disability
5 Chenell Drive, Suite 301, Concord, New Hampshire 03301
www.centerforstartservices.org

1

Outline

1

Understand individual and systemic challenges for crisis response for individuals with intellectual and developmental disabilities.

2

Discuss common vulnerabilities those with intellectual and developmental disabilities face increasing their susceptibility to crisis.

3

Explore ways to improve crisis response and mental health evaluations for individuals with intellectual and developmental disabilities.

2

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Defining a Crisis

A stressful event without the tools to address it

Unplanned and Unpredictable

More than simple stress

More than just mental illness

Immediate danger to self or others

Difficult and important decisions must be made

Presents an opportunity for growth

Defined by the person(s) experiencing it

3

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Emergency Department Usage for Individuals with Intellectual and Developmental Disability (IDD)

Higher emergency department usage

Frequent and **multiple** visits

Higher rate of admittance

Aggression is the leading precipitating factor for emergency department utilization

4

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

What Are People Saying about Crisis

Individual	Family / Caregiver	Emergency Services
• Scared • Misunderstood • Blamed • Invisible • Alone • Want help • Misdiagnosed	• Not heard, understood, or included • Worried or scared • Unsure of what to do to help • Don't feel safe • Last resort	• Limited knowledge of the person's history and unsure how to gather information • Limited expertise in IDD • Not appropriate for care • Time-consuming and challenging • Recidivism – *nothing's changed* • Unrealistic expectations

5

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

At Our Best

Individual	Family / Caregiver	Emergency Services
• Treated with empathy and understanding • Their voice is heard • Concerns are taken seriously • Assessed and matched to the relevant level of support or care • Shared decision making	• Able to act as an advocate • Equipped to provide support to the person and feel safe/comfortable in doing so • Know who to go to for help • Accurate information sharing • Know the appropriate use of acute mental health resources • Shared decision making	• Comfortable and confident in supporting, assessing, and treating individuals with IDD • Collaboration and communication • Multi-model assessment • Shared decision making

6

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

3 A's and Crisis Response

Access

Timely

Available

Appropriateness

Assessment

Define Need

Responsive

Accountability

Disposition Matches Real Need

Provides Tools

Follow-up

7

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Emergency Department Usage for Individuals with Intellectual and Developmental Disability (IDD)

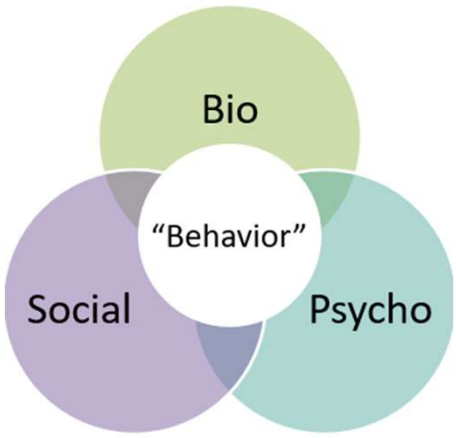
- **Higher** emergency department usage
- **Frequent** and **multiple** visits
- **Higher** rate of admittance
- **Aggression** is the leading precipitating factor for emergency department utilization

But Why?

8

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Intellectual and Developmental Disability (IDD) and Behavioral Health Symptoms



In most cases, co-occurring complex behavior problems in individuals with IDD are caused or maintained by a combination of factors.

9

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Intellectual and Developmental Disability (IDD)

A **neurodevelopmental disorder** characterized by significant limitations both in **intellectual functioning** and in **adaptive behavior**.

The onset of intellectual and adaptive deficits occurs during the **developmental period.**

- **Neurodevelopmental**
  Impairment of the growth and development of the brain
- **Intellectual Functioning**
  Deficits in reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experience
- **Adaptive Functioning**
  Results in a failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, deficits limit functioning.
- **Developmental Period**
  Birth to 18 (?)

10

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Factors that Increase Vulnerability and Risk for Crisis

- Communication Challenges
- Executive Functioning Limitations
- Biopsychosocial Factors

11

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Factors that Increase Vulnerability and Risk for Crisis

- **Communication Challenges**
- Executive Functioning Limitations
- Biopsychosocial Factors

12

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Communication and IDD

- Individuals with IDD commonly face communication challenges
- Communication challenges are often overlooked or not considered
- Difficulty self-reporting internal state, medical problems, side effects, and medical history
- When communication becomes challenging, individuals may resort to behavioral expression to communicate their needs or distress
- Evidence suggests that challenging behaviors, such as aggression or self-injury can be linked to unmet communication needs

13

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Factors that Increase Vulnerability and Risk for Crisis

- Communication Challenges
- **Executive Functioning Limitations**
- Biopsychosocial Factors

14

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

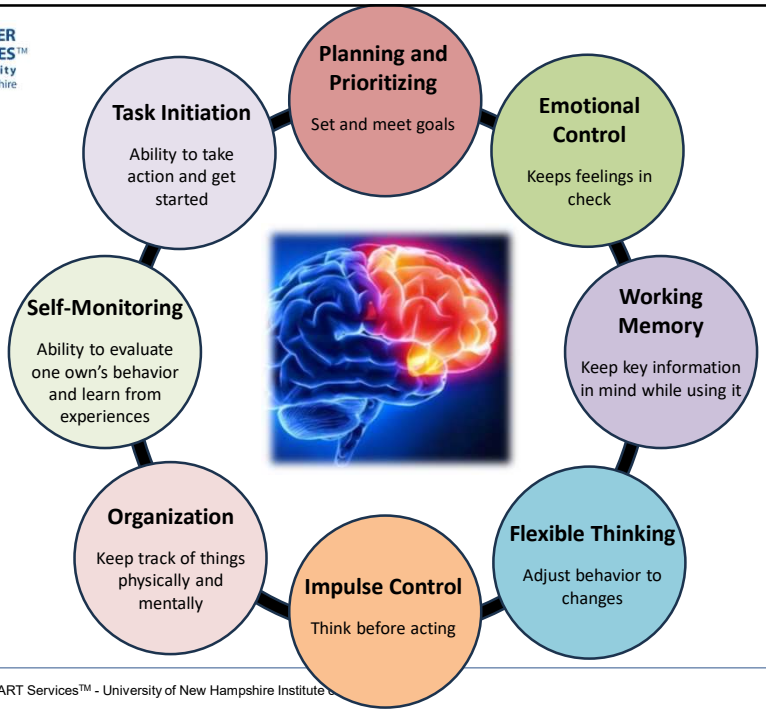
Executive Functioning

- Executive functioning refers to a set of **higher-level cognitive processes** that help individuals, plan, organize, and manage their thoughts, actions, and emotions to achieve goals.
  - "**CEO**" of the brain
  - Involves **complex mental tasks**
  - Guides behavior and decision-making

- Executive functioning primarily occurs in the prefrontal cortex of the brain
  - This area of the brain **sensitive to stress**
  - Even in **mild** stressful situations, this part of the brain can become **less active**, causing problems with thinking and decision-making. The brain prioritizes survival over long-term planning.

15

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire



16

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Executive Functioning and IDD

- Research indicates that IDD can have a significant impact on cognitive processes.
- As such, individuals with IDD commonly face challenges in various aspects of executive functioning.
- The degree of executive functioning challenges can vary depending on the severity and specific type of IDD
- Challenges in executive functioning can result in unrealistic expectations and misdiagnosis

17

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

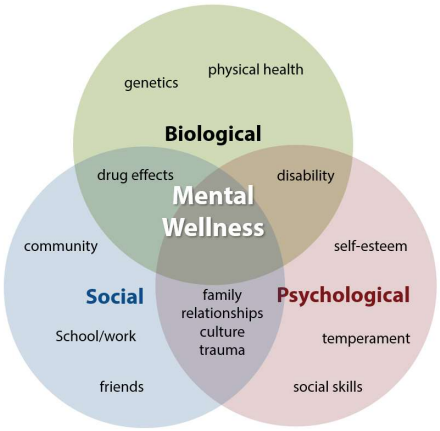
Factors that Increase Vulnerability and Risk for Crisis

- Communication Challenges
- Executive Functioning Limitations
- **Biopsychosocial Factors**

18

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

The Biopsychosocial Approach



19

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Biological Factors

Biological Factors	Genetics, medical conditions, neurodevelopmental history, medications, family history, substance use, in-utero exposure
Biological Risk Factors for Individuals with IDD	• Higher rates of medical conditions and earlier onset • 2x more likely to have coexisting conditions and at a younger age • Prescribed psychotropic medication at a higher rate • Higher rates of polypharmacy • May have few ways to express distress – often missed or not understood • Medical problems can cause significant changes in mood, behavior, and mental state that "mimic" acute psychiatric illness • Medical problems are often the "cause" of the presenting problem
Common Biological Vulnerabilities for Individuals with IDD	• Constipation • GERD/GI • Dental • Infections • Medication side effects • Sleep Problems • Seizures • Diabetes • Sinus problems • Headache • Pain • Thyroid

20

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Psychological Factors

Psychological Factors	Emotional state, cognitive patterns, thought process, perception, emotional regulation, mental health, personality traits, coping mechanisms (response to stressors), communication, beliefs
Psychological Risk Factors for Individuals with IDD	• Higher rate of mental health conditions (1.5 -3 times) • Higher rates of trauma (estimated 90%) and negative life experiences • Intellectual, cognitive, and executive functioning limitations at baseline • May be difficult to express internal state • Mental health symptoms can present differently • Often misdiagnosed, underdiagnosed, or undiagnosed
Common Psychological Vulnerabilities for Individuals with IDD	• Lack of coping skills/resiliency • Impaired communication abilities • Executive functioning impairments • Anxiety • Depression • Trauma

21

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Social Factors

Social Factors	Relationship, family dynamics, social support networks, cultural background, environment, services, socioeconomic status, access, loss, separation, trauma
Social Risk Factors for Individuals with IDD	• Often overlooked or not considered • Access to services and supports can be limited • Often lack of opportunities and/or support to build/maintain relationships, be included, or contribute • Often need help to address these things • More dependent on external structures – emotional challenges can arise when expectations or supports change • Can act as “triggers”
Common Social Vulnerabilities for Individuals with IDD	• Loneliness, isolation or boredom • Traumatic experiences • History of rejection • Lack of control • Lack of routine / changes in routine • Challenges/changes in relationships • Noise • Temperature • Lack of control

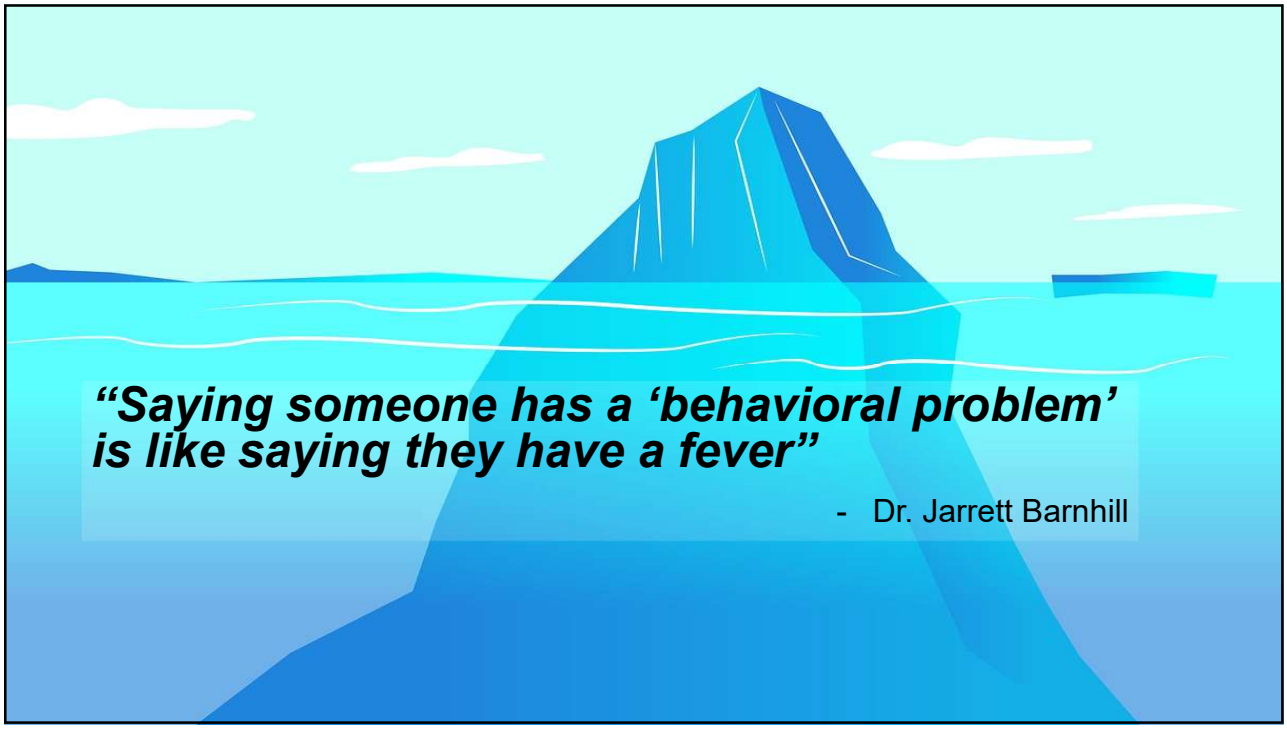
22

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Same Patient, Same Problem, Different Day

Presenting Problem	Influencing Factor
• Aggression	• Constipation
• Aggression	• EPS and sedation
• Aggression	• Reflux
• Aggression	• Depression
• Aggression	• Agitated friend
• Aggression	• Boredom
• Aggression	• Family stress
• Aggression	• Impacted wisdom tooth
• Aggression	• Psychosis

23



24

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

What Do We Know About Aggression

- Aggression is like a fever - *not diagnostically significant*
- Aggression is the final common pathway – *it's a sign of distress*
- The severity of the aggression does not necessarily indicate the seriousness of the underlying cause of the aggression
- **A**ll **B**ehavior is **C**ommunication
- But how do we understand what they're trying to communicate?
  What is the actual **problem**?

25

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

What's the Problem

- The **presenting problem** *(i.e. aggression)*
  - Is a symptom of an underlying vulnerability that resulted in crisis
  - Does not provide enough information
- Understanding what the **true problem** is requires structural-systemic interventions
  - Further exploration and assessment
    - Accurate context and history
    - Biopsychosocial assessment – expect the problem to have multiple contributing factors
  - Systemic and Interdisciplinary Collaboration
  - Trauma-informed approach
  - Strengths-based and solutions-focused
  - Takes time

26

Optimize Information Gathering, Assessment, and Intervention

- Identify accurate informants
  - The person who has the information you need may not be in the room
- Engagement
  - Connect with the system of support
  - Engage the individual
- Collaboration and shared decision making is needed
  - Build rapport
  - Clarify roles and goals

27

Optimize Information Gathering, Assessment, and Intervention

Effective Communications

- Use simple/plain language
- Speak slowly
- Use a calm/low voice and a non-judgmental tone
- Pause, give time for a response
- Sensitivities to non-verbal cues
- Visuals
- Gestures
- Be mindful of your non-verbal body language
- Use active listening – focus on the feeling
- Show warmth and positive regard
- Avoid the **escalator** - Don't talk about them in front of them and not include them, make threats, rehash the event, or place blame

28

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Optimize Information Gathering, Assessment, and Intervention

Sign vs Symptom

- Sign - Objective, measurable, observable, and typically external.
- Symptom - subjective experiences or sensations reported by the person experiencing it. They may not be directly observable or measurable by others.

Informants

- Overemphasize externalizing **signs**
- Under report internalizing **symptoms**

Individuals with IDD

- Have difficulty reporting internalizing **symptoms**
- May not know what they need to report

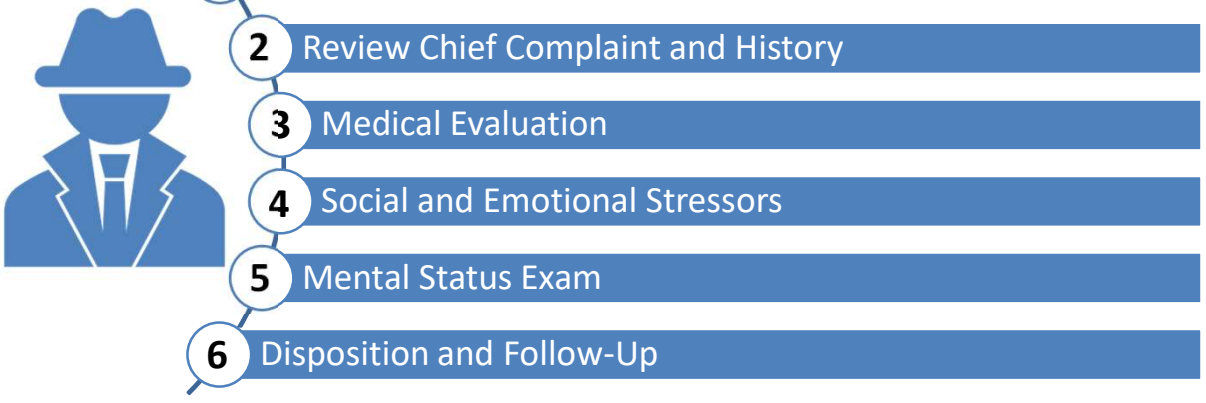
Accurate Assessment

- Relies on 3rd party information
- We must make sure we are interpreting the signs appropriately and considering the potential symptoms
- Ask what people **SEE** instead of what they **THINK**
- **DESCRIBE** not label

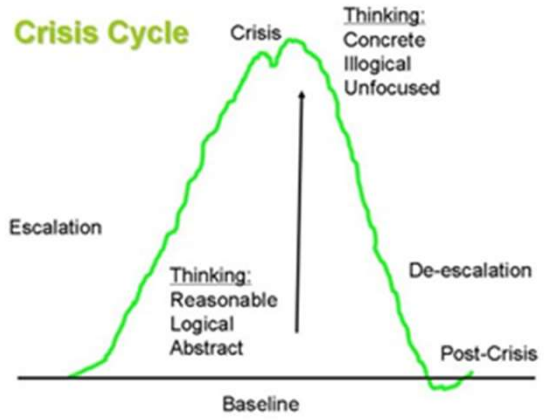
29

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

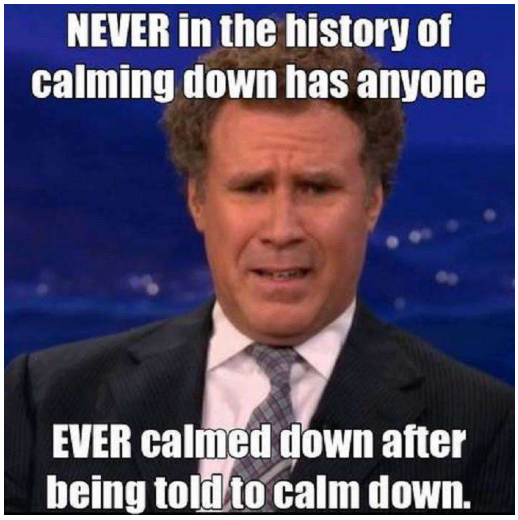
The Evaluation Process



30



31



32

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Step 1: Safety and De-Escalation

- Reassurance
- Maintain physical space if needed
- Be present without demands or time limits
- Reduce sensory input
  - Lower lights
  - Limit people in the area
  - Limit noise
  - Avoid scents
- Ask about any other known triggers that might be able to be addressed
- Offer calming/sensory or preferred items
- Try to address any immediate concerns and needs
- Review crisis plan if available
- May need to use PRN medications

33

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

REMEMBER

- Collaboration is NEEDED to get an accurate assessment
- Throughout the assessment ask for a **description**. What do they **see?**
- Avoid assigning judgment or coming to a decision too soon

"I don't listen to the evidence, I like to make up my own mind."

34

Step 2: Review Chief Complaint and History

- **Age, Level of Intellectual Disability** *(more on this later)*
- **Presenting Issue** *(remember description vs. label)*
  - Summary of the reason for the assessment today per the patient
  - Summary of the reason for the assessment today per informants
- **History of presenting challenges** *(remember description vs. label)*
  - When was the last time the person was doing well? What did it look like?
  - Has this happened before? What did it look like?
  - What precipitated/triggered the behavior?
  - Which interventions have helped in the past? Which did not? Which interventions have been tried today?

35

Step 3: Medical Evaluation

- Commonly **diagnostically overshadowed** due to externalizing symptoms and limitations in reporting internalized symptoms
  - Medical problems can “masquerade” as mental health symptoms
- In some cases, the only indicator of a medical problem may be a change in behavior or daily functioning
- Consider a complete review of systems and physical example

“Imagine the only way you received treatment for a medical condition is if someone notices without you telling them”

36

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Step 3: Medical Evaluation

- **Gather History**
  - Known medical conditions or medical conditions that have precipitated crises in the past?
  - Current medications
  - How would you know the person is in pain?
  - How has the person shown signs of pain, discomfort, or illness in the past?
- **Identify changes in the last 6 months**
  - A new medical problem was identified
  - A new medication was started
  - A medication was changed
  - An old health problem recently worsened
  - Vision or hearing loss/change
  - Loss or change in mobility
  - New or unusual movements
  - Urinary or fecal incontinence
  - Person appears as if they may be in pain
- **When in doubt, rule it out**
  - Constipation
  - GERD/GI
  - Dental
  - Infections
  - Medication side effects
  - Sleep problems
  - Seizures
  - Thyroid
  - Headache
  - Sinus problem
  - Diabetes
  - Pain

37

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Step 4: Social and Emotional Stressors

- Individuals with IDD are often more **dependent on external structures** – emotional problems can arise when expectations and supports change or are inappropriate
- Emotional Issues – sensitive to stress and may lack coping skills
- Even small stressors, especially when compounded can have a significant impact
  - Remember what we know about the prefrontal cortex

38

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Step 4: Social and Emotional Stressors

- **Gather History**
  - Significant People
  - Current Living Situation
  - Day Services or Educational Setting
- **Identify Recent Changes, Stressful Events, or Emotional Circumstances**
  - Changes in staff
  - New living situation
  - Changes in routine or task
  - New peers
  - Loss of peers
  - Change in a day program, job, or school
  - Limited or lack of natural supports
  - Changes in doctors, therapists, teachers
  - Family, friends, housemates having problems
  - Illness or death of a loved one
  - Changes in level, rate, or type of contact with family or friends
  - Suspected or confirmed abuse
  - Inconsistencies or changes in support
  - Bullying
  - Conflict

39

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Step 5: Mental Status Exam

- Looking for symptoms of psychiatric illness
  - Don't forget these changes may result from medical disorders, problems with expectations/support, or emotional upsets.
- Look for significant **changes** in baseline level of functioning outside the normal variation for the person.
  - New?
  - Change in intensity or frequency?
  - Meet criteria for diagnosis?
- Be familiar with the varied ways in **which development can affect the presentation of many disorders**.
  - Resources: DSM-ID 2, Integrated MH Treatment Guidelines for Prescribers of IDD (NCSS website)

40

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Step 5: Mental Status Exam

- **Gather History**
  - Baseline Functioning - *cognitive and adaptive functioning, vegetative, communication, social engagement*
  - Current psychiatric diagnosis
  - What do/have symptoms looked like in the past for these diagnoses
  - Current medications
  - What's the person's ability to express their internal state?
- **Ask and observe for presence, changes, onset, and duration**
  - Physical Appearance
  - Hygiene
  - Eye Contact
  - Motor Behavior
  - Primary Mode of Communication
  - Speech
  - Ambulation
  - Mood
  - Affect
  - Thought Process
  - Impulse Control
  - Hallucinations
  - Delusions
  - Sleep
  - Appetite
  - Energy
  - Memory
  - Alcohol / Drug Use
  - Executive Functioning
    - Orientation
    - Attention
    - Judgement
  - Risk Assessment
    - Suicidal, Access to means, Plan, History
    - Homicidal, Access to means, Plan, History

41

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Diagnostic Factors the May Impact Assessment

Diagnostic Overshadow	**Definition:** When all behavioral symptoms, emotional, or social issues are attributed to one diagnosis and other factors are not taken into consideration. Behavior becomes the diagnosis or focus of treatment. **Example:** Any difficulties a person has are because they have IDD.
Baseline Exaggeration	**Definition:** Presentation that exists at low rates and intensity may dramatically increase under stress or a mental health condition. **Example:** A person with ASD usually paces but now it's increased and they're also jumping.
Intellectual Distortion	**Definition:** Questions or ideas are more complex or abstract than the person can understand. The person may not understand/have a concept of what you're asking or why. **Example:** Asking a person with ASD if they hear voices and they respond with "yes" because they can hear the person talking to them and have no concept of hallucination.
Psychosocial Masking	**Definition:** Something that is developmentally appropriate is seen as a possible psychiatric symptom. Misunderstanding of developmental delay – what may be developmentally appropriate for the person. **Example** An imaginary friend may be mistaken for a delusion. Or a delusion of being the police chief may be mistaken for a harmless fantasy.
Cognitive Disintegration	**Definition:** Due to a lack of cognitive reserve, people with IDD may dramatically decompensate under stress. Stress can have a significant impact and lead to a decline in skills or abilities. **Example:** Stress leads to a decline in communication and coping skills but the stressors or not considered.

42

Considerations for Emergency Treatment for Psychiatric Disorder in IDD

- If symptoms meet the criteria for a psychiatric episode identify the best **provisional** diagnosis – avoid making a definitive diagnosis
- Medication – indicate used to manage the emergency – does not imply diagnosis (especially if just used as safety intervention)
- Recommend follow-up and re-evaluation of diagnosis and treatment
- Consider what information supports need to know
  - What to track
  - What side effects to be aware of

43

Step 6: Disposition and Follow-Up

- Consider all **biopsychosocial** factors that may contribute to presenting problem
  - Systemic and multi-disciplinary approach
  - Expect the problem to have multiple contributing factors
  - Disposition should match the needs identified through the assessment
  - Remember – behavior is a symptom
- Appropriate place to manage the person's current needs
  - Home
  - Alternative Crisis Home
  - Inpatient
- What will be needed in terms of support and communication at any level to address the person and system's needs, promote stability, and safety
- Follow-up and future planning

44

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Final Thoughts

- Crisis is a stressful event for everyone
- **Aggression** is a **symptom**, not a diagnosis
- Individuals with IDD require multi-model assessment
- System collaboration and communication is needed – *Shared decision making*
- Disposition planning and follow-up should address the needs identified in the assessment

45

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

46

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

References

- Centers for Disease Control and Prevention. (2022, May 16). CDC's work on developmental disabilities. https://www.cdc.gov/ncbddd/developmentaldisabilities/about.html
- Charlot, L., Abend, S., Ravin, P., Mastis, K., Hunt, A., & Deutsch, C. (2011). Non-psychiatric health problems among psychiatric inpatients with intellectual disabilities. *Journal of intellectual disability research: JIDR*, *55*(2), 199–209. https://doi.org/10.1111/j.1365-2788.2010.01294.x
- Diagnostic and Statistical Manual of Mental Disorders, 5th Ed. (DSM5) 2013 American Psychiatric Association
- DM-ID: Diagnostic Manual – Intellectual Disability: A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability, 1st Edition 2007 NADD Press
- Durbin, A., Balogh, R., Lin, E. ***et al.*** (2018) Emergency Department Use: Common Presenting Issues and Continuity of Care for Individuals With and Without Intellectual and Developmental Disabilities. *J Autism Dev Disord* 48, 3542–3550. https://doi.org/10.1007/s10803-018-3615-9
- Emerson, E., Hatton, C., Baines, S., & Robertson, J. (2016). The physical health of British adults with intellectual disability: cross sectional study. *International journal for equity in health*, *15*, 11. https://doi.org/10.1186/s12939-016-0296-x
- Glover, G., Williams, R., Heslop, P., Oyinlola, J., & Grey, J. (2016). Mortality in people with intellectual disabilities in England. Journal of Intellectual Disability Research, 60(1), 57-67. https://doi.org/10.1111/jir.12314
- "Healthcare for adults with Intellectual and Developmental Disabilities: ER-IDD Stabilization Protocol. (2023, October). Toolkit for Primary Care Providers." [Website]. https://iddtoolkit.vkcsites.org/
- "Healthcare for adults with Intellectual and Developmental Disabilities: Initial Management of Behavioral Crisis In Primary Care. (2023, October). Toolkit for Primary Care Providers." [Website]. https://iddtoolkit.vkcsites.org/
- Kalb, L., Stuart, E., Freedman, B., Zablotsky, B., & Vasa, R. (2012). Psychiatric-related emergency department visits among children with an autism spectrum disorder. Pediatric Emergency Care, 28(12), 1269-1276.

47

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

References

- Lineberry, S., Bogenschutz, M., Broda, M., Dinora, P., Prohn, S., & West, A. (2023). Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities. *Community mental health journal*, *59*(6), 1119–1128. https://doi.org/10.1007/s10597-023-01091-4
- Lin, J.-D., Yen, C.-F., Loh, C.-H., Hsu, S.-W., Huang, H.-C., Tang, C.-C., Li, C.-W., & Wu, J.-L. (2006). A cross-sectional study of the characteristics and determinants of emergency care utilization among people with intellectual disabilities in Taiwan. Research in Developmental Disabilities, 27(6), 657-667.
- Lunsky, Y., Balogh, R., & Cairney, J. (2012). Predictors of emergency department visits by persons with intellectual disability experiencing a psychiatric crisis. *Psychiatric services (Washington, D.C.)*, *63*(3), 287–290. https://doi.org/10.1176/appi.ps.201100124
- McBride, O., Heslop, P., Glover, G., Taggart, T., Hanna-Trainor, L., Shevlin, M., & Murphy, J. (2021). Prevalence estimation of intellectual disability using national administrative and household survey data: The importance of survey question specificity. *International journal of population data science*, *6*(1), 1342. https://doi.org/10.23889/ijpds.v6i1.1342
- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. Journal of Intellectual Disability Research, 51(11), 850-865.
- Peña-Salazar, C., Arrufat, F., Santos, J. M., Fontanet, A., González-Castro, G., Más, S., Roura-Poch, P. & Valdés-Stauber, J. (2018). Underdiagnosis of psychiatric disorders in people with intellectual disabilities: Differences between psychiatric disorders and challenging behaviour. Journal of Intellectual Disabilities
- Van den Bemd, M., Schalk, B. W. M., Bischoff, E. W. M. A., Cuypers, M., & Leusink, G. L. (2022). Chronic diseases and comorbidities in adults with and without intellectual disabilities: comparative cross-sectional study in Dutch general practice. *Family practice*, *39*(6), 1056–1062. https://doi.org/10.1093/fampra/cmac042

48

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Supporting literature for the START Model

The following publications provide additional information and context about the development and refinement of the START model by Joan Beasley, PhD, and colleagues.

Beasley, J., Kroll, J., & Sovner, R. (1992). Community-based crisis mental health services for persons with developmental disabilities: The START model. *The Habilitative Mental Healthcare Newsletter*, *11*(9), 55-58.

Beasley, J. (1997). The three A's in policy development to promote effective mental healthcare for people with developmental disabilities. *The Habilitative Mental Healthcare Newsletter, 16 (2)*, 31-33

Beasley, J. B., Kroll, J. (1999). Family caregiving part II: Family caregiver professional collaboration in crisis prevention and intervention planning. *Mental Health Aspects of Developmental Disabilities, 2*(1), 1-5.

Beasley, J. B. (2000). Family caregiving part III: Family assessments of mental health service experiences of individuals with mental retardation in the northeast region of Massachusetts from 1994 to 1998. *Mental Health Aspects of Developmental Disabilities, 3*(3), 105-113.

Beasley, J. B. (2001). Collaborative services in Massachusetts: The START/Sovner Center Program. *Impact*, *14*(3), 16-17.

Beasley, J. B., & duPree, K. (2003). A systematic strategy to improve services to individuals with coexisting developmental disabilities and mental illness: National trends and the 'Connecticut blueprint'. *Mental Health Aspects of Developmental Disabilities*, *6*(2), 50-58.

Beasley, J. B. (2003). The START/Sovner Center Program in Massachusetts. *The NADD Bulletin, 6*(3), 57-59.

49

NATIONAL CENTER for START SERVICES™ Institute on Disability University of New Hampshire

Acknowledgement

The University of New Hampshire (UNH) recognizes the decades-long contributions of Dr. Joan Beasley, to the field of therapeutic interventions for individuals with intellectual and developmental disabilities and mental health needs. Beginning in 1992, Dr. Beasley and co-authors published a series of papers describing protocols that would ultimately become the **S**ystemic, **T**herapeutic, **A**ssessment, **R**esources, and **T**reatment (START)/Sovner Center Model.

The National Center for START Services™ (NCSS) was founded in 2011 at the University of New Hampshire's Institute on Disability. Through the efforts and dedication of Dr. Beasley and her colleagues, the National Center for START Services™, provides technical assistance, training, evaluation, and certification to START programs and resource centers in more than 15 states, serving the mental health needs of thousands of individuals with intellectual disabilities. Today, START is an evidence-informed and evidence-based model which strives to build capacity across systems to meet the needs of individuals with IDD-MH.

Dr. Beasley is a Research Professor at the University of New Hampshire where she conducts research on the mental health aspects of intellectual and developmental disabilities. She currently leads the National Research Consortium on Mental Health in Intellectual and Developmental Disabilities at UNH.

50