

Primary care of adults with intellectual and developmental disabilities

2018 Canadian consensus guidelines

William F. Sullivan MD CCFP(COE) FCFP PhD Heidi Diepstra MA PhD John Heng MA Shara Ally RN MN
 Elspeth Bradley MB BS PhD FRCPC FRCPSych Ian Casson MD MSc FCFP Brian Hennen MD MA FCFP FRCGP
 Maureen Kelly MPA Marika Korossy Karen McNeil MD CCFP FCFP Dara Abells MD CCFP MScCH
 Khush Amaria PhD CPsych Kerry Boyd MD FRCPC Meg Gemmill MD CCFP Elizabeth Grier MD CCFP
 Natalie Kennie-Kaulbach ACRP PharmD RPh Mackenzie Ketchell MS BCBA Jessica Ladouceur MD CCFP
 Amanda Lepp MD PhD Yona Lunsky PhD CPsych Shirley McMillan RN MN CDDN PhD Ullanda Niel MD CCFP
 Samantha Sacks MD CM CCFP Sarah Shea MD FRCPC Katherine Stringer MB ChB CCFP FCFP
 Kyle Sue MD MHM CCFP(PC) Sandra Witherbee RN

Abstract

Objective To update the 2011 Canadian guidelines for primary care of adults with intellectual and developmental disabilities (IDD).

Methods Family physicians and other health professionals experienced in the care of people with IDD reviewed and synthesized recent empirical, ecosystem, expert, and experiential knowledge. A system was developed to grade the strength of recommendations.

Recommendations Adults with IDD are a heterogeneous group of patients and have health conditions and factors affecting their health that can vary in kind, manifestation, severity, or complexity from those of others in the community. They require approaches to care and interventions that are adapted to their needs. These guidelines provide advice regarding standards of care. References to clinical tools and other practical resources are incorporated. The approaches to care that are outlined here can be applied to other groups of patients that have impairments in cognitive, communicative, or other adaptive functioning.

Conclusion As primary care providers, family physicians play a vital role in promoting the health and well-being of adults with IDD. These guidelines can aid their decision making with patients and caregivers.

The following guidelines for the primary care of adults with intellectual and developmental disabilities (IDD) update those previously published in *Canadian Family Physician*.¹ In these guidelines, *IDD* refers to various life-long limitations in intellectual functioning and conceptual, social, or practical skills that emerge in persons before the age of 18 years. These limitations differ in severity and type among people with IDD and can vary during a person's lifespan. Intellectual and developmental disabilities encompass intellectual disability, developmental disability, learning disability (as used in the United Kingdom), and autism spectrum disorder.²

Adults with IDD are patients that most family physicians have in their practices. As primary care providers, family physicians play a key role in promoting the health and well-being of these patients. People with IDD often have complex health care needs and factors affecting their health that can vary in kind, manifestation, or severity from others in the community. They require approaches to care and interventions that are adapted to their needs.

Editor's key points

- ▶ Adults with intellectual and developmental disabilities (IDD) have preventable health conditions that can vary from those of other patients.
- ▶ Primary care of adults with IDD is often complex and requires knowledge from various sources. These updated guidelines categorize complementary types of knowledge (empirical, ecosystem, expert, and experiential) to improve holistic primary care.
- ▶ A new section on approaches to primary care is applicable to patients with IDD and other patients with similar needs.
- ▶ These guidelines emphasize periodic preventive health assessments, health action plans, and systematic assessment of behaviours that challenge.

The revisions in the updated guidelines are based on feedback from users of the previous guidelines and on review and discussion of current knowledge by family physicians and other health professionals experienced in the primary care of adults with IDD. The approaches to care that are outlined in these guidelines can be applied to other groups of patients that have impairments in cognitive, communicative, or other adaptive functioning. References to clinical tools and other practical resources are incorporated to facilitate implementation.

Objective and scope of the guidelines

The updated guidelines aim to help family physicians and other providers of primary care to make informed decisions with their patients with IDD and patients' caregivers. Their focus is on health issues that are specific to adults with IDD. These tend sometimes to be overlooked because they can vary from what is encountered in other patients.

As in previous guidelines, emphasis is placed on measures to avoid occurrence of health disorders (primary prevention) and to detect disorders early for effective intervention (secondary prevention). Some new guidelines also address monitoring the health of patients who are living with chronic physical or mental health conditions to mitigate symptoms and avoid additional complications (tertiary prevention). Adults with IDD experience high rates of chronic diseases.³ They might not have the skills and support needed for self-care.

These guidelines outline standards of care for which there is a good basis in current knowledge. Other factors, however, were considered for deciding whether a proposed action is "strongly recommended" or "recommended," including availability and use of resources. Implementing some recommendations might entail flexibility in managing resources or enabling patients and caregivers to access resources in the community to which they are entitled. The latter might involve promoting better distribution of resources in the health care and social services systems. These are competencies associated with being a health advocate, one of the CanMEDS–Family Medicine roles of family physicians identified by the College of Family Physicians of Canada.⁴

Rationale for revising the guidelines

At colloquia held in 2016, 45 Canadian family physicians and other health professionals who use the 2011 guidelines suggested revisions and additional topics. Studies published since 2011 also prompted a review of the previous guidelines.

Rationale for method

Our method for updating the guidelines considered international efforts to improve the quality of clinical guidelines while making adaptations for addressing the primary care of adults with IDD. The 2011 guidelines

used an evidence-based medicine (EBM) framework with no separate grading of strength of recommendations. To update our guidelines, this approach was revised. We classified and profiled the types of knowledge reviewed as *empirical knowledge* (derived from randomized controlled trials [RCTs] and observational studies), *ecosystem knowledge* (population-level data from studies of prevalence, environments, and health care systems), *expert knowledge* (from practitioners or professional bodies proposed with or without an explicit consensus process), and *experiential knowledge* (patient and caregiver perspectives). These various types of knowledge were not ranked hierarchically because they offer complementary insights, each contributing a different perspective necessary for making informed clinical judgments. We distinguished the strength of recommendations using a separate grading system that considered other factors such as the proportion of benefit relative to harm, preferences and values of patients and caregivers, and the availability and use of resources. This approach was adapted from that used by the Canadian Task Force on Preventive Health Care for its guidelines.

Underlying these methodologic changes is our view that, while the EBM framework widely used to develop guidelines is helpful for many patient groups, it has some limitations when developing guidelines for certain patient groups such as people with IDD.⁵ The EBM framework adopts a hierarchical ranking of the quality of evidence that places RCTs at the highest level of quality of evidence and expert opinion at the lowest. This grading system is problematic in developing guidelines for primary care of people with IDD for several reasons. First, very few RCTs involve participants with IDD. Recruiting such participants is difficult and often judged to be ethically inappropriate by research ethics boards.

Second, RCT design can be used most effectively when the number of relevant variables among participants is small. People with IDD, however, are a heterogeneous group of patients with different, sometimes rare, causes of their disabilities, a range of intellectual and adaptive functioning, and multiple comorbidities. These variations often affect health outcomes or response to interventions.

Third, RCTs are not designed to investigate the sorts of holistic interventions that adults with IDD require for comprehensive primary care. In such interventions, effects often interact and cannot be studied in isolation; nor can all outcomes of such interventions be quantified.

Fourth, as Greenhalgh and colleagues have argued, there are potential biases implicit in the EBM framework that run counter to a relational, person-centred approach to care, which is valued in family medicine and in the care of people with IDD.⁶ Qualitative studies eliciting patient and caregiver perspectives are important in such care.

Moreover, there has been a positive shift within family medicine from approaches to care based exclusively

on the medical model of disability, which focuses on patients' impairments, to approaches that incorporate insights from the social model of disability. The latter elucidates ways in which inappropriate environments, inadequate social supports, and systemic barriers also contribute to disability.⁷ An ecosystem perspective highlights these contextual factors that are likely to influence service use and patient outcomes in local settings for primary care of adults with IDD.

Finally, in the care of adults with IDD, the cumulative knowledge of expert clinicians who have extensive experience in such care and are aware of current knowledge is another valid and important basis for recommending interventions. The characterization of expert knowledge as "opinion" and its relegation to the lowest level of evidence quality in the EBM framework does not do justice to this valuable type of knowledge.

— Methods —

Updating the guidelines involved a group of 45 primary care providers (family physicians, psychiatrists, nurses, and other health professionals) from urban and rural areas across Canada. They participated in a colloquium on February 24, 2016, and another on June 15 and 16, 2016. Participants were invited because they had extensive experience in the primary care of people with IDD. Many were involved in developing the previous guidelines. Before and after these colloquia, most attendees participated in smaller working groups. A health librarian experienced in the field of IDD conducted searches of electronic databases, books, and other publications on IDD between January 2010 and November 2017 (details on the search strategy are available from **CFPlus***). Pertinent search results were entered in a bibliographic management system (RefWorks) accessible to members of the various working groups. The groups reviewed knowledge on specific topics assigned to them according to their respective areas of expertise. They also proposed wording for revising or adding to the previous guidelines for discussion at the June 2016 colloquium. A standard form was used to record the publications that the group members considered relevant for their revisions or additions. Leaders were designated to coordinate groups for each section of the guidelines.

After the June 2016 colloquium, a Colloquium Synthesis Group (CSG) and an editorial group were established. The latter was a subgroup of the former. The CSG consisted of 5 family physicians (W.F.S., I.C., B.H., E.G., K.M.), a psychiatrist (E.B.), 2 nurses (S.A., M. Kelly), an ethicist (J.H.), a librarian (M. Korossy), and a research associate (H.D.). Two additional external consultants with expertise in methods of guideline development provided

advice. The CSG and editorial group worked in tandem to formulate the text of the guidelines based on discussions at the June 2016 colloquium. The CSG guided decisions regarding the systems employed for categorizing the types of knowledge and for distinguishing the strength of recommendations (**Tables 1** and **2**). Based on these decisions, the first authors of these guidelines (a family physician [W.F.S.] and a research associate [H.D.]) independently categorized the type of knowledge of publications that the working groups reviewed and proposed the grading of the strength of recommendations. The leaders designated for each section of the guidelines (4 family physicians [I.C., B.H., E.G., K.M.] and a psychiatrist [E.B.]) also separately ranked what they considered to be the most important recommendations to promote in any clinical practice and those recommendations that pertain to health issues that are most commonly overlooked in patients with IDD. Discrepancies were noted and all were then resolved by discussion. The final results were communicated to all the participants in the June 2016 colloquium for their approval.

— Recommendations —

What is new in the updated guidelines?

Most guidelines have been revised and new ones added. The updated guidelines begin with a new section on approaches to care. Feedback from users of the previous guidelines suggested that the quality of primary care experienced by adults with IDD is correlated not only with *what* their family physicians know medically but also *how* they relate to their patients and caregivers. These guidelines emphasize placing the person with IDD at the centre of communication, planning, and decisions regarding care. This might require more time than that allocated to the typical office visit, getting to know the patient as a person and the patient's community, and engaging additional supports. The College of Family Physicians of Canada supports primary care that is person-centred, relational, and integrated.^{8,9} While these approaches to care apply to all patients, they apply especially to adults with IDD who often face challenges in having their health needs understood. They and their caregivers need to be given opportunities to share their perspectives.

Guideline 3 on capacity for informed consent was renamed *capacity for decision making* to place the focus less on assessment of intellectual functioning and more on enhancing communication with adults with IDD and assessing their need for accommodations and supports to contribute as much as possible to decisions affecting their health care.

The term *behaviours that challenge* (BTC) is adopted in these guidelines. This term situates such behaviour in the context of the interaction between people with IDD who have unique developmental needs and their environments and supports. Behaviours that challenge

*The search strategy details are available in English at www.cfp.ca. Go to the full text of the article online and click on the **CFPlus** tab.

occur when the health, developmental, and personal needs of the individual with IDD might not be fully understood, where necessary supports are not available, when expectations might be inappropriate, and when needed environmental accommodations are not made.

This entails a comprehensive and systematic approach to assessing the causes of BTC (eg, the HELP approach outlined in guideline 27).




A new guideline on life transitions (guideline 12) proposes preventive measures to mitigate the distressing

Table 1. Types of knowledge: This table presents the types of knowledge and their definitions; blue and gray circles for each type of knowledge indicate different subtypes; blue indicates a stronger or especially relevant knowledge subtype for the recommendation compared with gray; open circles indicate that reviewed publications pertain to the guideline's background (first guideline column).

TYPE OF KNOWLEDGE	DEFINITION
Empirical	Knowledge of the outcome of exposure or intervention acquired from the following: <ul style="list-style-type: none"> ● experimental studies (eg, RCTs) and systematic review or meta-analysis of such studies ● observational studies (eg, case report, case-control, cross-sectional, cohort, or longitudinal studies) or systematic review and meta-analysis of such studies
Ecosystem	Knowledge, usually descriptive or employing population-level data, regarding illness prevalence, patient or caregiver characteristics, environmental or socioeconomic factors, or availability or use of health care resources and services. Such studies use the following: <ul style="list-style-type: none"> ● Canadian data ● non-Canadian data
Expert	Knowledge, including skills, acquired through clinical practice. It can be elicited using qualitative approaches (eg, surveys, focus groups). It includes consensus guidelines, framing statements, position papers, or topic reviews developed as follows: <ul style="list-style-type: none"> ● through an explicit consensus process (eg, systematic review, synthesis of knowledge, consultation, or discussion) ● without an explicit consensus process
Experiential	Reflections on experiences of a health condition, care approach, intervention, or health care system derived from the following: <ul style="list-style-type: none"> ● patients with IDD or caregivers ● other informants

IDD—intellectual and developmental disabilities, RCT—randomized controlled trial.

Table 2. Strength of recommendations

STRENGTH OF RECOMMENDATION	DESCRIPTION
 Strongly recommend	A strong recommendation is one that can be supported without qualification by family physicians and other health professionals providing primary care. They can be confident that all of the following conditions apply: <ul style="list-style-type: none"> • There are at least 3 types of knowledge supporting a recommendation or at least 2, 1 of which is in a category subtype indicated by a blue full or half circle (● or ◐). This condition is taken to be an indication of the breadth, depth, and special relevance of knowledge • There is a greater balance of anticipated medical benefit or positive clinical outcome over risk of harm • Most people with IDD and their caregivers would find the intervention to be tolerable • The family physician or other primary care provider would typically have the resources (eg, time, materials, training, supports) to engage in the approach or offer the intervention, or would be able to accommodate or advocate for the approach or intervention • The approach or intervention is an effective use of resources, taking into consideration factors such as effects on the time, priorities, and out-of-pocket expenses of patients and their caregivers and the limits of the practice or health care system
 Recommend	These recommendation have a good basis in current knowledge. Family physicians and other health professionals providing primary care will need more extensive discussion than usual, however, with patients with IDD and caregivers, or consultation with other health professionals, ethicists, or health care administrators before deciding to implement the recommendation
 Top picks by clinicians	These recommendations were selected by 5 clinicians who were section leads (family physicians [I.C., B.H., E.G., K.M.] and a psychiatrist [E.B.]) as the 3 most important per section to promote in any clinical practice or recommendations that pertain to health issues that are most commonly overlooked in patients with IDD

IDD—intellectual and developmental disabilities.

effects on people with IDD of losses and changes they experience during these transitions and to prepare for a smooth transfer to new services and supports. Guidelines 27 and 28 emphasize screening for distressing life experiences that sometimes contribute to emerging BTC in adults with IDD or that might precipitate adjustment disorders in some patients if unaddressed.

The health risks and unwanted side effects associated with long-term use of certain medications or combinations of medications by adults with IDD are a concern that underlies several updated recommendations. Guidelines 27, 29, and 30 give advice on the appropriate use and standards for review of psychotropic medications.

To address gaps in the previous guidelines, new recommendations have been developed on care of families and other caregivers of patients with IDD (guideline 4), women’s gynecologic and reproductive health (guideline 19), and sleep problems (guideline 25).

In these updated guidelines, we worded recommendations as easy-to-understand actions that can be applied. Clinical tools and other practical resources are incorporated into the recommendations to aid guideline implementation. The top recommendations by clinicians in each section of the guidelines are highlighted. The central recommendations are those of performing a periodic comprehensive health assessment using adapted tools such as the Preventive Care Checklist Form,^{10,11} developing a health action plan, and using a comprehensive and systematic approach to assessing the causes of BTC.

The recommendations are presented in full in **Table 3.**^{8,10-333}

Future dissemination and implementation

Future dissemination and implementation strategies

involve education (eg, online learning modules, curricula), integration of the guidelines in electronic medical record systems, and developing guideline implementation tools in collaboration with stakeholders (eg, primary care providers, patients, caregivers).

Limitations and implications for improvement

The aim of these guidelines is to inform family physicians and other primary care providers of the most prevalent health issues of adults with IDD and optimal standards of care based on current knowledge. Any such guidelines, however, will inherently be limited in their application by the reality that adults with IDD are not a homogeneous group of patients and do not experience health disorders or respond to interventions in the same ways. The guidelines provide advice on reasonable standards of care in general. They are not intended to replace skilled clinical diagnoses or judgments regarding interventions based on discussions with patients and their caregivers.

To identify gaps in the 2011 guidelines and assess new knowledge, we drew on the expertise of family physicians and others who provide primary care to people with IDD at every stage of the updating process. There was not analogous involvement, however, of adults with IDD and their caregivers in this process. This limitation will be addressed in future updates.

Through profiling the range of types of knowledge for recommendations in the updated guidelines, we conclude that there is a need generally for more studies that elicit experiential knowledge from patients with IDD and their caregivers. There is also need for more studies contributing to knowledge of health ecosystems that affect the health and access to health care of adults with IDD.

Table 3. Canadian consensus guidelines on the primary care of adults with IDD: *Recommendations with   are strongly recommended; the  symbol indicates clinicians’ top recommendations;  or  indicates that reviewed publications pertain to the guideline background; blue indicates a stronger or especially relevant knowledge subtype for the recommendation compared with gray (see Tables 1 and 2).*

















BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
Approaches to care			
1. A person-centred approach to care of adults with IDD can positively affect their health and well-being. ¹² In person-centred care relationships, the person is at the centre of communication, planning, and decisions regarding care. This might require additional time and supports to meet individual needs	1.1 Engage patients and their caregivers to find effective ways of collaborating ¹³	 Expert  Experiential	 
	1.2 Identify with them someone who knows the patient well who will attend health care appointments, help to coordinate care, and monitor ongoing health and social needs ^{13,14}	 Expert  Experiential	  
	1.3 Provide sufficient time and supports to ensure that individuals can make their specific health concerns, needs, and perspectives understood ¹⁴⁻¹⁶	 Expert  Experiential	  
	1.4 Discuss with patients and their caregivers their goals of care and values to guide health care decisions ¹⁷	 Expert	

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
<p>2. Effective communication is considered essential to good health care by people with IDD and their health care providers.¹⁸⁻²⁰ Adults with IDD, however, might have challenges in communication (eg, language comprehension, expression or social interaction)^{21,22}</p>	2.1 Address patients directly ¹³	<ul style="list-style-type: none"> ○ Expert ● Experiential 	✓✓
	2.2 Find ways of engaging the patient. Attend to both verbal and nonverbal cues ²³	<ul style="list-style-type: none"> ● Expert ○ Experiential 	✓✓
	2.3 Use the patient’s preferred communication method and tools (eg, Easyhealth easy-read leaflets) to facilitate communication ^{18,24-26}	<ul style="list-style-type: none"> ● Expert ● Experiential 	✓✓
	2.4 Slow down in communicating ^{13,27,28} (see Communicating Effectively tool ²⁷)	<ul style="list-style-type: none"> ○ Expert ● Experiential 	✓✓
	2.5 Involve caregivers familiar with the patient to help communicate, but be attentive to inappropriate taking over of decision making ²⁸	<ul style="list-style-type: none"> ○ Expert ● Experiential 	✓✓
	2.6 Try to have a short period alone with the patient to address safety or other concerns ²⁹	<ul style="list-style-type: none"> ● Expert ○ Experiential 	✓✓
<p>3. Capacity for decision making is relational. Many patients with IDD can participate to some extent in decision making if provided with accommodations and supports by health professionals and family and other committed caregivers (eg, for communication [see guideline 2]³⁰ or deliberation. Decision-making capacity varies with the complexity of a decision. It can be affected by factors such as the patient’s limited or adverse previous health care experiences, level of distress, and mental health conditions. These factors can be difficult to recognize in people with IDD but can often be addressed when identified (see guidelines 9 and 28)^{17,31}</p>	3.1 Assess decision-making capacity of adults with IDD using a tool that is adapted to them and considers their need for accommodations and supports (eg, the Decision-Making Checklist ³²). Screen for factors that can affect decision-making capacity, such as those listed in the background, and address with interventions or supports. When uncertain, refer to a psychologist or other professional who is familiar with assessing people with IDD or similar needs ^{31,33}	<ul style="list-style-type: none"> ● Expert ○ Experiential 	✓✓✓
	3.2 In assessing decision-making capacity and supporting a patient’s decision making, adapt communication to the patient and involve family and other caregivers familiar with the patient, as in guideline 2 ²⁷	<ul style="list-style-type: none"> ○ Expert ○ Experiential 	✓✓
<p>Deliberating on interventions that both meet the health needs of the patient and reflect the patient’s preferences and intentions is the goal of person-centred decision making. Patients with IDD might need support to deliberate. Patients who do not meet the legal requirements for giving or refusing consent have life histories and are able sometimes to provide signs of their preferences and intentions to trusted family and other caregivers that can inform deliberations. Substitute decision makers should be guided by knowledge of this person gained from those closest to her or him^{17,31}</p>	3.3 Engage in a shared decision making process with patients and their caregivers. When the legal substitute decision maker does not know the patient well, propose consulting trusted family and other caregivers to inform deliberations ^{31,33}	<ul style="list-style-type: none"> ● Expert ● Experiential 	✓✓
<p>4. Families and other caregivers often experience considerable mental, physical, or economic stress in balancing the person with IDD’s support needs with other responsibilities^{34,35}</p>	4.1 Regularly screen for and proactively attend to the support needs of caregivers. ^{36,37} Recommend interventions that reduce BTC in people with IDD (eg, positive behaviour support ^{38,39}) and increase coping and reduce stress experienced by caregivers (eg, mindfulness ^{40,41})	<ul style="list-style-type: none"> ● Empirical ○ Ecosystem ● Expert ● Experiential 	✓✓
<p>An increase or change in needs or a negative life event can lead to a crisis situation.⁴²⁻⁴⁴ Families’ need for respite has been increasing⁴⁵</p>	4.2 When concerns arise, assess and monitor family or caregiver stress (eg, through the Brief Family Distress Scale ⁴⁶) and advocate for respite or additional supports ⁴⁷	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ○ Expert ○ Experiential 	✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
5. Interprofessional health care teams can assess and address holistically a range of health and developmental needs ⁴⁸ and, with sufficient supports, can improve outcomes of care. ⁴⁹ Such teams should be integrated (eg, the Patient's Medical Home model) ^{8,14}	5.1 Engage in or support developing an integrated health care team of professionals, preferably ones who are familiar with adults with IDD (eg, medical specialists, pharmacists, audiologists, speech and language pathologists, dentists, dietitians, occupational therapists, physiotherapists, psychologists, behaviour therapists, and those providing community supports) ^{14,50,51}	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓✓
	5.2 Designate someone to lead, coordinate, and integrate team input ⁴⁸	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓✓
Assessments and considerations important for all care			
6. Health assessments that attend to specific health issues of people with IDD increase preventive care actions and disease detection ^{52,53}	6.1 Perform a periodic comprehensive health assessment using guidelines for primary care of people with IDD and adapted tools (eg, the Preventive Care Checklist Form). ^{10,11} Include a physical health examination, mental health assessment, and review of the adequacy of financial and other community supports ^{14,51}	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓✓📄
	Success in implementing health assessments depends on making changes to the context and organization of primary care practices ^{54,55}	6.2 Monitor and seek ways of improving rates and outcomes of comprehensive health assessments of patients with IDD in your practice (eg, by proactively inviting patients, training staff, and aligning such assessments with guidelines for primary care of people with IDD) ^{10,11,55,56}	<ul style="list-style-type: none"> ● Empirical ● Expert
A health action plan helps to set goals, clarify responsibilities for health care, and facilitate partnerships among patients, caregivers, and members of the interprofessional health care team ²⁹	6.3 Based on health assessments, develop a health action plan that identifies health and related issues in an order of priority and with timelines acceptable to patients and their caregivers. Give a copy to the patient and caregiver ⁵¹	<ul style="list-style-type: none"> ● Expert 	<ul style="list-style-type: none"> ✓📄
7. The cause of IDD is important to establish because it can inform preventive care, support, and treatment decisions ⁵⁷⁻⁵⁹	7.1 Determine whether an assessment of cause has ever been done. If cause was established, consult available relevant management guidelines (eg, Health Watch Tables for specific syndromes ^{57,60,61})	<ul style="list-style-type: none"> ● Expert 	<ul style="list-style-type: none"> ✓
	Advances surrounding genetic and environmental causes of IDD continue to increase the proportion of disorders with known origin. Clinical geneticists carry out assessment of causes and offer genetic counseling ^{62,63}	7.2 If cause is unknown, contact a genetics centre for advice on referring patients for an assessment or reassessment ^{62,64-66}	<ul style="list-style-type: none"> ● Expert
8. Cognitive ability and adaptive functioning are assessed for a diagnosis of IDD and can vary throughout the lifespan ⁶⁷⁻⁷⁰	8.1 If there is a concern about cognitive ability or adaptive functioning and there has been no assessment during adolescence or adulthood, refer to a psychologist or, for adaptive functioning, to an occupational therapist with the expertise to assess ^{67,68,70}	<ul style="list-style-type: none"> ● Expert 	<ul style="list-style-type: none"> ✓
	8.2 Use tools such as the Adaptive Functioning and Communication Tool ⁷¹ as a guide if specialist assessments are unavailable or delayed	<ul style="list-style-type: none"> ● Expert 	<ul style="list-style-type: none"> ✓
Changes in cognitive ability and adaptive functioning might affect eligibility for support services and can also account for behavioural changes ^{67,69}	8.3 Reassess cognitive and adaptive functioning to inform planning for expected service transitions (see guideline 12) or whenever a substantial change in behaviour occurs ^{67,69}	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
<p>9. Pain and distress can manifest atypically in patients with limited communication and can be difficult to recognize. Nonspecific changes in vital signs, appearance, and behaviour, including being less responsive and more withdrawn or new onset of BTC (see guideline 27), might be the only indicators of pain and distress^{72,73}</p>	<p>9.1 With caregiver input and adapted tools, such as the Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities^{74,75} or the Non-Communicating Adult Pain Checklist,^{76,77} assess for pain and its intensity</p>	<ul style="list-style-type: none"> ● Empirical ● Expert 	<p>✓✓</p>
<p>Common sources of pain include injury, dental caries, GERD, arthritis, constipation, and dysuria.⁷⁸⁻⁸⁰ Distress can be a response to pain, challenges in the person's environment (eg, sensory hypersensitivity), lack of supports, or some negative life experiences^{72,73}</p>	<p>9.2 Employ a comprehensive and systematic approach to assessing BTC that might be communicating pain or other causes of distress (see guideline 27)^{84,72,81,82}</p>	<ul style="list-style-type: none"> ● Empirical ● Expert 	<p>✓✓</p>
<p>10. Polypharmacy and long-term use of certain medications are prevalent among people with IDD.⁸³ This has been shown to cause considerable adverse drug reactions and effects that negatively affect patients' quality of life.⁸⁴⁻⁸⁶ The UK campaign STOMP-LD (Stopping Over Medication of People with Learning Disabilities, Autism or Both) addresses inappropriate psychotropic medication-related polypharmacy⁸⁷</p>	<p>10.1 Review regularly (eg, every 3 mo) the date of initiation, indications, dose, effectiveness, and adverse drug reactions or unwanted effects of all medications.⁸⁸ Involve a pharmacist to review medications whenever possible⁸⁶</p>	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<p>✓✓+</p>
	<p>10.2 For potentially toxic medications, or those with drug-organ or drug-drug interactions, establish a baseline for the patient and monitor at the recommended interval for each⁸⁸</p>	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<p>✓✓</p>
	<p>10.3 Educate the person and caregivers about appropriate use of medications, interactions with over-the-counter, alternative, and as-needed medications, and to report potential adverse drug events. Provide patients and caregivers an opportunity to discuss questions about medication.^{89,90} Determine the patient's capacity and need for supports for both decision making and medication adherence.⁹¹ Simplify the medication administration routines and recommend appropriate medication administration aids (eg, dosettes, blister packs) and other needed supports</p>	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert ● Experiential 	<p>✓✓</p>
<p>11. Abuse, exploitation, and neglect of people with IDD occur more commonly compared with the general population.⁹²⁻⁹⁵ These are often perpetrated by people known to the victim.^{92,94} They include emotional, verbal, physical, or sexual abuse, and financial exploitation.⁹⁶ Abuse can present as unexplained changes in physical health (eg, malnutrition⁹⁷) or mental health (eg, anxiety, depression), as well as changes in behaviour (eg, withdrawal, disruptive behaviour, inappropriate attachments, sexualized behaviour).⁹⁸ Neglect can present as a recurring pattern of inadequate care (eg, missed appointments, nonengagement and nonadherence)⁹⁹</p>	<p>11.1 Assess for risk factors (eg, residential living) and for possible indicators of abuse, exploitation, and neglect (see background column)⁹³</p>	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert ● Experiential 	<p>✓✓</p>
	<p>11.2 Report suspected abuse, exploitation, or neglect to the appropriate authorities (eg, police or, for Ontario, via ReportON)^{100,101}</p>	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert ● Experiential 	<p>✓✓</p>
	<p>11.3 Refer all victims of abuse, exploitation, or neglect to appropriate local resources and services for support,⁹⁹ especially those with expertise in working with people with IDD</p>	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert ● Experiential 	<p>✓✓</p>
<p>12. Life transitions, such as to adolescence, adulthood, frailty (which can have an early onset), and end of life, are periods of change that are among the most challenging for people with IDD and their caregivers. These are times that require different or greater supports^{44,102-104}</p>	<p>12.1 Proactively discuss the effects of anticipated transitions with patients, their caregivers, and other members of the health care team^{44,105,106}</p>	<ul style="list-style-type: none"> ● Empirical ● Expert ● Experiential 	<p>✓✓</p>

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
Changing expectations and roles during transitions can result in emotional, behavioural, social, and spiritual distress due to changes in and loss of previous relationships and supports ¹⁰³ and limited ability to cope with such causes of distress ¹⁰⁷	12.2 Proactively engage psychosocial and spiritual supports (eg, meditation, participation in a support group or faith community) to enhance resilience and coping skills of patients. Refer to a behaviour therapist or psychologist for interventions like social skills training (see guideline 26). ^{108,109} Promote friendships and positive social networks ¹¹⁰	<ul style="list-style-type: none"> ● Empirical ● Expert ● Experiential 	✓✓
Effective communication and planning contribute to successful transfers of health care during life transitions, such as change of health care providers, systems, and settings of care and support	12.3 Collaborate with the individual, caregivers, and involved partners in care to develop a transition plan, comprehensive medical summary, and completed transition readiness checklist (eg, Healthcare Transition Tools and Resources ¹¹¹ or Ask: a health advocacy program ¹¹²). Regularly review and update the transition plan ^{113,114}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓✓
Physical health			
13. Physical inactivity and obesity are prevalent among people with IDD and are associated with cardiovascular disease, diabetes, constipation, osteoporosis, early mortality, and other health risks. Being underweight, with its associated health risks, is also common ^{115,116}	13.1 Monitor weight trends regularly and assess risk status using body mass index, waist circumference, or waist-hip ratio measurement standards ¹¹⁷⁻¹¹⁹	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	✓✓
	13.2 Counsel patients and their caregivers annually regarding targets for an optimal diet and level of physical activity using general population guidelines by age. Advise patients regarding possible changes to their daily routines to meet these targets ^{120,121}	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Experiential 	✓✓
Environmental and social factors often contribute to obesity and low physical activity rates ^{122,123}	13.3 Address modifiable risk factors for obesity such as medications and environmental or social barriers to optimal diet and physical activity ^{120,121}	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Experiential 	✓✓
A health promotion program can improve attitudes toward physical activity and satisfaction with life, ¹²⁴ but people with IDD often have difficulty finding programs that will accommodate their needs	13.4 For anyone who is not meeting diet and physical activity targets, refer to interprofessional health promotion resources (eg, dietitians, support workers, and community programs adapted for people with IDD) ¹²⁵⁻¹²⁷	<ul style="list-style-type: none"> ● Empirical ● Experiential 	✓✓
14. Vision and hearing impairments among people with IDD are often underdiagnosed and can result in substantial changes in behaviour and in social and adaptive functioning ¹²⁸⁻¹³⁰	14.1 Perform an annual office-based screening of vision and hearing (eg, Snellen eye chart and the whisper test) or when symptoms or signs of visual or hearing problems are noticed, including changes in behaviour or function ¹³¹	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓✓
	14.2 Refer for optometry assessments to detect glaucoma and cataracts every 2 y after age 40 ^{132,133}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓✓
	14.3 Refer for audiology assessments based on screening and for age-related hearing loss every 5 y after age 45 ^{131,134}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓✓
Cerumen impaction resulting in substantial hearing loss is more prevalent among people with IDD than in the general population and is a reversible cause of hearing loss ¹³⁵	14.4 Screen for cerumen impaction every 6 mo and address (eg, by advising periodic use of mineral oil drops) ^{134,136}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓
15. Oral disease (eg, periodontal disease, caries, missing teeth and dental erosions that are associated with GERD) is more prevalent among people with IDD than in the general population ^{137,138}	15.1 When dental erosions are detected, assess for GERD ^{139,140}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
Poor oral health substantially affects nutrition and respiratory and cardiac health and can contribute to behavioural disturbances. ^{140,141} However, people with IDD can have difficulty maintaining oral hygiene routines and accessing dental services that accommodate their needs ¹⁴²	15.2 Monitor oral health status and encourage daily oral hygiene routines, periodic professional dental care, and other preventive oral care measures ¹⁴³	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓✓
16. Cardiovascular disease is prevalent among people with IDD, especially those with Down, 22q11 deletion, and Prader-Willi syndromes. ¹⁴⁴⁻¹⁴⁶ Risk factors for cardiac disorders are increased owing to physical inactivity, smoking, obesity, and prolonged use of certain psychotropic medications ^{147,148}	16.1 Screen for cardiovascular risk factors earlier and more regularly than in the general population and promote prevention ^{149,150}	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
The proportion of adults with IDD who have CHF is 3 times higher than in the general population ¹⁵¹ ; CHD, which is very common in individuals with Down syndrome, can lead to CHF ^{152,153}	16.2 Assess annually for signs and symptoms of CHF and cardiac decompensation or when these are detected. If detected, refer the person to a cardiologist or, if the cause is CHD, to an adult CHD clinic. ¹⁵⁴⁻¹⁵⁶ Consult the Canadian Congenital Heart Alliance for clinic locations ¹⁵⁷	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
17. Respiratory disorders (eg, aspiration pneumonia) are among the common causes of death for people with IDD. ¹⁵⁸ Swallowing difficulties can increase the risk of aspiration or asphyxiation. ¹⁵⁹⁻¹⁶³ Such difficulties are prevalent among people with neuromuscular dysfunction (eg, cerebral palsy) or those who are taking medications with anticholinergic effects	17.1 Assess annually for overt or silent aspiration and signs of swallowing difficulty (eg, throat clearing after swallowing, coughing, choking, drooling, long meal times, aversion to food, weight loss, and frequent chest infections or asthma) or when these signs are detected ¹⁶⁴	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
	17.2 Refer to a speech and language pathologist to assess swallowing function when signs and symptoms of swallowing difficulty are detected ¹⁵⁹	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
Asthma is more prevalent among people with IDD than in the general population ^{165,166}	17.3 Screen for asthma. Consider other causes of a cough or wheeze, such as aspiration ¹⁶⁵	<ul style="list-style-type: none"> ● Empirical ● Ecosystem 	<ul style="list-style-type: none"> ✓✓
	17.4 Use spirometry or pulmonary function tests to confirm the diagnosis of asthma. These might need to be adapted to the needs of some people with IDD who find these tests difficult ¹⁶⁵	<ul style="list-style-type: none"> ● Empirical ● Ecosystem 	<ul style="list-style-type: none"> ✓✓
COPD is more prevalent in adults with IDD than adults without IDD ¹⁶⁵	17.5 Ask about smoking and exposure to second-hand smoke. Screen for COPD as in the general population ¹⁶⁵	<ul style="list-style-type: none"> ● Ecosystem 	<ul style="list-style-type: none"> ✓
	17.6 Screen for obstructive sleep apnea (see recommendation 25.3)	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓
18. Gastrointestinal problems are common among people with IDD and are manifested by food aversions, changes in behaviour, or weight loss ¹⁶⁷⁻¹⁷²	18.1. Screen annually for GERD or when symptoms or signs are detected. Manage GERD. If introducing medications (eg, NSAIDs) that might aggravate GERD, monitor for onset of GERD symptoms ¹⁶⁸	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
	18.2 If unexplained weight, gastrointestinal, or behavioural changes are detected, assess for common issues (eg, constipation, GERD, peptic ulcer disease, celiac disease, and pica) ^{169,173-175}	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
People with IDD are at increased risk of acquiring <i>Helicobacter pylori</i> infection if they have ever lived in group-living settings ^{176,177}	18.3 Test for <i>H pylori</i> infection in symptomatic patients or asymptomatic patients who live or have lived in a group residence. ¹⁷⁸ Retest at regular intervals (eg, 3-5 y) ¹⁷⁹	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
People with IDD frequently experience constipation related to neurologic dysfunction, lack of physical activity, a low-fibre diet, or medications with anticholinergic effects, which can lead to substantial morbidity. Pain associated with constipation might present as distress, sleep disturbance, or behavioural changes including self-harm ^{169,173,180,181}	18.4 Ask about frequency and consistency of bowel movements regularly to detect constipation (eg, using the Bristol Stool Chart) and address reversible medical causes. ¹⁷³	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔
	18.5 For patients with constipation or diarrhea, use a bowel movement monitoring chart ¹⁸² that patients and caregivers can complete	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔
19. Women's gynecologic and reproductive health. Menstrual disorders adversely affect the health and well-being of some women with IDD. Issues include menstrual-related pain, excessive bleeding and anemia, reduced seizure control, negative effects on hygiene, functioning, and behaviour, social isolation, and increased caregiver burden ^{183,184}	19.1 Ask about menstrual-related symptoms and concerns regularly. Provide education regarding symptom management and options, including the use of nonhormonal interventions (eg, NSAIDs) ¹⁸⁵	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔
	There is insufficient evidence currently to recommend one method of menstrual regulation or suppression over others for women with IDD ^{186,187}	19.2 Discuss methods of menstrual regulation with women with IDD and their caregivers. In deciding together on a method, consider safety and effectiveness, the patient's health circumstances, and the patient's and caregiver's views on the benefits and burdens to the patient ^{184,187}	<ul style="list-style-type: none"> ● Expert
Medical considerations regarding fertility regulation for women with IDD are similar to those for other women. In Canada, the law prohibits parents or other substitute decision makers from consenting on behalf of persons with IDD who are incapable of giving consent to surgical sterilization for contraceptive purposes ¹⁸⁸	19.3 Screen for sexual exploitation and unintentional risky or harmful sexual practices. When these are present, facilitate deliberation with the patient and her caregiver of a range of methods to reduce risk of infections and to regulate fertility	<ul style="list-style-type: none"> ● Expert 	✔
Pregnancy poses increased risk of adverse health outcomes for women with IDD. They have higher rates of obesity, epilepsy, polypharmacy, mental health issues, and poverty than similar-aged women in the general population. They are also more likely to have complications of pregnancy, such as venous thromboembolism and preeclampsia, and to undergo labour induction and cesarean section than pregnant women without IDD are ^{189,190}	19.4 Provide women with IDD with increased monitoring during pregnancy (eg, longer and more frequent appointments) ¹⁹¹	<ul style="list-style-type: none"> ● Ecosystem 	✔
	19.5 Address modifiable risk factors (eg, smoking cessation) before or as soon as possible during pregnancy ¹⁸⁹	<ul style="list-style-type: none"> ● Ecosystem 	✔
	19.6 Engage local resources that can support and educate mothers with IDD and their partners as soon as possible during pregnancy and after childbirth ¹⁸⁹	<ul style="list-style-type: none"> ● Ecosystem 	✔
Menopause occurs earlier among women with IDD, especially those with certain genetic disorders such as Down syndrome, than among women in the general population. Women with IDD are often unaware of symptoms associated with menopause (eg, disturbed sleep) ¹⁹²	19.7 Ask perimenopausal women with IDD about menopausal symptoms at an earlier age than women without IDD ¹⁹²	<ul style="list-style-type: none"> ● Experiential 	✔
Relationships, intimacy, and sexuality are important issues that are often not considered or addressed in the primary care of adolescents and adults with IDD ¹⁹³	19.8 Ask male and female patients, their family, or other caregivers about the patient's relationships, intimacy, and sexuality (eg, sexual behaviour, gender identity, sexual orientation, genetic risks). ¹⁹⁴ Provide or refer for education and counseling services that are adapted to the needs of people with IDD ¹⁹³	<ul style="list-style-type: none"> ● Expert 	✔ 

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
<p>20. Neuromuscular and skeletal disorders (eg, scoliosis, contractures, spasticity, and ligamentous laxity) are possible sources of unrecognized pain and occur frequently among people with IDD, especially those with cerebral palsy. This can result in reduced mobility and physical activity with associated adverse health outcomes¹⁹⁵⁻¹⁹⁷</p>	20.1 Promote mobility and regular physical activity (see guideline 13) ^{198,199}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔
	20.2 Consult a physical or occupational therapist regarding adaptations to promote mobility and physical activity (eg, wheelchair, walker, modified seating, splints, orthotics, and safety devices such as handrails) ¹⁹⁸	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔✔
	20.3 Actively monitor foot health and ensure properly fitting footwear in consultation with a podiatrist or orthotist ²⁰⁰	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔
<p>Osteoporosis and osteoporotic fractures are more prevalent and occur at a younger age among people with IDD than among those in the general population^{201,202}</p>	20.4 Screen both male and female patients for osteoporosis starting in early adulthood ^{201,203}	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	✔✔
	20.5 Seek advice from a radiologist regarding alternative methods to assess risk of fragility fractures if the patient cannot be assessed using the usual nuclear BMD test, such as by assessing the patient's forearm only ²⁰⁴	<ul style="list-style-type: none"> ● Ecosystem ● Expert 	✔✔
<p>Risk factors for osteoporosis specific to people with IDD include increased severity of IDD; long-term use of certain medications such as anticonvulsants, glucocorticoids, and injectable long-acting progesterone in women; vitamin D deficiency; prolactinemia; immobility; and presence of certain genetic syndromes^{202,204,205}</p>	20.6 Recommend early and adequate intake or supplementation of calcium and vitamin D unless contraindicated (eg, among people with Williams syndrome) ^{202,204}	<ul style="list-style-type: none"> ● Expert 	✔
	20.7 Be aware of concurrent medical conditions and medications in patients with IDD when considering osteoporotic treatment options (eg, renal insufficiency or swallowing difficulty) and seek advice (eg, from an endocrinologist or pharmacist) ^{202,204}	<ul style="list-style-type: none"> ● Expert 	✔
<p>21. Epilepsy occurs in about 1 in 5 people with IDD compared with 1 in 100 people without IDD.²⁰⁶ The prevalence increases with the severity of IDD. It contributes to early mortality.²⁰⁷ It can be difficult to diagnose.^{208,209} Choice of medications and importance of regular monitoring are the same as for those in the general population²⁰⁸</p>	21.1 For people with IDD and epilepsy, make a comprehensive epilepsy health action plan involving patients, family, and other caregivers. ²⁰⁸ Follow guidelines for diagnosis and management of epilepsy ^{208,210,211} and use tools for periodic reviews ²¹²	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔✔
	21.2 Review this plan at least annually. Review more frequently (eg, every 3 to 6 mo) the efficacy and safety of antiepileptic medications, including any drug reactions adversely affecting cognitive functioning or behaviour ²¹⁰	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔✔
<p>22. Endocrine disorders can be challenging to diagnose in people with IDD. They have a higher incidence of thyroid dysfunction compared with those in the general population²¹³</p>	22.1 Test annually for thyroid function in patients with elevated risk of thyroid dysfunction (eg, people with Down syndrome). Also test when changes in behaviour or adaptive functioning are detected ^{214,215}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔✔
	22.2 For patients taking lithium, atypical or second-generation antipsychotics, or seizure medications, establish a thyroid function baseline followed by annual reassessment ^{216,217}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✔✔
<p>The prevalence of diabetes is higher among people with IDD compared with those in the general population and slightly higher among women than men^{218,219}</p>	22.3 Include patients with IDD among those at high risk of diabetes. Screen for type 2 diabetes at an earlier age than is recommended for the general population ²¹⁸	<ul style="list-style-type: none"> ● Ecosystem ● Experiential 	✔✔
	22.4 Provide diabetes education to patients with IDD who have diabetes and their family and other caregivers that is adapted for people with IDD ²²⁰⁻²²²	<ul style="list-style-type: none"> ● Expert ● Experiential 	✔✔

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
<p>23. Infectious diseases (eg, influenza, <i>Streptococcus pneumoniae</i> infection, and hepatitis B). People with IDD living in group residential settings are at higher risk of developing such infections²²³⁻²²⁵ but have lower rates of immunization and screening compared with the general population^{226,227}</p> <p>People with IDD are at a greater risk of developing chronic, invasive, and life-threatening forms of infection because of factors such as increased infectious sources, compromised immunity, inability to report symptoms, and absence of fever and other signs of infection.^{226,227} They are also at greater risk of not having these infections detected promptly</p>	23.1 Include patients with IDD in routine immunization programs targeting high-risk populations for influenza and <i>S pneumoniae</i> infections ^{223,227}	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert ● Experiential 	✓✓
	23.2 Offer hepatitis A and B immunization to all at-risk patients, such as those who require long-term, potentially hepatotoxic medications or who live in group settings ^{225,228}	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert ● Experiential 	✓✓
	23.3 Screen patients for infectious disease according to guidelines for high-risk populations and other special risk factors (eg, group residence, sexual practices, IV drug use) ²²⁹	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓
	23.4 Reduce risk factors for invasive lung infections, such as by supporting safe feeding practices, positioning to enable secretion clearance, and respiratory therapy ²²⁶	<ul style="list-style-type: none"> ● Expert 	✓
	23.5 If a patient manifests changes in behaviour or mental status, perform a head-to-toe examination to detect infection. Alert caregivers to signs and symptoms of infection	<ul style="list-style-type: none"> ● Expert 	✓
<p>24. Cancer screening (eg, for cervical, breast, and colorectal cancer) is less likely to be received by people with IDD than by those in the general population.^{230,231} Factors include lack of knowledge of family history to inform screening intervals, logistic challenges performing certain screening, lack of adapted patient education tools, and family member reluctance and fears related to the perceived excessive burdens of possible cancer treatment^{232,233}</p> <p>People with IDD are less likely to be supported to self-monitor and report early symptoms and signs of cancer. Those who do develop cancer often have more advanced cancer at the time of detection than those in the general population do²³⁶</p>	24.1 Proactively obtain information on family history of cancer and review annually ²³⁴	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert ● Experiential 	✓✓
	24.2 Use clinical tools adapted for people with IDD to promote education and uptake of cancer screening tests ²³⁵	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Experiential 	✓✓✓📄
	24.3 Discuss concerns regarding cancer and symptom management with family and other caregivers and provide information regarding management and palliative care ²³²	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Experiential 	✓✓
	24.4 Perform a total-body screen for skin lesions and breast and testicular examination in adults with IDD during periodic health assessments. Use easy-to-read materials to inform people with IDD about these examinations before assessment (eg, Easyhealth easy-read leaflets). ²⁶	<ul style="list-style-type: none"> ● Empirical 	✓
	24.5 Proactively instruct patients regarding self-monitoring, as is considered routine among those in the general population (eg, being breast aware, reporting gross hematuria, melena, and changes in moles) ²³⁷	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓
	24.6 Instruct family and other caregivers regarding observable signs and symptoms of cancer and, if detected, to seek prompt medical attention ^{237,238}	<ul style="list-style-type: none"> ● Empirical ● Expert 	✓
	25. Sleep problems (eg, difficulties settling, night walking, or early awakening) are common among adults with IDD and often result in increased caregiver stress ²³⁹	25.1 Screen regularly for sleep problems and for associated caregiver stress. ²³⁹ Review with and educate patients and their caregivers on helpful sleep hygiene practices ²⁴⁰	<ul style="list-style-type: none"> ● Empirical

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
Sleep problems can be caused by physical health issues (eg, GERD, pain that the person with IDD might be unable to communicate, ²⁴¹ or obstructive sleep apnea); environmental factors (eg, noise, electronic screen time); distressing life experiences (eg, bereavement or adjustment to change); or effects of medications (eg, certain psychotropics, antiepileptics, and antidepressants). Also, BTC and psychiatric disorders can be associated with sleep disturbance ²³⁹	25.2 Review medications that might negatively affect sleep and other physical health issues, as well as environmental, life experience, and psychiatric issues that might cause sleep problems ²³⁹	● Empirical	✔
	25.3 Assess for obstructive sleep apnea in patients, especially those who are obese (see guideline 13) and those with craniofacial abnormalities or certain genetic disorders (eg, Down syndrome) ²⁴¹⁻²⁴³	● Empirical ● Expert	✔
	25.4 Refer to a behaviour therapist or occupational therapist familiar with people with IDD to assess or address sleep hygiene and environmental factors ²⁴⁰	● Empirical	✔
Mental health			
26. Psychosocial context and mental well-being. Mental health disturbances, common among adults with IDD, are associated with sensory impairments, negative life events, ²⁴⁴ lack of suitable supports (emotional, social, community, work, and recreational), ²⁴⁵ stress, ²⁴⁶ and coping capacity ^{107,247}	26.1 Screen for sensory impairments (see guideline 14), negative social circumstances, stressful life events (eg, abuse, neglect, bullying, and exclusion), and coping capacity (see guidelines 11 and 27)	● Empirical ● Ecosystem ● Expert ● Experiential	✔✔
	26.2 Promote friendships, social networks, and accommodations for inclusion and participation to decrease isolation and loneliness ²⁴⁸	● Empirical ● Ecosystem ● Expert	✔✔
	26.3 Engage with community services and interprofessional partners or teams to enhance coping skills ⁷³	● Empirical ● Ecosystem ● Expert	✔✔
	26.4 Get the person with IDD's perspective on their situation whenever possible. Use visual aids as well as words (eg, Books Beyond Words) ^{24,110}	● Expert ● Experiential	✔✔
The effects of these circumstances can best be understood by inviting and appreciating the perspectives of persons with IDD, in combination with those who support them ²⁴⁹⁻²⁵¹			

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
<p>27. Behaviours that challenge (eg, self-injury, aggression, outbursts of anger, and irritability) are not psychiatric disorders; BTC often communicate underlying distress, sometimes from multiple causes^{72,73,252}</p> <p>BTC sometimes occur owing to an absence of necessary environmental accommodations, insufficient supports (eg, inappropriate expectations and environments that are stressful, unresponsive, understimulating or overstimulating, noisy, restrictive, or intrusive, or that lack privacy), and a lack of adaptations for coexisting disabilities such as cerebral palsy and hearing and vision impairments</p> <p>An “enabling environment” exists when an individual’s developmental needs match their supports.⁷³</p> <p>BTC can be symptoms of negative life experiences (eg, bullying, disappointment, losses, grief, and trauma)²⁵³⁻²⁵⁶</p> <p>BTC might be a symptom of psychiatric illness. A systematic diagnostic formulation, such as HELP, will identify whether BTC that appear “psychiatric” might be due to one or more other causes^{72,257}</p>	<p>27.1 Develop a diagnostic formulation (eg, HELP) that considers causes sequentially and systematically, such as the following⁵⁰:</p> <p>H—Assess for possible physical health problems, (consult the above physical health recommendations for head-to-toe sequence of common medical concerns), pain, and adverse and other side effects of medications</p> <p>E—Facilitate “enabling environments” that meet these unique developmental needs and can diminish or eliminate BTC. Work with an interprofessional team and caregivers to address problematic environmental circumstances (see guidelines 1, 2, 26).⁷³ Ascertain whether existing supports match needs (see guideline 8).²⁵⁸ Plan for a functional behavioural assessment by a behavioural therapist or psychologist</p> <p>L—Screen for distressing life experiences that might be contributing to BTC (see guideline 12)^{72,252,259,260}</p> <p>P—Having attended to the above, consider psychiatric conditions (eg, adjustment difficulties, mood and anxiety concerns). Refer as needed for assessment to an interprofessional mental health team (see guideline 5)^{48,72,252,261,262}</p>	<ul style="list-style-type: none"> ● Empirical ● Expert ● Experiential 	
<p>Despite the evidence of non-benefit and concerns regarding potential harm, psychotropic medications are often used to manage BTC^{263,264}</p>	<p>27.2 Review regularly (eg, every 3 mo) the rationale and use of prescribed psychotropic medications, including those used as needed.^{263,265-268} See guideline 29 for psychotropic prescribing practices for psychiatric disorders</p>	<ul style="list-style-type: none"> ● Ecosystem ● Expert 	
<p>Efforts should focus on the need to adequately assess the cause of BTC rather than solely using medication to suppress them</p>	<p>27.3 Use psychotropic medication to manage BTC of people with IDD only as a last resort and for a short term to risk of harm while ascertaining causes^{72,263}</p>	<ul style="list-style-type: none"> ● Expert 	
<p>For some people with IDD, additional supports might first have to be provided for successful discontinuation of medications²⁶⁹⁻²⁷¹</p>	<p>27.4 Consider tapering and stopping, at least on a trial basis, long-term psychotropic medications not prescribed for a specific psychiatric diagnosis.^{266,268} Refer and work with an interprofessional mental health team for this purpose^{266,268,271}</p>	<ul style="list-style-type: none"> ● Empirical ● Expert 	
<p>Antipsychotic medications are often inappropriately prescribed for adults with BTC and IDD in the absence of a robust diagnosis of a psychotic disorder^{269,272}</p>	<p>27.5 Do not use antipsychotic medications as a first-line or routine treatment of BTC²⁶⁸⁻²⁷⁰</p>	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	
<p>28. Psychiatric disorders. People with IDD have increased vulnerability to mental stress compared with those in the general population. Developmental challenges, transitions, greater exposure to adversity and traumatic life events, limited coping skills, and insufficient supports contribute further to this vulnerability. If adjustment issues are not adequately addressed, they might give rise to adjustment disorders, which are diagnosed when a life event or trigger has contributed to the mental distress²⁶⁰</p>	<p>28.1 Screen for antecedents, life events, and other triggers of mental distress. Explore the importance of the event for the person and obtain collateral history²⁶⁰</p>	<ul style="list-style-type: none"> ● Expert 	
	<p>28.2 Proactively plan with the person with IDD, caregivers, and appropriate services to attend to predictable developmental challenges and stressors and to ensure that the necessary supports will be in place (see guidelines 12 and 29)²⁵⁹</p>	<ul style="list-style-type: none"> ● Expert 	
	<p>28.3 Offer or facilitate supportive counseling before developmental challenges and life stressors occur (see guideline 29)</p>	<ul style="list-style-type: none"> ● Expert 	

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
Psychiatric disorders (eg, mood and anxiety disorders) are common among adults with IDD, but the signs and symptoms might be seen as part of the IDD (ie, diagnostic overshadowing) rather than a change indicating a psychiatric disorder. Consequently, psychiatric disorders might not be recognized and addressed ^{252,273-275}	28.4 Screen for a possible psychiatric disorder by looking for changes from baseline in mental state and behaviour (see psychiatric symptoms and behaviour screening tool, page 75) ²⁵⁸	<ul style="list-style-type: none"> ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
Establishing a diagnosis of a psychiatric disorder in adults with IDD is often complicated by communication barriers or atypical presentation. ^{274,275} In general, anxiety, mood, trauma, and stressor-related disorders (eg, PTSD and adjustment disorder) are underdiagnosed while psychotic disorders are overdiagnosed in people with IDD ^{252,276-280}	28.5 Seek interprofessional assessment from specialists in psychiatry, psychology, or speech-language pathology, preferably those with expertise in IDD. Review previous psychiatric diagnoses. Consider use of self-report and informant questionnaires developed for people with IDD (eg, Glasgow Depression Scale for People with a Learning Disability, Glasgow Anxiety Scale for People with an Intellectual Disability, Glasgow Depression Scale–Carer Supplement) ²⁸¹⁻²⁸³	<ul style="list-style-type: none"> ● Empirical ● Ecosystem ● Expert 	<ul style="list-style-type: none"> ✓✓
Some IDD syndromes are associated with increased risk of particular developmental, neurologic, or behavioural manifestations and emotional disturbances (ie, “behavioural phenotypes”) ^{284,285}	28.6 Consult available information regarding behavioural phenotypes associated with specific syndromes (eg, autism spectrum disorder, ²⁸⁶ fetal alcohol spectrum disorder, ²⁸⁷ and Williams syndrome) ²⁸⁸	<ul style="list-style-type: none"> ● Expert 	<ul style="list-style-type: none"> ✓
PTSD is underdiagnosed and might manifest as anxiety, mood disturbance, or change in behaviour (eg, “noncompliance,” self-injury, aggression, outbursts of anger, irritability) and might occur in response to events not typically considered to be traumatizing (eg, siblings leaving home) ²⁸⁹⁻²⁹¹	28.7 Explore for possible trauma, possibly unknown to new care providers; be alert for signs of PTSD such as reexperiencing (eg, psychotic presentations and behavioural enactments; avoidance, which might be interpreted as noncompliance; and increased arousal, which can present as irritability) ²⁹¹	<ul style="list-style-type: none"> ● Expert ● Experiential 	<ul style="list-style-type: none"> ✓✓ 📄
Psychotic disorders, which include schizophrenia and traumatic psychosis, are especially difficult to diagnose in people with IDD when their delusions and hallucinations cannot be expressed verbally. ^{279,280,292} Developmentally appropriate fantasies and imaginary friends might be mistaken for delusions, and self-conversation mistaken for hallucination ^{279,280,293}	28.8 Work with an interprofessional team to help clarify diagnoses in patients with limited or atypical use of language ^{294,295}	<ul style="list-style-type: none"> ● Expert 	<ul style="list-style-type: none"> ✓
Sexual abuse occurring during childhood can be associated with hearing voices in adulthood ^{296,297}	28.9 Screen for trauma ²⁹¹	<ul style="list-style-type: none"> ● Expert 	<ul style="list-style-type: none"> ✓
There is increased risk of psychosis associated with visual ²⁷⁷ and hearing ²⁹⁸ impairment and social isolation	28.10 Screen for and address possible hearing and vision impairments (see guideline 14)	<ul style="list-style-type: none"> ● Empirical 	<ul style="list-style-type: none"> ✓
	28.11 Work with caregivers to ensure optimal communication ^{299,300} (see guideline 2) and inclusion to prevent social isolation (see guideline 11)	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓
Emotional, psychiatric, and medical conditions can coexist and give rise to clinical and diagnostic complexity. ³⁰¹ A biopsychosocial approach assists in unraveling these complexities ^{50,252,302}	28.12 Implement a systematic and sequential approach, such as the HELP approach (guideline 27), to identify contributing causes or seek consultation from an interprofessional mental health team ^{276,277}	<ul style="list-style-type: none"> ● Empirical ● Expert 	<ul style="list-style-type: none"> ✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
<p>29. Mental health intervention. Psychological therapies. When people with IDD experience emotional distress, various individual or group interventions are effective (eg, counseling, CBT, positive behaviour support, psychotherapy, trauma-informed therapies, mindfulness practices).^{108,252,290} Adaptations to the needs of people with IDD and supports can improve access to these therapies</p>	29.1 Inform patients of psychological interventions and supports available from the interprofessional team or community. Ensure that supports to access these services are provided (eg, transportation) and include the active participation of an IDD-informed support person ¹⁰⁸	<ul style="list-style-type: none"> 👤 Expert 	✅
<p>Psychotropic medications can be effective, along with other psychological therapies, when a psychiatric disorder (eg, ADHD, anxiety and mood disorder) is confirmed by comprehensive assessment.^{216,252,263,303} Psychotropic medications, however, should be used judiciously with people with IDD. Some might be taking multiple medications and thus be at increased risk of adverse drug-drug interactions (see guideline 10), have atypical responses, and have adverse reactions or unwanted effects even at low doses. Adults with IDD might be unable to describe harmful or distressing effects other than through changes in their behaviour^{264,304-307}</p>	29.2 When a psychiatric diagnosis is confirmed by comprehensive assessment, consider indicated, disorder-specific psychotropic medication along with other possible interventions as outlined below ^{252,263}	<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
	29.3 Consult prescribing guidelines for psychiatric disorders in IDD ^{88,263,267}	<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
	29.4 Refer to medication algorithms for specific diagnostic categories (eg, ADHD, anxiety, mood) ^{216,303}	<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
	29.5 Start low and go slow in initiating, increasing, or decreasing doses of medications ^{88,305}	<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
	29.6 Seek and document informed consent using adapted tools, such as the Informed Consent Checklist ³² (see guideline 3) ⁸⁸	<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
	29.7 Educate and arrange to receive feedback regularly from patients and their caregivers during medication trials ^{252,303}	<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
	<p>Antipsychotic medications are commonly prescribed to adults with IDD despite the absence of a diagnosis of a psychotic or mood disorder.^{83,264} Adverse drug reactions and unwanted effects can be considerable. Antipsychotic medications increase the risk of CNS effects (eg, sedation, behavioural disturbance), extrapyramidal symptoms (eg, parkinsonism, akathisia, tardive dyskinesia), anticholinergic effects (eg, swallowing difficulties, bowel dysfunction), cardiovascular effects (eg, orthostatic hypotension, tachycardia), and endocrine effects (eg, metabolic syndrome, sexual dysfunction), as well as longer-term adverse effects^{267,308}</p>	29.8 Review response, adverse reactions, or unwanted effects every 3 mo (see guideline 10). Review the psychiatric diagnosis and appropriateness of prescribed medications whenever there is nonresponse, worsening of symptoms, behavioural change, or patient or caregiver request ^{88,263,306}	<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert
29.9 Monitor and address adverse drug reactions and unwanted effects of antipsychotic medications, such as those listed in the background column ⁸⁸		<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
29.10 If adverse drug reactions or unwanted effects are present, consider dose reduction, tapering, or switching medications ^{263,308}		<ul style="list-style-type: none"> 👤 Empirical 👤 Ecosystem 👤 Expert 	✅✅
<p>Other therapeutic interventions include environmental modification with attention to sensory hypersensitivities and hyposensitivities; education and skill development; communication aids; behaviour support; art, drama, and music therapies; healthy lifestyle and physical activity interventions; and caregiver support, training, and stress-reduction practices^{124,126,252}</p>	29.11 Educate patients and caregivers to incorporate a healthy diet, physical activity and good sleep habits into their lifestyles ⁸⁸	<ul style="list-style-type: none"> 👤 Empirical 👤 Expert 	✅✅
	29.12 Advocate for and consider referral to professionals, agencies, and community programs that can be of therapeutic benefit, especially those that can be adapted to the needs of people with IDD ²⁵²	<ul style="list-style-type: none"> 👤 Empirical 👤 Expert 	✅✅

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
30. Behavioural crises arise from various circumstances and in response to stressors. When behaviour cannot be managed safely in the current environment, a situation can escalate to a crisis level and require assessment and management in an ED	30.1 Psychotropic medications can be used to ensure safety during a behavioural crisis and might need to be continued during assessment of the underlying causes. This use should be temporary and ideally stopped after 72 h ³⁰⁹	● Expert	✓
Some people with IDD who have visited EDs for behavioural crises do not have any follow-up with a primary care provider or psychiatrist within 30 d of discharge. ³¹⁰ Follow-up is crucial for continuity of care, prevention of recurrence, and the need to review any medication prescribed to manage the crisis ³¹¹	30.2 Debrief with the patient and caregivers as soon as possible (eg, within 72 h) after an ED visit in order to minimize the likelihood of recurrence. Include a review of crisis events and responses (eg, de-escalation measures, medications) and identify the possible triggers and underlying causes of the behavioural crisis ^{268,311}	● Ecosystem ● Expert	✓✓
Hospital staff, people with IDD, and caregivers consider crisis plans helpful in managing crises. ^{312,313} People with IDD with primary care involvement and crisis plans are less likely to visit an ED when a crisis arises ³¹⁴	30.3 If the patient is at risk of recurrent behavioural crises, involve local ED staff and other stakeholders to develop a proactive, integrated crisis plan (eg, Crisis Prevention and Management Plan). ³¹⁵ This should be available in the ED and updated regularly ³¹⁶	● Empirical	✓
31. Addictions are underrecognized among adults with IDD. ³¹⁷ High risk of addiction is associated with mild IDD, persons who live independently, males, those with psychiatric disorders, and those with legal issues. ³¹⁸ The most commonly used substance is alcohol, ^{319,320} followed by cannabis. ³²⁰ Lower amounts of alcohol consumed can lead to functional impairments in those with IDD relative to the general population ^{318,319}	31.1 Screen for risk and vulnerability factors for addictions as part of a comprehensive health assessment ³²¹	● Empirical ● Ecosystem ● Expert	✓✓
	31.2 Educate adults with IDD, family, and other caregivers about risks and vulnerabilities, including peer pressure and exploitation ³²²	● Empirical ● Ecosystem ● Expert	✓✓
	31.3 When addiction is present, review the environment, social relationships, and supports. Understanding how aware the person is of the problems and associated risks can assist in developing appropriate interventions ^{322,323}	● Empirical ● Ecosystem ● Expert	✓✓
	31.4 Work with the person, their family, and other caregivers using a harm-reduction approach, including planning regular office visits ³¹⁸	● Empirical ● Ecosystem ● Expert	✓✓
There are few addiction-related services adapted to the needs of people with IDD. ³²⁴ They are very likely to have comorbid psychiatric diagnoses and a range of physical health issues that require a multifaceted approach to management ^{317,318}	31.5 Advocate for adaptations to and arrange additional supports for people with IDD in order to benefit from generic addiction-related services designed for people without IDD. ^{321,325} Promote opportunities for meaningful socialization that do not involve exposure to addictive substances	● Ecosystem ● Expert	✓✓
32. Dementia (major neurocognitive disorder ⁶⁸) is more prevalent among adults with IDD compared with the general population (age of onset 60-65 y), with a statistically significantly increased risk in adults with Down syndrome and at an earlier age (50-55 y) ^{326,327}	32.1 Educate caregivers to recognize and report possible early signs of dementia, such as new onset of forgetfulness, incontinence, loss of personal skills, and changes in sleep patterns, personality, and behaviour ^{328,329}	● Empirical ● Expert	✓✓
	32.2 When signs of dementia are present, investigate for potential reversible causes including infections, thyroid disorder, cardiovascular disease, hearing and visual impairments, nutritional deficiencies, or medication effects ³³⁰	● Expert	✓
	32.3 Refer individuals who are known to be at risk of dementia to a psychologist for a baseline assessment of cognitive, adaptive, and communicative functioning after age 40 y and at age 30 y for people with Down syndrome ³²⁶	● Expert	✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
Differentiating dementia from depression and delirium can be especially challenging in adults with IDD ³³¹	32.4 Monitor with tools designed for people with IDD and dementia (eg, NTG–Early Detection Screen for Dementia) ^{329,332,333}	● Empirical ● Expert	✓✓
	32.5 Apply the differential diagnosis criteria for dementia and delirium as in the general population using a systematic and sequential approach, such as the HELP framework (see guideline 27), to review signs and symptoms of concern ³³⁰	● Expert	✓
	32.6 After addressing any medical findings and precipitating life events, consider the possibility of depression and a trial of an antidepressant medication to resolve symptoms and support the diagnosis of depression ³²⁷	● Expert	✓
	32.7 Refer to the appropriate specialist (eg, IDD mental health team, geriatric service, or neurologist) if it remains uncertain whether symptoms and behaviour are due to emotional disturbance, psychiatric disorder, or dementia ³²⁶	● Expert	✓

ADHD—attention deficit hyperactivity disorder, BMD—bone mineral density, BTC—behaviours that challenge, CBT—cognitive-behavioural therapy, CHD—congenital heart disease, CHF—congestive heart failure, CNS—central nervous system, COPD—chronic obstructive pulmonary disease, ED—emergency department, GERD—gastroesophageal reflux disease, IDD—intellectual and developmental disabilities, IV—intravenous, NSAID—nonsteroidal anti-inflammatory drug, NTG—National Task Group, PTSD—posttraumatic stress disorder.

We hope that our approach of classifying and profiling types of knowledge in these guidelines will prompt greater interest and support for research in these areas.

Finally, as noted above, these updated guidelines outline optimal standards of care while indicating that the resources and supports required for following them are not readily available in some settings (eg, specialists who are knowledgeable about IDD, interprofessional teams or programs adapted to the needs of people with IDD). While advocacy to obtain such resources is encouraged, and advocacy is indeed one of the CanMEDS–Family Medicine roles, changes in practices and health systems take time and might not always be possible to achieve. Some of these updated guidelines propose alternative measures that can be considered while awaiting such resources.

Future updates

To keep these guidelines current, a comprehensive review will be conducted within 5 years of publication.

Conclusion

Adults with IDD have different and often more complex health needs and factors affecting their health than other patients do. As primary care providers, family physicians play a vital role in promoting the health and well-being of adults with IDD. While they are familiar with common health issues that affect most patients in the community, they can also benefit from knowing what to attend to in their patients with IDD and how best to care for them. These updated guidelines are based on a review and synthesis of current knowledge

by colleagues who are experienced in the care of people with IDD. They offer advice that is intended to support clinical decision making in an area of primary care in which they encounter high levels of complexity and ambiguity and in which few comprehensive guidelines by family physicians exist. Papers in a special supplement to *Canadian Family Physician* elaborate on some of the recommendations.³³⁴

Dr Sullivan is Associate Professor in the Department of Family and Community Medicine at the University of Toronto in Ontario, a staff physician in Medical Services at Surrey Place Centre and the Family Practice Unit at St Michael's Hospital, and Director of the Developmental Disabilities Primary Care Program at Surrey Place Centre. **Dr Diepstra** is a research associate at Surrey Place Centre. **Mr Heng** is Assistant Professor in the Department of Philosophy and the Department of Interdisciplinary Studies at King's University College in London, Ont. **Ms Ally** is an advanced practice nurse at Surrey Place Centre, Adjunct Lecturer in the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto, and an MBA candidate. **Dr Bradley** is Associate Professor in the Department of Psychiatry at the University of Toronto and a consulting psychiatrist and psychotherapist in intellectual disabilities. **Dr Casson** is Associate Professor in the Department of Family Medicine at Queen's University in Kingston, Ont. **Dr Hennen** is Professor Emeritus at Western University in London and Dalhousie University in Halifax, NS. **Ms Kelly** is a retired nurse from Toronto. **Ms Korossy** is a retired librarian from Surrey Place Centre in Toronto. **Dr McNeil** is Assistant Professor in the Department of Family Medicine at Dalhousie University. **Dr Abells** is a family physician at Forest Hill Family Health Centre in Toronto and the Integrated Services for Autism and Neurodevelopmental Disorders, and Lecturer in the Department of Family and Community Medicine at the University of Toronto. **Dr Amaria** is a clinical and health psychologist and team lead for the Good 2 Go Transition Program at the Hospital for Sick Children in Toronto. **Dr Boyd** is Associate Clinical Professor in the Department of Psychiatry and Behavioural Neurosciences at McMaster University in Hamilton, Ont, and Chief Clinical Officer for Bethesda Community Services in Thorold, Ont. **Dr Gemmill** is Assistant Professor in the Department of Family Medicine at Queen's University. **Dr Grier** is Assistant Professor in the Department of Family Medicine at Queen's University. **Dr Kennie-Kaulbach** is University Teaching Fellow and a coordinator in the Skills Lab in the College of Pharmacy at Dalhousie University. **Ms Ketchell** is a behaviour analyst and Professor in the School of Social and Community Services at Humber Institute of Technology and Advanced Learning in Toronto. **Dr Ladouceur** is Adjunct Professor in the Belleville Queen's University Family Medicine Centre. **Dr Lepp** is a resident in the Discipline of Family Medicine at McMaster University. **Dr Lunsky** is Senior Scientist at the Centre for Addiction and Mental Health in Toronto and Professor and Developmental Disability Lead at the University of Toronto. **Dr McMillan** is a clinical nurse specialist in the adult program at Surrey Place Centre. **Dr Niel** is a family physician at the Scarborough Centre for Healthy

Communities in Ontario. **Dr Sacks** is Clinical Faculty Lecturer in the Department of Family Medicine at McGill University in Montreal, Que, and a family physician at See Things My Way Centre for Innovation in Autism and Intellectual Disabilities. **Dr Shea** is Professor in the Department of Pediatrics at Dalhousie University. **Dr Stringer** is Associate Professor and Chair of Family Medicine at Memorial University of Newfoundland in St John's. **Dr Sue** is Clinical Assistant Professor in the Discipline of Family Medicine at Memorial University of Newfoundland. **Ms Witherbee** is a family practice nurse in the Dalhousie Family Medicine Clinic.

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Contributors

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Correspondence

Dr William F. Sullivan; e-mail bill.sullivan@utoronto.ca

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