

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 behavioural 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 behavioural 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 behavioural concerns offers opportunities for **early intervention** to prevent the development of psychiatric disorders. See [Identifying Symptoms and Signs](#)^[i]

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 behavioural concerns](#)^[ii], for a systematic approach to understanding the difference between emotional and behavioural 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**. See key principles in [Trauma-informed health care](#).^[iii]

Not being or feeling safe where, or with whom they are living and supported by, often contributes to patients' emotional and behavioural 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. See [Trauma-informed health care](#)^[iii]

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](#)^[iv] and [Decision-making in health care for adults with IDD](#).^[v]

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

Clinical practice guidelines

- ▶ The recommendations in this resource 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 29: Mental health intervention.

Other relevant clinical guidelines and tools are mentioned throughout this resource.

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 non-verbal patient (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, behaviours, 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 centred 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

- Trauma-informed Health Care for Adults With Intellectual and Developmental Disabilities. Developmental Disabilities Primary Care Program of Surrey Place, Toronto, [in progress]
- [Communicate CARE: Guidance for person-centred care of adults with intellectual and developmental disabilities](#). Developmental Disabilities Primary Care Program, Surrey Place, Toronto, 2019
- [Decision making in health care of adults with intellectual and developmental disabilities: Promoting capabilities](#). Developmental Disabilities Primary Care Program, Surrey Place, Toronto, 2019
- [HELP with emotional and behavioural concerns in adults with intellectual and developmental disabilities](#). Developmental Disabilities Primary Care Program, Surrey Place, Toronto, 2019



Further learning

- Calvey J. Gaining the power of initiation through intensive interaction. *Learning Disability Practice*. 2017; 20, Issue 1, p19-23. doi: 10.7748/ldp.2017.e1797
- Calvey J. Understanding and managing trauma in people with severe and profound learning disabilities. *Learning Disability Practice*. 2022;25 Issue 1, p14-20. doi: 10.7748/ldp.2021.e2165
- Elbard K. "Inside out not outside in – A change of attitude for all: A self-advocate's vision for those with intellectual and developmental disabilities". *Journal of Religion and Society*. 2015(Supplement Series [12] Caring for persons with intellectual and developmental disabilities. Edited by Jos Welie):8-12.

- [How do you want to be treated?](#) Curriculum of Caring, McMaster University, Hamilton. [video]
- [Understanding special voices.](#) Curriculum of Caring, McMaster University, Hamilton. [video]
- [H-CARDD Best Practice Series: Improving primary care \(Teaching points\)](#), Health Care Access and Developmental Disabilities Research (H-CARDD), CAMH, Toronto [video]

Prevention

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 socio-emotional connections (arts, sports, music, book clubs, recreation)
- Consider social prescribing
- Support staff in accessing developmental services and resources (e.g., needed assessments, behavioural supports, providing advocacy as needed)
- Support caregivers 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-centred care of adults with intellectual and developmental disabilities.](#) Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019
- [Decision making in healthcare of adults with intellectual and developmental disabilities: Promoting capabilities.](#) Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2020
- [HELP with emotional and behavioural concerns in adults with intellectual and developmental disabilities.](#) Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019
- Marcal S, Trifoso S.A. [Trauma-informed toolkit for providers in the field of intellectual & developmental disabilities.](#) (2017) Center for Disabilities Services, Albany, NY.



Further learning

- [Canadian Institute for Social Prescribing, Canadian Red Cross \[website\]](#)

Psychological therapies

Patients with intellectual and developmental disabilities with emotional and behavioural concerns may also have mental health (psychiatric) conditions that could benefit from individual or group psychological therapies (e.g., counseling, positive behaviour support adapted, psychotherapy, adapted CBT or DBT, 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 caregiver) 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

- Patterson, C. W. (2023). Adults with intellectual disabilities and third-wave therapies: A systematic review and meta-ethnography. *Journal of Applied Research in Intellectual Disabilities : JARID.*, 36(1), 13–27. <https://doi.org/10.1111/jar.13045>
- Evan 2020: Evans, L. (2020). People with intellectual disabilities' experiences of psychological therapy: A systematic review and meta-ethnography. *Journal of Intellectual Disabilities.*, 24(2), 233–252. <https://doi.org/10.1177/1744629518784359>
- 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, behaviours 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^[iii].

Primary care providers are 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 behaviours and affect of states
- Monitor possible adverse effects
- Start low and go slow in initiating, increasing, or decreasing doses of medications
- Educate patients and caregivers 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
- 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 behaviours that signal patient distress is considered off label and warrants assessment^[ii] 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, behavioural change, or upon request
- Consider adverse drug reactions and effects in patients with IDD
 - CNS (sedation, emotional and behavioural 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, “behaviours” and “affective states” with no benefits or poor response
- If needed, refer to professionals, 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)
- Mental health problems in people with learning disabilities: prevention, assessment and management. 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 behaviours 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](#). Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
- Psychotropic Medication Issues, Developmental Disabilities Primary Care Initiative, Surrey Place, Toronto, 2011 [under revision]

- [HELP with emotional and behavioural concerns in adults with intellectual and developmental disabilities](#). Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019



Further learning

- Alexander RT, Shankar R, Cooper SA, Bhaumik S, Hastings R, Kapugama CL, et al. Challenges and pitfalls of antipsychotic prescribing in people with learning disability. *Br J Gen Pract*. 2017 August 01;67(661):372-3.
- 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.

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)
- Behaviour supports
- Environment adaptations (safe, enriched)
- Education and skill development (person, caregivers, teams)
- Promote of caregiver support, training, and stress-reduction practices
- 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 above)

Supplemental materials

- i. [Identifying Symptoms and Signs of Mental Distress in Adults with Intellectual and Developmental Disabilities](#). Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023 <https://ddprimarycare.surreyplace.ca/tools-2/mental-health/psychiatric-symptoms-and-behaviour-screen/>
- ii. [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/>
- iii. [Trauma-informed Health Care of Adults With Intellectual and Developmental Disabilities](#). Developmental Disabilities Primary Care Program of Surrey Place, Toronto [in progress] <https://ddprimarycare.surreyplace.ca/tools-2/mental-health/trauma-informed-health-care/>
- iv. [Communicate CARE: Guidance for Person-Centred Care of Adults With Intellectual and Developmental Disabilities](#). Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019 <https://ddprimarycare.surreyplace.ca/tools-2/general-health/communicating-effectively/>
- v. [Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities: Promoting Capabilities](#). Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2020 <https://ddprimarycare.surreyplace.ca/tools-2/general-health/capacity-for-decision-making/>

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Some of these supporting materials are hosted by external organizations and the accessibility of these links cannot be guaranteed. The DDPCP will make every effort to keep these links up to date.