

Mental Health Interventions for Adults With Intellectual and Developmental Disabilities

Introduction

This resource provides an overview of supports and interventions for adults with intellectual and developmental disabilities presenting with emotional and behavioral concerns. It guides primary care providers through general considerations and practice recommendations for therapeutic interventions for mental health distress, including: therapeutic engagement, trauma-informed care, prevention, psychological therapies, pharmacological and other therapies.

How to use this tool

General considerations

Most emotional and behavioral concerns in patients with intellectual and developmental disabilities (IDD) are not psychiatric disorders per se; but, if not addressed, patient distress may progress to meet psychiatric disorder criteria. The reporting of emotional and behavioral concerns offers opportunities for **early intervention** to prevent the development of psychiatric disorders. See [Identifying Symptoms and Signs of Mental Distress](#).

Intervention follows **identifying the cause(s)** of mental distress, which includes attending to health and medical conditions (H), environments (E) and lived experiences (L) that are stressful and emotionally overwhelming. See [HELP with Emotional and Behavioral Concerns](#), for a systematic approach to understanding the difference between emotional and behavioral distress and psychiatric disorders.

One of the most significant causes of mental health distress in people with IDD is trauma. Trauma arises not only from the experience of living with IDD, but also from greater exposure to adversity, abuse (physical, emotional, sexual) and other negative life events. Mental health intervention for emotional distress and psychiatric disorders, therefore, requires **screening for trauma, adversity and abuse and offering trauma-informed care**.

Not being or feeling safe where, or with whom they are living and supported by, often contributes to patients' emotional and behavioral distress. Screening whether a patient feels safe is important. Often, the mental health intervention required includes **advocacy to ensure the person is safe and feels safe** in wherever they are living, spending time and with others.

Therapeutic relationships that **embody respect, safety, and trust are** important in all interventions, not least in preventing further stress and trauma. Therapeutic relationships increase comfort for the patient to share concerns and explore preference for mental health interventions. Allow time to meet and provide supports that promote capabilities for **consent**. See [Communicate CARE](#) and [Decision-Making in Health Care of Adults with IDD](#).

When the patient's emotional and behavioral concerns are not understood, persist, or are beyond the scope of primary care provider practice, refer, if possible, to specialist mental health or developmental professionals with expertise in intellectual and developmental disabilities.

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THERAPEUTIC PRACTICES IN PRIMARY CARE

Therapeutic relationships that embody respect, safety and trust with patients are in themselves therapeutic.

Mental health interventions flow from an understanding of the person and sources of distress. The process can take time, repeated visits, and engaging with the person's circle of care in the process of discovery.

A trauma-informed approach embraces key principles of safety, trustworthiness, collaboration, empowerment, voice and choice.



Practice recommendations

- ▶ Engage the person with sensitivity, adapting communication and creating a respectful, supportive and safe experience
- ▶ Allow time to meet, often repeatedly, fostering a therapeutic relationship
- ▶ Being attuned to and attentive listening to the patient optimizes an experience of being understood and, importantly, of feeling safe
- ▶ Emotional engagement and attunement with the patient who has limited or no communicative skills (e.g., intensive interaction approach) can optimize their mental health assessment
- ▶ Offer opportunities to explore needs and preferences appreciating the unique ways the patient with IDD may communicate (e.g., words, actions, behaviors, emotions, metaphors)
- ▶ Individualize mental health interventions and referrals
- ▶ Communicate benefits, risks and burden of proposed treatments with the patient adapted to understanding and communication style, including support for decision-making where needed



Practice guidelines

- ▶ Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines: [A person centered approach to care \(guideline 1\)](#), [Effective communication \(guideline 2\)](#), [Capacity for decision-making \(guideline 3\)](#), [Families and caregivers \(guideline 4\)](#), [Mental health intervention \(guideline 29\)](#)



Practice tools

- ▶ [Communicate CARE: Guidance for Person-Centered Care of Adults With Intellectual and Developmental Disabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities
- ▶ [Decision-Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities
- ▶ [HELP with Emotional and Behavioral Concerns in Adults with Intellectual and Developmental Disabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities

Prevention of mental distress is effective intervention. Primary care provider promotion of essentials for health and well-being is a fundamental intervention.



Practice recommendations

- ▶ Ensure physical safety and trust in relationships where the patient spends time and is supported
- ▶ Promote healthy environments that are supportive and adapted to emotional, communication and sensory needs (hypersensitivities and impairments)
- ▶ Promote a healthy lifestyle (physical activity, nutrition, sleep)
- ▶ Support daily opportunities for getting out into nature
- ▶ Promote opportunities for meaningful social-emotional connections (arts, sports, music, book clubs, recreation)
- ▶ Consider social prescribing (e.g. such as referrals to community activities or organizations)
- ▶ Support staff in accessing developmental services and resources (e.g., needed assessments, behavioral supports, providing advocacy as needed)
- ▶ Support family members/support persons in self-care and stress-reduction practices
- ▶ If unsure, be guided by asking the question: would it be acceptable for you or a family member to live in the same circumstances as is provided for your patient?



Practice guidelines

- ▶ Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines: [Mental health intervention - Other therapeutic interventions](#) (guidelines 29.11, 29.12)
- ▶ Mental health problems in people with learning disabilities. NICE guideline [NG54]: [1.5 Social and physical environment interventions](#); [1.11 Occupational interventions](#).



Practice tools

- ▶ [Communicate CARE: Guidance for Person-Centered Care of Adults With Intellectual and Developmental Disabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities
- ▶ [Decision-Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities
- ▶ [HELP with Emotional and Behavioral Concerns in Adults with Intellectual and Developmental Disabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities
- ▶ Marcal S, Trifoso S.A. [Trauma-Informed Toolkit for Providers in the Field of Intellectual & Developmental Disabilities](#). (2017) Center for Disabilities Services, Albany, NY.

PSYCHOLOGICAL THERAPIES

Patients with intellectual and developmental disabilities with emotional and behavioral concerns may also have mental health (psychiatric) conditions that could benefit from individual or group psychological therapies (e.g., counseling, positive behavior support, psychotherapy, adapted cognitive behavioral therapy or dialectical behavioral therapy, trauma-informed therapies, mindfulness practices)



Practice recommendations

- ▶ Consider local and regional specialized services for patients with IDD. Advocate for adaptation of psychological therapies to the needs of the patient (communication, cognitive, emotional)
- ▶ Consider supports to improve access (e.g., transportation, funds, virtual or blended models)
- ▶ Involve an IDD-informed support person to facilitate (access, engagement where needed)
- ▶ Check with the patient (and family/support persons) about response to therapy (adaptations for inclusion, the therapeutic environment and relationships, concern about power differentials, the impact of therapy on life)
- ▶ Continue primary care support in the context of your therapeutic relationship according to the patient's needs (e.g., as needed or regular follow-up appointments)



Practice guidelines

- ▶ Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines: [Mental health intervention – Psychological therapies](#) (guidelines 29.1)
- ▶ Mental health problems in people with learning disabilities: prevention, assessment and management. NICE guideline [NG54]: [1.9 Psychological interventions](#), and how to adapt these for people with learning disabilities



Further learning

- ▶ Beail N, Faculties for Intellectual Disabilities of the Royal College of Psychiatrists and the Division of Clinical Psychology, British Psychological Society. *Psychological therapies and people who have intellectual disabilities*. United Kingdom: The British Psychological Society, Division of Clinical Psychology; 2016.

PSYCHO-PHARMACOLOGICAL THERAPIES

PSYCHOTROPIC MEDICATIONS

Psychotropic medications can be effective, along with other therapies, when psychiatric disorders (e.g., ADHD, anxiety, mood disorders) are confirmed through a robust process of assessment and involving specialist expertise in IDD mental health where indicated.

A trial of psychotropic medication monitored against target symptoms, behaviors and affective states might be tried to determine whether medication is helpful overall in treating psychiatric disorder and dysregulated affective states. Continue to assess and address underlying reasons for crisis and distress.

Primary care providers may be in a position to review and monitor psychotropic medications, providing continuity and holistic care, with input from developmental and psychiatric specialists.



Practice recommendations

- ▶ Consider indicated, disorder-specific psychotropic medications along with other applicable interventions
- ▶ Consult prescribing guidelines for psychiatric disorders and any specific guidelines for patients with IDD (e.g., see Frith practice guidelines below)
- ▶ Use psychotropic medications judiciously and cautiously, monitoring responses against target behaviors and affect of states
- ▶ Monitor possible adverse effects
- ▶ Start low and go slow in initiating, increasing, or decreasing doses of medications. Educate patients and family/support persons about medications including recognizing and managing side effects
- ▶ Review response, adverse reactions and unwanted effects at agreed-upon intervals (frequently when initiating or changing doses, then every three months)
- ▶ Discuss and obtain consensus about reducing doses and discontinuing medication
- ▶ Follow psychotropic PRN medication prescribing guidelines, and possible limits on PRN medications for those patients in state-funded supported living.
- ▶ Work closely with pharmacists and/or interdisciplinary teams including pharmacy expertise

ANTIPSYCHOTIC MEDICATIONS

Antipsychotic medications have been commonly prescribed (often with other psychotropic medication) to adults with IDD despite the absence of a diagnosis or a psychotic or mood disorder. Prescription of antipsychotics for behaviors that signal patient distress is considered off label and warrants assessment of causes of patient distress and psychotropic medication review.



Practice recommendations

- ▶ Review psychiatric diagnoses and appropriateness of medications when there is no clear indication, non-response, worsening of symptoms, behavioral change, or upon request
- ▶ Consider adverse drug reactions and effects in patients with IDD
 - CNS (sedation, emotional and behavioral disturbance)
 - Extrapyramidal system (e.g., acute dystonic reactions, parkinsonism, akathisia, tardive dyskinesia)
 - Anticholinergic effects (e.g., dry mouth, swallowing difficulties, bowel and bladder dysfunction)
 - Cardiovascular (e.g., orthostatic hypotension, tachycardia, QT prolongation)
 - Endocrine effects (metabolic syndrome, sexual dysfunction)
 - Longer-term consequences on health and well-being
- ▶ Consider dose reduction, tapering (deprescribing) where medications are tried for target symptoms, distressing behaviors and “affective states” with no benefits or poor response
- ▶ If needed, refer to specialists, and community programs for additional supports



Practice guidelines

- ▶ Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines: Mental health intervention – Psychotropic medications (guideline 29.2-29.7); Antipsychotic medications (guideline 29.8-29.10); Polypharmacy and long term use of certain medications (guideline 10)
- ▶ Bhaumik S, Branford D, Barrett M, Gangadharan SK, editors. *The Frith Prescribing Guidelines for People with Intellectual Disability*. 3rd ed. Chichester, West Sussex ; Hoboken, NJ: John Wiley & Sons Inc.; 2015. (Fourth edition in press) <https://onlinelibrary.wiley.com/doi/book/10.1002/9781118897164>



Practice guidelines (continued)

- ▶ Mental health problems in people with learning disabilities: prevention, assessment and management. (Learning disability is the British phrase for IDD) NICE guideline [NG54]: [1.10 Pharmacological interventions](#)
- ▶ Alexander, R., Branford D., Devapriam J. *Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviors that challenge: Practice guidelines* London, UK: The Royal College of Psychiatrists. 2016. Accessed 2023 Jul 24. Available from: https://www.rcpsych.ac.uk/docs/default-source/members/faculties/intellectual-disability/id-fr-id-095701b41885e84150b11ccc989330357c.pdf?sfvrsn=55b66f2c_4.



Practice tools

- ▶ [Psychotropic Medication Review for Adults With Intellectual and Developmental Disabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities
- ▶ [HELP with Emotional and Behavioral Concerns in Adults with Intellectual and Developmental Disabilities](#). Health Care for Adults with Intellectual and Developmental Disabilities



Further learning

- ▶ Royal College of Psychiatrists, Biswas AB. *Stopping the overprescribing of people with intellectual disability, autism or both (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP)*. London, UK: The Royal College of Psychiatrists; 2021. <https://pearl.plymouth.ac.uk/bitstream/handle/10026.1/17746/position-statement-ps0521-stomp-stamp.pdf>

OTHER THERAPEUTIC INTERVENTIONS

Offer other therapeutic interventions based on presenting problems and patient's and caregivers' preferences.

Examples include:

- ▶ Art, drama, and music therapies
- ▶ Communication (aids, enhance functional communication)
- ▶ Behavior supports
- ▶ Adaptations to environment (safe, enriched, sensory-friendly)
- ▶ Education and skill development (person, family/support persons, teams)
- ▶ Promote support, training and stress-reduction practices for family/support persons
- ▶ Consider whether paid staff is adequately supported (e.g., in delivery of client care, self-care) within their organizational setting. Advocacy may be required.
- ▶ Revisit essentials of prevention (see Prevention section above)

Supporting materials

- i. Identifying Symptoms and Signs of Mental Distress in Adults with Intellectual and Developmental Disabilities.**
Health Care for Adults with Intellectual and Developmental Disabilities
<https://iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/psychiatric-symptoms-and-behaviors-screen/>
- ii. HELP with Emotional and Behavioral Concerns in Adults with Intellectual and Developmental Disabilities.**
Health Care for Adults with Intellectual and Developmental Disabilities
<https://iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/help-with-emotional-and-behavioral-concerns/>
- iii. Communicate CARE: Guidance for Person-Centered Care of Adults With Intellectual and Developmental Disabilities.**
Health Care for Adults with Intellectual and Developmental Disabilities
<https://iddtoolkit.vkcsites.org/communicate-care/>
- iv. Decision-Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities.**
Health Care for Adults with Intellectual and Developmental Disabilities
<https://iddtoolkit.vkcsites.org/decision-making/>

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