SURREY PLACE

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 problem behaviours. Psychiatric diagnostic assessment of people with intellectual and developmental disabilities is complex, especially in those with severe to profound disabilities who have little or no verbal language. This tool supports primary care providers in determining whether the patient's distress and behaviours 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 Behavioural Concerns in Adults with Intellectual and Developmental Disabilities*[iv]

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 intellectual and developmental disabilities 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.

Differentiate between disorders

Differentiating between the three groups of psychiatric disorders relies on a) whether there is specific trauma or life event, b) whether a stable period (baseline) without behaviours of concern preceeded the onset of behaviours of concern, c) the age of onset, d) reports from the patient about their feelings and mental experiences (symptoms), d) observations of the patient's behaviours and emotional state(s) (signs). Differentiating between these groups of disorder 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 caregivers to identify, monitor, and document target behaviours and emotions of concern, using the *Symptoms and Signs List* (Table 2) and *Symptoms and Signs Form* in this tool. 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., behavioural or psychological therapy, environmental changes, targeted medication to stabilize emotion/affect).

- The recommendations and practice tips in this tool are based on the publication: *Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines*, *Canadian Family Physician*, 2018, Vol 64: 254-2. In particular, guideline 28: Psychiatric disorders.

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)	2. Anxiety, mood, and psychotic disorders	3. Lifespan (neuro-developmental) disorders; genetic syndromes; dementia; and 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 behaviours.	▸ Sustained episode of significant change in behaviour, 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 behaviours of concern. ▸ Not recognising baseline socio-emotional functioning can give rise to inappropriate expectations and further trauma. ▸ Meeting full diagnostic criteria may be impossible when verbal communication is difficult. ▸ Engage directly with patient using pictures, signs, gestures, facial expression and other 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 (behaviour, 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 behavioural 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), introduce cues of safety (e.g., safe people, safe living space, trauma-informed care); refer for trauma-informed therapy 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, behavioural and psychological interventions for these conditions are available. ▸ Stressor-related and adjustment disorders (column 1) and anxiety, mood, and psychotic disorder (column 2) can be concurrent.

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

Trauma- and stressor-related disorder

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 behavioural distress to an identifiable stressor (e.g., change of caregiver or living circumstance)
- Overall, trauma responses are underpinned by ANS reactivity to real and perceived danger and life threat and include:
  - Behaviours of fight: self injury, hitting out, damage to environment, hypervigilance
  - Behaviours of flight: running away, withdrawng, not engaging, anxiety
  - Behaviours of freeze: resisting, refusing, catatonic-like

Episodes of disorder

Anxiety-like

- Anxiety
- Panic
- Phobias
- Obsessive thoughts
- Compulsive behaviours
- Rituals and routines

Mood-related

- Agitation
- Irritability
- Aggression
- Intrusiveness
- Hyper-sexuality
- Self-harm behaviour
- 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 behaviour or talk, delusions, hallucinations)

Lifespan and other conditions

a) Neurodevelopmental

- **ADHD-related**
  - Inattention
  - Hyperactivity
  - Impulsivity
- **Movement-related**
  - Catatonia ('stuck')
  - Tics
  - Stereotypies

b) Genetic syndromes

- Behavioural 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.

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Surrey Place Developmental Disabilities Primary Care Program

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 caregiver.
- 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 physician office (e.g., disruptive behaviour, anxiety), arrange a home or virtual visit instead.

❶ PATIENT INFORMATION

Name

First | Last

DOB

IDD etiology

IDD severity

☐ mild ☐ moderate ☐ severe ☐ profound ☐ unknown

Sensory impairments and sensitivities

Hearing impairment: ☐ Yes ☐ No
Hearing sensitivity (hyper, hypo): ☐ Yes ☐ No
Vision impairment: ☐ Yes ☐ No
Vision sensitivity (hyper, hypo): ☐ Yes ☐ No

Other exteroception (e.g.,olfactory, tactile) and interoception:

Autism Spectrum Disorder

☐ Yes ☐ No

Social-emotional functioning and needs:

Person accompanying patient

First | Last

Relation to patient

How long have they known the person?

❷ DESCRIBE SYMPTOMS AND SIGNS

Practice tips

- Explore current symptoms (feelings and mental experiences) and signs (behaviours, emotional states, and physiological responses) with the patient and someone who knows the patients well.
- Use assessment tools (e.g., self-report and observational scales) designed for adults with intellectual and developmental disabilities and their caregivers.
- 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 non-verbal 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[i] and Glasgow anxiety scale[ii]
- NTG Early Detection Screen for Dementia[iii]
- HELP with Emotional and Behavioural Concerns[iv]

Concerns

Caregiver perspective:

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

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 caregivers 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 caregiver/others
Behaviours 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):
Behaviours 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:

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)?

❸ MONITOR SYMPTOMS AND SIGNS

Practice tips

- If available, arrange for a functional analysis of behaviours with a behavioural therapist to understand the patient's behaviour 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 careprovider which target behaviours to monitor over time. Look for patterns, associations with events or persons, life events.
- Identify triggers to behavioural and emotional escalation: what makes the patient feel safe (cues of safety) or unsafe (cues of danger) from the patient's perspective?

Practice tools

- Direct Observation System[v]
- Monitoring chart: Antecedent-Behaviour-Consequence[vi]

Target behaviours	Triggers, antecedents, associations with events, safety cues

❹ SUMMARY AND CLINICAL FORMULATION

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

❺ 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 behaviours 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[vii]

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.

ii. **Glasgow Anxiety Scale for People with an Intellectual Disability**
Glasgow University, Mindham & Espie, JIDR, 2003

iii. **NTG Early Detection Screen for Dementia**
National Task Group on Intellectual Disabilities and Dementia Practice, American Academy of Developmental Medicine and Dentistry

iv. **HELP with Emotional and Behavioural Concerns in Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2020 https://ddprimarycare.surreyplace.ca/tools-2/mental-health/guide-to-understanding-behaviour/

v. **Direct Observation System**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019 https://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/06/3.11-Direct-Observation-System-1.pdf

vi. **Monitoring Chart: Antecedent-Behaviour-Consequence**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto https://ddprimarycare.surreyplace.ca/tools-2/mental-health/abc-chart/

vii. **Mental Health Interventions**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023 https://ddprimarycare.surreyplace.ca/tools-2/mental-health/mental-health-interventions/

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This document complements the Canadian consensus guidelines on the primary care of adults with developmental disabilities, published by the Developmental Disabilities Primary Care Program (DDPCP) of Surrey Place and Canadian Family Physician, (Volume 64 (4): April 2018, p254-279). This document is an updated version of *Psychiatric Symptoms and Behaviours Screen*, published in: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. Tools for the primary care of people with developmental disabilities. Toronto: MUMS Guideline Clearing House; 2011. p. 65.

This publication was made possible through support from the Ontario Ministry of Health and the Ontario Ministry of Children, Community and Social Services.

The content of this tool was subject to review by primary care providers and other relevant stakeholders.

This tool is developed as a guide only. While great effort has been taken to assure the accuracy of the information provided, Surrey Place, the Developmental Disabilities Primary Care Program, the reviewers, printer and others contributing to the preparation of this document cannot accept liability for errors, omissions or any consequences arising from the use of the information. Primary care providers and other healthcare professionals are required to exercise their own clinical judgement in using this tool.

PLEASE USE THIS CITATION WHEN REFERENCING THIS TOOL Identifying symptoms and signs of mental distress in adults with intellectual and developmental dsiabilities. Bradley E., Korossy M., Boyd K., Green L., Kelly M., Lunsky Y., McNeil K., Niel U., Thakur A., Thatcher A., Sullivan W., Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023.

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