Identifying symptoms and signs of mental distress in adults with intellectual and developmental disabilities

Introduction

Emotional distress is common in adults with intellectual and developmental disabilities, associated with medical conditions, unmet social-emotional developmental needs, life events, adversity and trauma. It frequently presents as distressing behaviors. Psychiatric diagnostic assessment of people with intellectual and developmental disabilities is complex, especially in those with severe to profound disabilities who have limited or no ability to communicate their thoughts or internal feelings. This tool supports the primary care clinician in determining whether the patient's distress and behaviors of concern are likely caused by emotional distress from current or past life circumstances or by psychiatric disorder.

How to use this tool

Use this tool after having assessed a person's health (H), environment (E), and lived experiences (L), to determine if referral for psychiatric assessment (P) or intervention is needed. See: HELP with Emotional and Behavioral Concerns.

Diagnostic complexity

Table 1 shows three major groups of psychiatric disorders and conditions relevant to intellectual and developmental disabilities: 1) trauma-related and adjustment disorders (e.g., PTSD, bereavement); 2) mood, anxiety, and psychotic disorders; and 3) lifespan disorders (neurodevelopmental disorders, e.g., autism, ADHD); genetic syndromes; dementia; and other conditions (alcohol misuse).

Part of the complexity in diagnosing psychiatric disorders in IDD is the overlap of diagnostic criteria (i.e., symptoms and signs) for disorders in these different groups. For example, a person can show irritability and sleep disturbance associated with both trauma-related disorders and anxiety or mood disorders as well as autism spectrum disorder.

Differentiate between disorders

Differentiating between the groups of psychiatric disorders relies on a) whether there is specific trauma or life event, b) whether a stable period (baseline) without distressing behavior preceded the onset of behavior issues, c) the age of onset, d) reports from the patient about their feelings and mental experiences, if possible, d) observations of the patient's behavior and emotional state(s). Differentiating between these groups has implications for treatment.

Screen for stressors and autism

Emotional distress can be a sign of a triggered autonomic nervous system in response to stressors (e.g., life events, trauma, abuse) and being overwhelmed. Without attending to stressors, symptoms like anxiety may mistakenly be considered an anxiety disorder rather than an adaptive response to triggers or trauma.

Sensory sensitivities and idiosyncratic language in autism can be mistaken for psychiatric disorder (e.g., phobias and psychotic disorders).

In addition, it is important to understand the patient's baseline social-emotional functioning.

Recognize symptoms and signs

Work together with family/support persons to identify, monitor, and document target behaviors and emotional concerns, using the *Symptoms and Signs List* (Table 2) and *Symptoms and Signs Form* (page 3 – 5). Describe how they fluctuate over time, associated with events, environments, and people in the patient's life.

This process of information collection contributes to a psychiatric evaluation, when it is required. If psychiatric evaluation is not available, the information will help to inform a trial of intervention (e.g., behavioral or psychological therapy, environmental changes, targeted medication to stabilize emotion/affect).

Table 1: Onset, diagnostic considerations, intervention implications, and symptoms and signs for the most common mental health disorders affecting people with intellectual and developmental disabilities.

1. Trauma- and stressor-related disorders (e.g., PTSD, C-PTSD, adjustment disorder)	2. Anxiety, mood, and psychotic disorders	3. Lifespan (neurodevelopmental) disorders; genetic syndromes; dementia; other conditions
ONSET CONSIDERATIONS		
▸ Dysregulation of the autonomic nervous system due to stressors and triggers (e.g., trauma, abuse, life event) can arise at any time resulting in fight-flight-freeze and shutdown behaviors.	▸ Sustained episode of significant change in behavior, emotions, functioning, thoughts and feelings from the person's usual baseline and patterns of being. ▸ Diagnosis reflects changes in affect (e.g., mood and anxiety disorders) and thought processes (psychosis).	▸ Onset in the developmental period and typically diagnosed in childhood (e.g., autism, ADHD); or ▸ Present from conception (e.g., Down syndrome); or ▸ Onset in later adulthood (e.g. dementia).
DIAGNOSTIC CONSIDERATIONS		
▸ Diagnosis requires identification of past or present traumas, adversity, life events, stressor(s) and trigger(s) associated with the distressing behavior. ▸ Not recognizing baseline social-emotional functioning can give rise to inappropriate expectations and further trauma. ▸ Meeting full diagnostic criteria may be impossible when verbal or assistive communication is difficult. ▸ Engage with patient using pictures, signs, gestures, facial expressions and body language to engage emotionally and assess emotional state, affect, and responses to the environment.	▸ Diagnosis requires monitoring of identified target symptoms (feelings) and signs (behavior, emotions) over time, including physiological changes, appearance, and affect. ▸ Symptoms and signs may overlap with those of stressor and adjustment disorders (column 1).	▸ Can complicate the manifestation of any co-existing emotional or psychiatric disorder. ▸ Consult information about syndrome-specific behavioral phenotypes and associated mental health vulnerability. ▸ Sensory sensitivities, communication and idiosyncratic language in autism can lead to diagnostic errors and errors in ascribing intentional states.
INTERVENTION TRIAL CONSIDERATIONS		
▸ The first line of treatment is to ensure the patient is safe and feels safe. Safety is treatment and crucial for healing from trauma. ▸ Attend to the impact of trauma: remove current triggers (cues of danger) if possible, introduce cues of safety (e.g., safe people, safe living space, trauma-informed care); refer for trauma-informed therapy if available, as needed; help to manage dysregulated states. ▸ Medication is not the first line of treatment but may be helpful to manage symptoms in the short term.	▸ These disorders respond to psychological therapies, environmental adjustments, and targeted medication.	▸ Pharmacological, behavioral and psychological interventions for these conditions are available, although access to behavioral and psychological therapies may be limited in many areas. ▸ Stressor-related and adjustment disorders (column 1) and anxiety, mood, and psychotic disorder (column 2) can be concurrent.

Table 2: Symptoms and signs (behaviors) to consider in assessing the need for psychiatric assessment and treatment

Trauma- and stressor-related disorders	Episodes of disorder	Life-span and other conditions
PTSD ▸ e.g, from a single trauma leading to: re-experiencing, avoidance, changes in mood, physical and emotional reactions, hypervigilance **Complex PTSD** ▸ e.g., from chronic, repeated, prolonged trauma, leading to: emotional dysregulation, change in relational capacities, distortions of self-identity, dissociation **Adjustment disorder** ▸ Emotional and behavioral distress to an identifiable stressor (e.g., change of caregiver/support person or living circumstance) ▸ Overall, trauma responses are underpinned by ANS reactivity to real and perceived danger and life threat and include: • Behaviors of fight: self-injury, hitting, damage to environment, hypervigilance • Behaviors of flight: running away, withdrawing, not engaging, anxiety • Behaviors of freeze: resisting, refusing, catatonic-like	**Anxiety-like** ▸ Anxiety ▸ Panic ▸ Phobias ▸ Obsessive thoughts ▸ Compulsive behaviors ▸ Rituals and routines **Mood-related** ▸ Agitation ▸ Irritability ▸ Aggression ▸ Intrusiveness ▸ Hyper-sexuality ▸ Self-harm or self-injurious behavior ▸ Loss of interest ▸ Unhappy or miserable ▸ Changes in: • Appetite or interest in food • Eating pattern • Sleep ▸ Under- and over-activity ▸ Change in weight **Psychotic-related** ▸ Psychotic and psychotic-like symptoms (e.g., new unusual behavior or talk, delusions, hallucinations)	**a) Neurodevelopmental** ▸ ADHD-related • Inattention • Hyperactivity • Impulsivity ▸ Movement-related • Catatonia (‘stuck’) • Tics • Stereotypies **b) Genetic syndromes** ▸ Behavioral phenotypes **c) Dementia-related** ▸ Concentration ▸ Memory **d) Other** ▸ Alcohol misuse ▸ Drug abuse ▸ Sexual issues and problems ▸ Psychosomatic complaints (medically unexplained symptoms), possibly related to ANS dysregulation and trauma.

Identifying Symptoms and Signs of Mental Distress in Adults with Intellectual and Developmental Disabilities

Practice tips

- Obtaining all information required to decide whether referral to a mental health team is beneficial, may involve multiple visits with the patient and family/support persons.
- Information about symptoms and signs should always be obtained from the patient and someone who knows the person well. Otherwise, do not proceed the assessment.
- If the patient is unable to visit the clinician's office (e.g., disruptive behavior, anxiety), arrange a home or virtual visit instead

1. PATIENT INFORMATION

Name

First Last

Date of Birth

IDD etiology

Level of IDD

☐ mild ☐ moderate ☐ severe ☐ profound ☐ unknown

Sensory impairments and sensitivities

Hearing impairment: ☐ Yes ☐ No

Hearing sensitivity: ☐ Yes ☐ No ☐ Hyper ☐ Hypo

Vision impairment: ☐ Yes ☐ No

Vision sensitivity: ☐ Yes ☐ No ☐ Hyper ☐ Hypo

Other sensory impairments and sensitivities, including a lack of awareness of the body's internal signals (e.g. heart racing, hunger):

Autism Spectrum Disorder

☐ Yes ☐ No

Level

☐ 1 ☐ 2 ☐ 3

Social-emotional functioning and needs:

Person accompanying patient

First Last

Relation to patient/How long have they known the person?

2. DESCRIBE SYMPTOMS AND SIGNS

Practice tips

- Explore current symptoms (feelings and mental experiences) and signs (behaviors, emotional states, and physiological responses) with the patient and someone who knows the patient well.
- Use assessment tools (e.g., self-report and observational scales) designed for adults with intellectual and developmental disabilities and their family/support persons.
- Be mindful of patient's sensitivity to exploring difficult experiences and consider how best to obtain information (e.g., time needed, comfortable relationship, patient feels safe).
- For nonverbal patients or those with communication difficulties, engage directly using alternative and adaptive ways of interaction, including body language, to assess and tune into the person's affect.

Practice tools

- Glasgow depression scale and Glasgow anxiety scale
- NTG Early Detection Screen for Dementia
- HELP with Emotional and Behavioral Concerns in Adults with IDD

Concerns

Patient perspective (e.g., feelings, worries, thoughts):

Family/support person's perspective:

When did these concerns first arise (and by whom)?

Baseline

Identify a day, date, or event, when the patient was last doing well, feeling their usual self. Ask the patient or family/support person to describe a "day in the life of the patient" to establish baseline daily functioning (e.g., ADLs, level of independence, social engagement, communication, interests):

Symptoms and signs reported by family/support persons

Behaviors toward self, others, or environment:

Appearance (e.g., body language, gestures, movements):

Physiological symptoms (e.g., sweating, weight, trembling, getting stuck, withdrawn, heart rate, blood pressure):

Overriding affect (e.g., sad, happy, fearful, spaced out, confused):

Emotional engagement with other people:

Other:

Symptoms and signs observed by primary care provider

Observation context (e.g., office, home, virtual, video):

Behaviors toward self, others, or environment:

Appearance (e.g., body language, gestures, movements):

Physiological symptoms (e.g., sweating, weight, trembling, getting stuck, withdrawn, heart rate, blood pressure):

Overriding affect (e.g., sad, happy, fearful, spaced out, confused):

Symptoms and signs observed by primary care provider

Emotional engagement with other people:

Other:

How do the symptoms and signs differ from baseline?

What life events have occurred and how did the person respond?

Past:	Current:

Has trauma occurred and how did the patient respond?

Past:	Current:

Are the current concerns related to trauma or life events (past or current)?

3. MONITOR SYMPTOMS AND SIGNS

Practice tips

- If available, arrange for a functional behavior analysis with a behavioral therapist to understand the patient's behavior in the context of their supports and environment. (Note: The patient may be responding to less obvious, internal triggers, e.g., pain, trauma).
- Discuss with the family/support person which target behaviors to monitor over time. Look for patterns, associations with events or persons, life events.
- Identify triggers to behavioral and emotional escalation: what makes the patient feel safe (cues of safety) or unsafe (cues of danger) from the patient's perspective?

Practice tools

- Monitoring chart: Antecedent-Behavior-Consequence

Target behaviors

Triggers, antecedents, associations with events, safety cues

4. SUMMARY AND CLINICAL FORMULATION

Findings, possible underlying causes, and action plan (See Tables 1 and 2, pages 2-3 above)

5. TRIAL OF INTERVENTIONS

Practice tips

- Try interventions according to the clinical formulation and possible causes within the three categories of disorders (Table 1) (e.g., address triggers, trauma-informed care, safety and feeling safety, psychological therapies, advocacy and social prescriptions, targeted medication for specific symptoms).
- Monitor and document changes in behaviors and affect in response to the intervention and effectiveness. Review the clinical formulation if no alleviation of distress in response to the interventions.

Practice tools

- Mental Health Interventions

Intervention(s)	Result(s)

Supporting materials

i. **Glasgow Depression Scale for People with a Learning Disability**
Glasgow University, Cuthill, Espie & Cooper, British J. Psychiat, 2003.
www.cambridge.org/core/services/aop-cambridge-core/content/view/4DF91A3D990E6AAFF40656DEADE3F7BC/S0007125000228341a.pdf/development_and_psychometric_properties_of_the_glasgow_depression_scale_for_people_with_a_learning_disability.pdf

ii. **Glasgow Anxiety Scale for People with an Intellectual Disability**
Glasgow University, Mindham & Espie, JIDR, 2003
https://onlinelibrary.wiley.com/doi/epdf/10.1046/j.1365-2788.2003.00457.x

iii. **NTG Early Detection Screen for Dementia**
National Task Group on Intellectual Disabilities and Dementia Practice, American Academy of Developmental Medicine and Dentistry
www.the-ntg.org/ntg-edsd

iv. **HELP with Emotional and Behavioral Concerns in Adults with Intellectual and Developmental Disabilities**
Health Care for Adults with Intellectual and Developmental Disabilities
iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/help-with-emotional-and-behavioral-concerns/

v. **Monitoring Chart: Antecedent-Behavior-Consequence**
Health Care for Adults with Intellectual and Developmental Disabilities
iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/abc-antecedent-behavior-consequence-chart/

vi. **My Coping Tool: How I Deal With Stress**
Health Care for Adults with Intellectual and Developmental Disabilities
iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/my-coping-tool/

vii. **Mental Health Interventions for Adults with Intellectual and Developmental Disabilities.**
Health Care for Adults with Intellectual and Developmental Disabilities
iddtoolkit.vkcsites.org/mental-health-interventions/

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