Primary care of adults with intellectual and developmental disabilities

2018 Canadian consensus guidelines

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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 lifelong 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

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*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: 🔵 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: 🔵 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: 🔵 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: 🔵 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: • 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
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]	2.1 Address patients directly[13]	◐ Expert 🔵 Experiential	✓✓
	2.2 Find ways of engaging the patient. Attend to both verbal and nonverbal cues[23]	● Expert ◑ Experiential	✓✓
	2.3 Use the patient's preferred communication method and tools (eg, Easyhealth easy-read leaflets) to facilitate communication[18,24-26]	🔵 Expert 🔵 Experiential	✓✓
	2.4 Slow down in communicating[13,27,28] (see Communicating Effectively tool[27])	◐ Expert 🔵 Experiential	✓✓
	2.5 Involve caregivers familiar with the patient to help communicate, but be attentive to inappropriate taking over of decision making[28]	◐ Expert 🔵 Experiential	✓✓
	2.6 Try to have a short period alone with the patient to address safety or other concerns[29]	● Expert ◑ Experiential	✓✓
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]	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]	🔵 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]	◐ Expert ◑ Experiential	✓✓
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]	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]	🔵 Expert 🔵 Experiential	✓✓
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]	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])	● Empirical ◐ Ecosystem ● Expert 🔵 Experiential	✓✓
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 increasing[45]	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]	● 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]	◑ Empirical ◑ Expert	✓✓
	5.2 Designate someone to lead, coordinate, and integrate team input[48]	◑ Empirical ◑ Expert	✓✓
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]	◑ Empirical ● Expert	✓✓✚
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]	● 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]	● Expert	✓✚
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])	● Expert	✓
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]	◑ 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]	● Expert	✓
	8.2 Use tools such as the Adaptive Functioning and Communication Tool[71] as a guide if specialist assessments are unavailable or delayed	◑ Expert	✓
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]	◑ Empirical ● Expert	✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
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]	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	● Empirical ◑ Expert	✓✓
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]	9.2 Employ a comprehensive and systematic approach to assessing BTC that might be communicating pain or other causes of distress (see guideline 27)[14,72,81,82]	◑ Empirical ● Expert	✓✓
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 polypharmacy[87]	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 possible[86]	● Empirical ◑ Ecosystem ● Expert	✓✓✚
	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 each[88]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
	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	● Empirical ◑ Ecosystem ◑ Expert ● Experiential	✓✓
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, malnutrition[97]) 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]	11.1 Assess for risk factors (eg, residential living) and for possible indicators of abuse, exploitation, and neglect (see background column)[93]	◑ Empirical ● Ecosystem ◑ Expert ◑ Experiential	✓✓
	11.2 Report suspected abuse, exploitation, or neglect to the appropriate authorities (eg, police or, for Ontario, via ReportON)[100,101]	◑ Empirical ◑ Ecosystem ● Expert ◑ Experiential	✓✓
	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	◑ Empirical ◑ Ecosystem ● Expert ◑ Experiential	✓✓
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]	12.1 Proactively discuss the effects of anticipated transitions with patients, their caregivers, and other members of the health care team[44,105,106]	◑ Empirical ● Expert ◑ Experiential	✓✓

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Table 3 *continued from page 261*

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]	◑ 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]	🔵 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]	⚫ 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]	◑ 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]	◑ 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]	🔵 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]	◑ Empirical 🔵 Expert	✓✓
	14.2 Refer for optometry assessments to detect glaucoma and cataracts every 2 y after age 40[132,133]	◑ 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]	◑ 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]	◑ 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]	◑ 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]	● Empirical ◑ Expert	✓✓
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]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
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]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
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]	● Empirical ◑ Ecosystem ◑ Expert	✓✓
	17.2 Refer to a speech and language pathologist to assess swallowing function when signs and symptoms of swallowing difficulty are detected[159]	◑ Empirical ◑ Ecosystem ◑ Expert	✓✓
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]	◑ Empirical ◑ Ecosystem	✓✓
	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]	◑ Empirical ◑ Ecosystem	✓✓
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]	◑ Ecosystem	✓
	17.6 Screen for obstructive sleep apnea (see recommendation 25.3)	◑ Empirical ● Expert	✓
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]	◑ Empirical ◑ Ecosystem ◑ Expert	✓✓
	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]	● Empirical ◑ Ecosystem ● Expert	✓✓
People with IDD are at increased risk of acquiring *Helicobacter pylori* infection if they have ever lived in group-living settings[176,177]	18.3 Test for *H pylori* 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]	● Empirical ● Expert	✓

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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]	◑ Empirical ● Expert	✓
	18.5 For patients with constipation or diarrhea, use a bowel movement monitoring chart[182] that patients and caregivers can complete	◑ 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]	● 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]	◑ 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	◑ 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]	● Ecosystem	✓
	19.5 Address modifiable risk factors (eg, smoking cessation) before or as soon as possible during pregnancy[189]	◑ 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]	◑ 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]	◑ 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]	● Expert	✓ ✚

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
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 outcomes[195-197]	20.1 Promote mobility and regular physical activity (see guideline 13)[198,199]	◑ 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]	◑ Empirical ● Expert	✓ ✚
	20.3 Actively monitor foot health and ensure properly fitting footwear in consultation with a podiatrist or orthotist[200]	● Empirical ◑ Expert	✓
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]	20.4 Screen both male and female patients for osteoporosis starting in early adulthood[201,203]	● 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]	◑ Ecosystem ● Expert	✓✓
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]	20.6 Recommend early and adequate intake or supplementation of calcium and vitamin D unless contraindicated (eg, among people with Williams syndrome)[202,204]	● 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]	● Expert	✓
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 population[208]	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]	● 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]	◑ Empirical 🔵 Expert	✓✓
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 population[213]	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]	◑ 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]	● Empirical 🔵 Expert	✓✓
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]	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]	🔵 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]	● Expert 🔵 Experiential	✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
23. ***Infectious diseases*** (eg, influenza, *Streptococcus pneumoniae* infection, and hepatitis B). People with IDD living in group residential settings are at higher risk of developing such infections[223-225] but have lower rates of immunization and screening compared with the general population[226,227]	23.1 Include patients with IDD in routine immunization programs targeting high-risk populations for influenza and *S pneumoniae* infections[223,227]	◑ 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]	● Empirical ◑ Ecosystem ● Expert ◑ Experiential	✓✓
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	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]	● 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]	● 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	◑ Expert	✓
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]	24.1 Proactively obtain information on family history of cancer and review annually[234]	◑ Empirical ◑ Ecosystem ● Expert ◑ Experiential	✓✓
	24.2 Use clinical tools adapted for people with IDD to promote education and uptake of cancer screening tests[235]	◑ 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]	◑ Empirical ◑ Ecosystem ● Experiential	✓✓
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 do[236]	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]	◑ 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]	◑ 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]	◑ 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]	● 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	✓
Adults with IDD and sleep problems can benefit from behavioural interventions, such as sleep hygiene training or environmental modifications[239]	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	✓✓
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]	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	✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
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]	27.1 Develop a diagnostic formulation (eg, HELP) that considers causes sequentially and systematically, such as the following[50]: **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	● Empirical ● Expert ◑ Experiential	✓✓✚
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 An "enabling environment" exists when an individual's developmental needs match their supports.[73]	**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		
BTC can be symptoms of negative life experiences (eg, bullying, disappointment, losses, grief, and trauma)[253-256]	**L**—Screen for distressing life experiences that might be contributing to BTC (see guideline 12)[72,252,259,260]		
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**—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]		
Despite the evidence of non-benefit and concerns regarding potential harm, psychotropic medications are often used to manage BTC[263,264]	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	◑ Ecosystem ● Expert	✓✓
Efforts should focus on the need to adequately assess the cause of BTC rather than solely using medication to suppress them	27.3 Use psychotropic medication to manage BTC of people with IDD only as a last resort and for a short term to attend to risk of harm while ascertaining causes[72,263]	● Expert	✓
For some people with IDD, additional supports might first have to be provided for successful discontinuation of medications[269-271]	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]	● Empirical ● Expert	✓✓
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]	27.5 Do not use antipsychotic medications as a first-line or routine treatment of BTC[268-270]	● Empirical ◑ Ecosystem ● Expert	✓✓
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 distress[260]	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 history[260]	● Expert	✓✚
	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]	● Expert	✓
	28.3 Offer or facilitate supportive counseling before developmental challenges and life stressors occur (see guideline 29)	◑ 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]	◐ Ecosystem ◑ Expert	✓✓
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]	● Empirical ◑ Ecosystem ◑ Expert	✓✓
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]	● Expert	✓
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]	● Expert ◑ Experiential	✓✓✚
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]	◑ Expert	✓
Sexual abuse occurring during childhood can be associated with hearing voices in adulthood[296,297]	28.9 Screen for trauma[291]	● Expert	✓
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)	◐ Empirical	✓
	28.11 Work with caregivers to ensure optimal communication[299,300] (see guideline 2) and inclusion to prevent social isolation (see guideline 11)	◐ Empirical ● Expert	✓
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]	● Empirical ◑ Expert	✓✓

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BACKGROUND	RECOMMENDATION	TYPES OF KNOWLEDGE	RECOMMENDATION STRENGTH
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	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]	◑ Expert	✓
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]	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]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
	29.3 Consult prescribing guidelines for psychiatric disorders in IDD[88,263,267]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
	29.4 Refer to medication algorithms for specific diagnostic categories (eg, ADHD, anxiety, mood)[216,303]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
	29.5 Start low and go slow in initiating, increasing, or decreasing doses of medications[88,305]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
	29.6 Seek and document informed consent using adapted tools, such as the Informed Consent Checklist[32] (see guideline 3)[88]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
	29.7 Educate and arrange to receive feedback regularly from patients and their caregivers during medication trials[252,303]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
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]	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]	◑ 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]	◑ Empirical ◑ Ecosystem ● Expert	✓✓
	29.10 If adverse drug reactions or unwanted effects are present, consider dose reduction, tapering, or switching medications[263,308]	● Empirical ◑ Ecosystem ● Expert	✓✓
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]	29.11 Educate patients and caregivers to incorporate a healthy diet, physical activity and good sleep habits into their lifestyles[88]	◑ 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]	◑ Empirical ● Expert	✓✓

Table 3 *continued on page 271*

Table 3 *continued from page 270*

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	✓✓
Diagnosis might be missed because changes in emotion, social behaviour, or motivation can be gradual and subtle. A baseline estimate of functioning against which to measure change is needed[326]	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	✓

Table 3 *continued on page 272*

Table 3 *continued from page 271*

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]

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References

1. Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, et al. Primary care of adults with developmental disabilities. Canadian consensus guidelines. *Can Fam Physician* 2011;57:541-53 (Eng), e154-68 (Fr).
2. Brown I, Wehmeyer ML, Shogren KA. What is meant by the terms intellectual disability and developmental disabilities? In: Wehmeyer ML, Brown I, Percy M, Shogren KA, Fung WLA, editors. *A comprehensive guide to intellectual and developmental disabilities.* 2nd ed. Baltimore, MD: Brookes; 2017. p. 7-18.
3. Balogh RS, Wood JR, Lunsky Y, Ouellette-Kuntz HMJ, Wilton AS, Cobigo V, et al. Chronic disease management. In: Lunsky Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013. p. 92-116. Available from: **www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e**. Accessed 2015 Dec 8.
4. Shaw E, Oandasan I, Fowler N, editors. *CanMEDS–Family Medicine, 2017: a competency framework for family physicians across the continuum.* Mississauga, ON: College of Family Physicians of Canada; 2017. Available from: **www.cfpc.ca/uploadedFiles/Resources/Resource_Items/Health_Professionals/CanMEDS-Family-Medicine-2017-ENG.pdf**. Accessed 2018 Feb 9.
5. Salvador-Carulla L, Lukersmith S, Sullivan W. From the EBM pyramid to the Greek temple: a new conceptual approach to guidelines as implementation tools in mental health. *Epidemiol Psychiatr Sci* 2017;26(2):105-14.
6. Greenhalgh T, Snow R, Ryan S, Rees S, Salisbury H. Six 'biases' against patients and carers in evidence-based medicine. *BMC Med* 2015;13:200.
7. Bach M. Changing perspectives on intellectual and developmental disabilities. In: Wehmeyer ML, Brown I, Percy M, Shogren KA, Fung WLA, editors. *A comprehensive guide to intellectual and developmental disabilities*. 2nd ed. Baltimore, MD: Brookes; 2017. p. 35-46.
8. College of Family Physicians of Canada. *A vision for Canada. Family practice. The patient's medical home.* Mississauga, ON: College of Family Physicians of Canada; 2011. Available from: **www.cfpc.ca/uploadedFiles/Resources/Resource_Items/PMH_A_Vision_for_Canada.pdf**. Accessed 2017 Oct 20.
9. College of Family Physicians of Canada. *Four principles of family medicine*. Mississauga, ON: College of Family Physicians of Canada; 2006.
10. Hennen B, O'Driscoll T, Berg JM, Block W, Forster-Gibson C, Joyce D, et al. Preventive care checklist for adult females with a developmental disability (DD). In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 35-41. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/preventive-care-checklist/**. Accessed 2016 Jul 18.
11. Hennen B, O'Driscoll T, Berg JM, Block W, Forster-Gibson C, Joyce D, et al. Preventive care checklist for adult males with a developmental disability (DD). In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities.* Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 35-41. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/preventive-care-checklist/**. Accessed 2016 Jul 18.
12. Caron RM. Systems of health care delivery: community setting. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan.* 3rd ed. Cham, Switz: Springer; 2016. p. 185-94.
13. Perry J, Felce D, Kerr M, Bartley S, Tomlinson J, Felce J. Contact with primary care: the experience of people with intellectual disabilities. *J Appl Res Intellect Disabil* 2014;27(3):200-11. Epub 2013 Sep 13.
14. Grier L. Medical home. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 289-300.
15. Robinson L, Escopri N, Stenfert Kroese B, Rose J. The subjective experience of adults with intellectual disabilities who have mental health problems within community settings. *Adv Men Health Intellect Disabil* 2016;10(2):106-15.
16. De Haas C, Ryan R. Family centered care in a health care setting. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan.* 3rd ed. Cham, Switz: Springer; 2016. p. 49-58.
17. Sullivan WF, Heng J. Ethics. In: Taggart L, Cousins W, editors. *Health promotion for people with intellectual and developmental disabilities*. Maidenhead, UK: Open University Press; 2014. p. 204-10.
18. Baumbusch J, Phinney A, Baumbusch S. Practising family medicine for adults with intellectual disabilities. Patient perspectives on helpful interactions. *Can Fam Physician* 2014;60:e356-61. Available from: **www.cfp.ca/content/60/7/e356.full.pdf+html**. Accessed 2016 Sep 21.
19. Lennox NG, Diggens JN, Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. *J Intellect Disabil Res* 1997;41(5):380-90.
20. Wilkinson J, Dreyfus D, Bowen D, Bokhour B. Patient and provider views on the use of medical services by women with intellectual disabilities. *J Intellect Disabil Res* 2013;57(11):1058-67. Epub 2012 Sep 14.
21. Espinoza KM, Heaton LJ. Communicating with patients with special health care needs. *Dent Clin North Am* 2016;60(3):693-705. Epub 2016 Mar 21.
22. Iacono T, Johnson H. Patients with disabilities and complex communication needs. The GP consultation. *Aust Fam Physician* 2004;33(8):585-9.
23. Forster S. Communication with patients, parents and other caregivers. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 619-28.
24. Bradley E, Hollins S. Books beyond words: using pictures to communicate. *J Dev Disabil* 2013;19(1):24-32.
25. Communicating with a person with developmental disability. In: *Management guidelines: developmental disability.* 3rd ed. Melbourne, Aust: Therapeutic Guidelines Limited; 2012. p. 13-22.
26. Easyhealth [website]. *Easyhealth. Health leaflets, food and exercise, health videos, useful things for your health care*. London, UK: Generate Opportunities. Available from: **www.easyhealth.org.uk**. Accessed 2017 Oct 25.
27. Kelly M. Communicating effectively with people with developmental disabilities. In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 18-20. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/communicating-effectively/**. Accessed 2017 Oct 24.
28. Wullink M, Veldhuijzen W, Lantman-de Valk HM, Metsemakers JF, Dinant GJ. Doctor-patient communication with people with intellectual disability—a qualitative study. *BMC Fam Pract* 2009;10:82.
29. Royal College of General Practitioners. *Health checks for people with learning disabilities toolkit.* London, UK: Royal College of General Practitioners; 2017. Available from: **www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx**. Accessed 2017 Sep 25.
30. O'Dell R, Leafman J, Nehrenz GM Sr, Bustillos D. Health care decision making and adults with intellectual disability: a descriptive survey. *AJOB Prim Res* 2012;3(1):8-13.
31. Heng J, Sullivan WF. Ethical issues relating to consent in providing treatment and care. In: Brown I, Percy M, editors. *Developmental disabilities in Ontario.* 3rd ed. Toronto, ON: Ontario Association on Developmental Disabilities; 2011. p. 552-60.
32. Gillis G, Gitta M, Heng J, Korossy M, Leong R, Sullivan WF, et al. Informed consent in adults with developmental disabilities & informed voluntary consent checklist and sample questions. In: Sullivan WF, Developmental Disabilities Primary Care Initiative, editors. *Tools for the primary care for people with developmental disabilities.* Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse, Surrey Place Centre; 2011. p. 11-7. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/capacity-for-decision-making/**. Accessed 2017 Jan 20.
33. United Nations. *Convention on the rights of persons with disabilities.* New York, NY: United Nations; 2006. Available from: **www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx**. Accessed 2017 Feb 21.
34. Williamson HJ, Perkins EA. Family caregivers of adults with intellectual and developmental disabilities: outcomes associated with U.S. services and supports. *Intellect Dev Disabil* 2014;52(2):147-59.
35. Dawson F, Shanahan S, Fitzsimons E, O'Malley G, Mac Giollabhui N, Bramham J. The impact of caring for an adult with intellectual disability and psychiatric comorbidity on carer stress and psychological distress. *J Intellect Disabil Res* 2016;60(6):553-63. Epub 2016 Mar 29.
36. Perkins EA, Hewitt A. Coping with caregiver stress. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan.* Cham, Switz: Springer; 2016. p. 2165-83.
37. Taggart L, Truesdale-Kennedy M, Ryan A, McConkey R. Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *J Intellect Disabil* 2012;16(3):217-34.
38. Gore NJ, McGill P, Toogood S, Allen D, Hughes JC, Baker PA, et al. Definition and scope for positive behavioural support. *Int J Posit Behav Support* 2013;3(2):14-23.
39. MacDonald A, McGill P. Outcomes of staff training in positive behaviour support: a systematic review. *J Dev Phys Disabil* 2013;25(1):17-33.
40. Lunsky Y, Robinson S, Reid M, Palucka A. Development of a mindfulness-based coping with stress group for parents of adolescents and adults with developmental disabilities. *Mindfulness* 2015;6(6):1335-44.
41. Hwang YS, Kearney P. Mindful and mutual care for individuals with developmental disabilities: a systematic literature review. *J Child Fam Stud* 2014;23(3):497-509.

42. James N. The formal support experiences of family carers of people with an intellectual disability who also display challenging behaviour and/or mental health issues: what do carers say? *J Intellect Disabil* 2013;17(1):6-23. Epub 2013 Jan 16.
43. Mckenzie K, Ouellette-Kuntz H, Blinkhorn A, Démoré A. Out of school and into distress: families of young adults with intellectual and developmental disabilities in transition. *J Appl Res Intellect Disabil* 2016;30(4):774-81. Epub 2016 Jun 9.
44. Ryan A, Taggart L, Truesdale-Kennedy M, Slevin E. Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *Int J Older People Nurs* 2014;9(3):217-26. Epub 2013 Mar 15.
45. Lunsky Y, Tint A, Robinson S, Gordeyko M, Ouellette-Kuntz H. System-wide information about family carers of adults with intellectual/developmental disabilities—a scoping review of the literature. *J Policy Pract Intellect Disabil* 2014;11(1):8-18.
46. Weiss JA, Lunsky Y. The Brief Family Distress Scale: a measure of crisis in caregivers of individuals with autism spectrum disorders. *J Child Fam Stud* 2011;20:521-8.
47. Sullivan WF, Cheetham T, Forster-Gibson C, Kelly M, Grier E, McDonell S, et al. Advocacy role of family physician/advanced practice nurse in caring for patients with developmental disabilities (DD). In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 26-7. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/advocacy-role**. Accessed 2017 Oct 20.
48. Charlot LR. Multidisciplinary assessment. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 1677-98.
49. Goreczny AJ, Hobbs ER, Peterson LM, Bosse RM, Perrell CJ. Improving quality of care for individuals with intellectual and developmental disabilities via consultation: process improvement and support of interprofessional teams. *Rev J Autism Dev Dis* 2015;2(1):19-25.
50. Bradley E, Korossy M. HELP with behaviours that challenge. *J Dev Disabil* 2016;22(2):101-20.
51. Lindsay P, Hoghton M. Practicalities of care for adults with intellectual and developmental disabilities. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 313-34.
52. Byrne JH, Lennox NG, Ware RS. Systematic review and meta-analysis of primary healthcare interventions on health actions in people with intellectual disability. *J Intellect Dev Disabil* 2016;41(1):66-74.
53. Robertson J, Hatton C, Emerson E, Baines S. The impact of health checks for people with intellectual disabilities: an updated systematic review of evidence. *Res Dev Disabil* 2014;35(10):2450-62.
54. Shooshtari S, Temple B, Waldman C, Abraham S, Ouellette-Kuntz H, Lennox N. Stakeholders' perspectives towards the use of the comprehensive health assessment program (CHAP) for adults with intellectual disabilities in Manitoba. *J Appl Res Intellect Disabil* 2017;30(4):672-83. Epub 2016 Jun 9.
55. Durbin J, Selick A, Casson I, Green L, Spassiani N, Perry A, et al. Evaluating the implementation of health checks for adults with intellectual and developmental disabilities in primary care: the importance of organizational context. *Intellect Dev Disabil* 2016;54(2):136-50.
56. Sullivan WF, Cheetham T, Forster-Gibson C, Kelly M, Grier E, McDonell S, et al. Office organizational tips: patients with developmental disabilities. In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 21-3. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/office-organizational-tips/**. Accessed 2017 Feb 26.
57. Cassidy SB, Allanson JE. *Management of genetic syndromes*. 3rd ed. Hoboken, NJ: Wiley-Blackwell; 2010.
58. Van Karnebeek CD, Houben RF, Lafek M, Giannasi W, Stockler S. The treatable intellectual disability APP www.treatable-id.org: a digital tool to enhance diagnosis & care for rare diseases. *Orphanet J Rare Dis* 2012;7:47.
59. Srour M, Shevell M. Genetics and the investigation of developmental delay/intellectual disability. *Arch Dis Child* 2014;99(4):386-9. Epub 2013 Dec 16.
60. Developmental Disabilities Primary Care Initiative. *Health watch tables for specific syndromes*. Toronto, ON: Surrey Place Centre. Available from: **surreyplace.ca/ddprimarycare/health-watch-tables/**. Accessed 2017 Nov 14.
61. Searle B, editor. *Unique: rare chromosome disorder & single gene guides* [website]. Surrey, UK: Unique; 2015. Available from: **www.rarechromo.org/html/DisorderGuides.asp**. Accessed 2017 Sep 13.
62. Moeschler JB, Shevell M; Committee on Genetics. Comprehensive evaluation of the child with intellectual disability or global developmental delays. *Pediatrics* 2014;134(3):e903-18.
63. Boycott K, Hartley T, Adam S, Bernier F, Chong K, Fernandez BA, et al. The clinical application of genome-wide sequencing for monogenic diseases in Canada: position statement of the Canadian College of Medical Geneticists. *J Med Genet* 2015;52(7):431-7. Epub 2015 May 7.
64. Forster-Gibson C. Genetic assessment: frequently asked questions. In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 2-5. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/genetic-assessment/**. Accessed 2017 May 10.
65. Provincial IODE Genetics Resource Centre, London Health Sciences Centre. *Genetic resources Ontario*. London, ON: London Health Sciences Centre; 2017. Available from: **www.geneticresourcesontario.ca**. Accessed 2017 Sep 13.
66. Adam MP, Ardinger HH, Pagon RA, Wallace SE, editors. *GeneReviews: medical genetics information resource*. Seattle, WA: University of Washington; 2017. Available from: **www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=gene**. Accessed 2017 Oct 9.
67. The AAIDD Ad Hoc Committee on Terminology and Classification. *Intellectual disability: definition, classification, and systems of supports*. 11th ed. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2010.
68. American Psychiatric Association, American Psychiatric Association DSM-5 Task Force. *Diagnostic and statistical manual of mental disorders*. 5th ed. Washington, DC: American Psychiatric Association; 2013.
69. Schalock RL, Luckasson R. A systematic approach to subgroup classification in intellectual disability. *Intellect Dev Disabil* 2015;53(5):358-66.
70. Tassé MJ, Luckasson R, Schalock RL. The relation between intellectual functioning and adaptive behavior in the diagnosis of intellectual disability. *Intellect Dev Disabil* 2016;54(6):381-90.
71. Edwards B, Temple V, Dunn L. Adaptive functioning and communication associated with different levels of developmental disabilities (DD). In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 6-7. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/adaptive-functioning/**. Accessed 2016 Dec 14.
72. National Institute for Health and Care Excellence. *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges. NICE guidelines*. London, UK: National Institute for Health and Care Excellence; 2015. Available from: **www.nice.org.uk/guidance/ng11/evidence/full-guideline-2311243668**. Accessed 2016 Mar 25.
73. Banks R, Bush A. *Challenging behaviour: a unified approach—update. Clinical and service guidelines for supporting children, young people and adults with intellectual disabilities who are at risk of receiving abusive or restrictive practices*. London, UK: Royal College of Psychiatrists; 2016. Available from: **www.rcpsych.ac.uk/pdf/FR_ID_08.pdf**. Accessed 2016 Apr 25.
74. Breau LM, Burkitt C, Salsman S, Sarsfield-Turner T, Mullan R. *Chronic pain scale for nonverbal adults with intellectual disabilities (CPS-NAID)*. Halifax, NS: Centre for Pediatric Pain Research; 2009. Available from: **http://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf**. Accessed 2017 Oct 11.
75. Burkitt C, Breau LM, Salsman S, Sarsfield-Turner T, Mullan R. Pilot study of the feasibility of the non-communicating children's pain checklist revised for pain assessment for adults with intellectual disabilities. *J Pain Manag* 2009;2(1):37-49.
76. Lotan M, Moe-Nilssen R, Ljunggren AE, Strand LI. Reliability of the non-communicating adult pain checklist (NCAPC), assessed by different groups of health workers. *Res Dev Disabil* 2009;30:735-45. Available from: **www.painbc.ca/sites/default/files/Non-Communicating%20Adult%20Pain%20Checklist.pdf**. Accessed 2017 Nov 6.
77. Lotan M, Moe-Nilssen R, Ljunggren AE, Strand LI. Measurement properties of the non-communicating adult pain checklist (NCAPC): a pain scale for adults with intellectual and developmental disabilities, scored in a clinical setting. *Res Dev Disabil* 2010;31(2):367-75.
78. Jansen DE, Krol B, Groothoff JW, Post D. People with intellectual disability and their health problems: a review of comparative studies. *J Intellect Disabil Res* 2004;48(Pt 2):93-102.
79. De Knegt NC, Pieper MJ, Lobbezoo F, Schuengel C, Evenhuis HM, Passchier J, et al. Behavioral pain indicators in people with intellectual disabilities: a systematic review. *J Pain* 2013;14(9):885-96. Epub 2013 Jul 3.
80. Kwok H, Cheung PW. Co-morbidity of psychiatric disorder and medical illness in people with intellectual disabilities. *Curr Opin Psychiatry* 2007;20(5):443-9.
81. Regnard C, Matthews D, Gibson L; Learning Disability and Palliative Care Team at Northgate Hospital. *DisDAT, version 20: disability distress assessment tool*. Northumberland, UK: Northumberland Tyne & Wear Trust, St Oswald's Hospice; 2008. Available from: **www.disdat.co.uk**. Accessed 2016 Dec 13.
82. Doody O, Bailey ME. Pain and pain assessment in people with intellectual disability: issues and challenges in practice. *Br J Learn Disabil* 2017;45(3):157-65.
83. Cobigo V, Ouellette-Kuntz HMJ, Lake JK, Wilton AS, Lunsky Y. Medication use. In: Lunsky Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults in Ontario*. Toronto, ON: Centre for Addiction and Mental Health and Institute for Clinical Evaluative Sciences; 2013. p. 117-36. Available from: **www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e**. Accessed 2015 Dec 8.
84. Haider SI, Ansari Z, Vaughan L, Matters H, Emerson E. Prevalence and factors associated with polypharmacy in Victorian adults with intellectual disability. *Res Dev Disabil* 2014;35(11):3071-80. Epub 2014 Aug 15.
85. O'Dwyer M, Peklar J, McCallion P, McCarron M, Henman MC. Factors associated with polypharmacy and excessive polypharmacy in older people with intellectual disability differ from the general population: a cross-sectional observational nationwide study. *BMJ Open* 2016;6(4):e010505,2015-010505.
86. Scheifes A, Egberts TC, Stolker JJ, Nijman HL, Heerdink ER. Structured medication review to improve pharmacotherapy in people with intellectual disability and behavioural problems. *J Appl Res Intellect Disabil* 2016;29(4):346-55.
87. NHS England. *Stopping over medication of people with a learning disability, autism or both (STOMP)*. Wakefield, UK: NHS England; 2016. Available from: **www.england.nhs.uk/learning-disabilities/stomp**. Accessed 2017 Sep 13.
88. Branford D, Bhaumik S. Prescribing practice. In: Bhaumik S, Branford D, Barrett M, Gangadharan SK, editors. *The Frith prescribing guidelines for people with intellectual disability*. 3rd ed. Chichester, UK: John Wiley & Sons Inc; 2015. p. 11-9.
89. Fish R, Hatton C, Chauhan U. "Tell me what they do to my body": a survey to find out what information people with learning disabilities want with their medications. *Br J Learn Disabil* 2017;45(3):217-25.

90. Erickson SR, LeRoy B. Health literacy and medication administration performance by caregivers of adults with developmental disabilities. *J Am Pharm Assoc* 2015;55(2):169-77.
91. Ferguson L, Murphy GH. The effects of training on the ability of adults with an intellectual disability to give informed consent to medication. *J Intellect Disabil Res* 2014;58(9):864-73. Epub 2013 Dec 16.
92. Sobsey D. *Family violence and people with intellectual disabilities.* Ottawa, ON: National Clearinghouse on Family Violence, Public Health Agency of Canada; 2002. Available from: **http://publications.gc.ca/collections/Collection/H72-22-22-2002E.pdf**. Accessed 2009 Jul 21.
93. Beadle-Brown J, Mansell J, Cambridge P, Milne A, Whelton B. Adult protection of people with intellectual disabilities: incidence, nature and responses. *J Appl Res Intellect Disabil* 2010;23(6):573-84.
94. Hughes RB, Lund EM, Gabrielli J, Powers LE, Curry MA. Prevalence of interpersonal violence against community-living adults with disabilities: a literature review. *Rehabil Psychol* 2011;56(4):302-19.
95. Hughes K, Bellis MA, Jones L, Wood S, Bates G, Eckley L, et al. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. *Lancet* 2012;379(9826):1621-9. Epub 2012 Feb 28.
96. Ombudsman Ontario. *Nowhere to turn: investigation into the Ministry of Community and Social Services' response to situations of crisis involving adults with developmental disabilities.* Toronto, ON: Ombudsman Ontario; 2016. Available from: **www.ombudsman.on.ca/Files/sitemedia/Documents/NTT-Final-EN-w-cover.pdf**. Accessed 2017 Oct 25.
97. Franssen JJL, Maaskant MA, van Schrojenstein Lantmande Valk HMJ. Qualitative study of malnutrition in people with intellectual disabilities. *J Policy Pract Intellect Disabil* 2011;8(4):239-46.
98. Northway R, Melsome M, Flood S, Bennett D, Howarth J, Thomas B. How do people with intellectual disabilities view abuse and abusers? *J Intellect Disabil* 2013;17(4):361-75. Epub 2013 Oct 23.
99. Robinson S, Chenoweth L. Preventing abuse in accommodation services: from procedural response to protective cultures. *J Intellect Disabil* 2011;15(1):63-74.
100. Ontario Ministry of Community and Social Services [website]. *ReportON*. Toronto, ON: Ontario Ministry of Community and Social Services; 2017. Available from: **www.mcss.gov.on.ca/en/mcss/programs/developmental/reportON/**. Accessed 2017 Oct 25.
101. Fudge Schormans A, Sobsey D. Maltreatment of children with developmental disabilities. In: Brown I, Percy M, editors. *A comprehensive guide to intellectual and developmental disabilities*. Baltimore, MD: Paul H. Brookes Publishing; 2007. p. 467-87.
102. Bhaumik S, Watson J, Barrett M, Raju B, Burton T, Forte J. Transition for teenagers with intellectual disability: carers' perspectives. *J Policy Pract Intellect Disabil* 2011;8(1):53-61.
103. Tuffrey-Wijne I, Bernal J, Hubert J, Butler G, Hollins S. Exploring the lived experiences of people with learning disabilities who are dying of cancer. *Nurs Times* 2010;106(19):15-8.
104. Baumbusch J, Mayer S, Phinney A, Baumbusch S. Aging together: caring relations in families of adults with intellectual disabilities. *Gerontologist* 2017;57(2):341-7.
105. Ramirez S, Collins S, Muñoz BL. Transitioning youth to adult health care: a person-centered and culturally competent approach. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 111-9.
106. Wood D, Edwards LR, Hennen B. Health care transition. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 219-28.
107. Hartley SL, MacLean WE Jr. Stressful social interactions experienced by adults with mild intellectual disability. *Am J Intellect Dev Disabil* 2009;114(2):71-84.
108. Beail N, editor. *Psychological therapies and people who have intellectual disabilities.* London, UK: British Psychological Society, Division of Clinical Psychology; 2016. Available from: **www.bps.org.uk/system/files/Public%20files/Policy/psychological_therapies_and_people_who_have_id_pdf_for_review.pdf**. Accessed 2017 Nov 6.
109. Tinney G, Forde J, Hone L, Flanagan L, Smith M. Safe and social: what does it mean anyway?? *Br J Learn Disabil* 2015;43(1):55-61.
110. Hall SA. Community involvement of young adults with intellectual disabilities: their experiences and perspectives on inclusion. *J Appl Res Intellect Disabil* 2017;30(5):859-71.
111. Developmental Disabilities Primary Care Initiative. *DDPCI healthcare transition tools and resources for families and caregivers of youth with developmental disabilities.* Toronto, ON: Surrey Place Centre; 2014. Available from: **surreyplace.ca/ddprimarycare/tools/general-health/transitions/**. Accessed 2017 Mar 4.
112. Lennox N, Ware R, Carrington S, O'Callaghan M, Williams G, McPherson L, et al. *Ask:* a health advocacy program for adolescents with an intellectual disability: a cluster randomised controlled trial. *BMC Public Health* 2012;12:750.
113. Canadian Association of Paediatric Health Centres, National Transitions Community of Practice. *A guideline for transition from paediatric to adult health care for youth with special health care needs: a national approach*. Toronto, ON: Canadian Association of Paediatric Health Centres, Knowledge Exchange Network; 2016. Available from: **https://ken.caphc.org/xwiki/bin/download/Transitioning+from+Paediatric+to+Adult+Care/A+Guideline+for+Transition+from+Paediatric+to+Adult+Care/2017%2005%2010%20CAPHC%20Transition%20to%20Adult%20HC%20Guideline.pdf**. Accessed 2017 Nov 6.
114. Kripke CC. Primary care for adolescents with developmental disabilities. *Prim Care* 2014;41(3):507-18.
115. Hsieh K, Rimmer JH, Heller T. Obesity and associated factors in adults with intellectual disability. *J Intellect Disabil Res* 2014;58(9):851-63. Epub 2013 Nov 20.
116. Grondhuis SN, Aman MG. Overweight and obesity in youth with developmental disabilities: a call to action. *J Intellect Disabil Res* 2014;58(9):787-99.
117. Casey AF. Measuring body composition in individuals with intellectual disability: a scoping review. *J Obes* 2013;2013:628428. Available from: **www.ncbi.nlm.nih.gov/pmc/articles/PMC3671262**. Accessed 2016 Jun 28.
118. Health Canada. *Canadian guidelines for body weight classification in adults.* Ottawa, ON: Health Canada; 2003. Available from: **www.canada.ca/en/health-canada/services/food-nutrition/healthy-eating/healthy-weights/canadian-guidelines-body-weight-classification-adults.html**. Accessed 2017 Aug 29.
119. Temple VA, Foley JT, Lloyd M. Body mass index of adults with intellectual disability participating in Special Olympics by world region. *J Intellect Disabil Res* 2014;58(3):277-84. Epub 2013 Jan 17.
120. Spanos D, Hankey CR, Boyle S, Koshy P, MacMillan S, Matthews L, et al. Carers' perspectives of a weight loss intervention for adults with intellectual disabilities and obesity: a qualitative study. *J Intellect Disabil Res* 2013;57(1):90-102. Epub 2012 Feb 28.
121. Kuijken NMJ, Naaldenberg J, Nijhuis-van der Sanden MW, van Schrojenstein-Lantman de Valk HMJ. Healthy living according to adults with intellectual disabilities: towards tailoring health promotion initiatives. *J Intellect Disabil Res* 2016;60(3):228-41.
122. Blick RN, Saad AE, Goreczny AJ, Roman K, Sorensen CH. Effects of declared levels of physical activity on quality of life of individuals with intellectual disabilities. *Res Dev Disabil* 2015;37:223-9. Epub 2014 Dec 17.
123. Robertson J, Emerson E, Baines S, Hatton C. Obesity and health behaviours of British adults with self-reported intellectual impairments: cross sectional survey. *BMC Public Health* 2014;14(1):219.
124. Ogg-Groenendaal M, Hermans H, Claessens B. A systematic review on the effect of exercise interventions on challenging behavior for people with intellectual disabilities. *Res Dev Disabil* 2014;35(7):1507-17. Epub 2014 Apr 21.
125. Brooker K, van Dooren K, McPherson L, Lennox N, Ware R. A systematic review of interventions aiming to improve involvement in physical activity among adults with intellectual disability. *J Phys Act Health* 2015;12(3):434-44. Epub 2014 May 6.
126. Carraro A, Gobbi E. Exercise intervention to reduce depressive symptoms in adults with intellectual disabilities. *Percept Mot Skills* 2014;119(1):1-5.
127. Spanos D, Melville CA, Hankey CR. Weight management interventions in adults with intellectual disabilities and obesity: a systematic review of the evidence. *Nutr J* 2013;12:132.
128. Hey C, Fessler S, Hafner N, Lange BP, Euler HA, Neumann K. High prevalence of hearing loss at the Special Olympics: is this representative of people with intellectual disability? *J Appl Res Intellect Disabil* 2014;27(2):125-33. Epub 2013 Apr 23.
129. Herer GR. Intellectual disabilities and hearing loss. *Comm Disord Q* 2012;33(4):252-60.
130. McClimens A, Brennan S, Hargreaves P. Hearing problems in the learning disability population: is anybody listening? *Br J Learn Disabil* 2015;43(3):153-60.
131. Evenhuis HM, Natzgam LMD. *IASSID international consensus statement: early identification of hearing and visual impairment in children and adults with an intellectual disability.* Leiden, Netherlands: International Association of Scientific Studies on Intellectual Disability (IASSID), Special Interest Group on Health Issues; 1997. Available from: **www.iassidd.org/uploads/legacy/pdf/consensir.alg.doc**. Accessed 2016 Jul 15.
132. Li JC, Wong K, Park AS, Fricke TR, Jackson AJ. The challenges of providing eye care for adults with intellectual disabilities. *Clin Exp Optom* 2015;98(5):420-9.
133. Robinson BE, Mairs K, Glenny C, Stolee P. An evidence-based guideline for the frequency of optometric eye examinations. *Prim Health Care* 2012;2(4):121.
134. Bent S, McShea L, Brennan S. The importance of hearing: a review of the literature on hearing loss for older people with learning disabilities. *Br J Learn Disabil* 2015;43(4):277-84.
135. Crandell CC, Roeser RJ. Incidence of excessive/impacted cerumen in individuals with mental retardation: a longitudinal investigation. *Am J Ment Retard* 1993;97(5):568-74.
136. Oron Y, Shushan S, Ben-David N, Flaksman H, Korenbrot F, Merrick J, et al. Guidelines for ear, nose, and throat examination of adults with intellectual disabilities: report of a clinical practice application. *J Policy Pract Intellect Disabil* 2015;12(4):272-8.
137. Anders PL, Davis EL. Oral health of patients with intellectual disabilities: a systematic review. *Spec Care Dentist* 2010;30(3):110-7.
138. Fernandez JB, Lim LJ, Dougherty N, LaSasso J, Atar M, Daronch M. Oral health findings in athletes with intellectual disabilities at the NYC Special Olympics. *Spec Care Dent* 2012;32(5):205-9.
139. Picos A, Chisnoiu A, Dumitrasc DL. Dental erosion in patients with gastroesophageal reflux disease. *Adv Clin Exp Med* 2013;22(3):303-7.
140. Oral health. In: *Management guidelines: developmental disability*. 3rd ed. Melbourne, Aust: Therapeutic Guidelines Limited; 2012. p. 240-3.
141. Binkley CJ, Haugh GS, Kitchens DH, Wallace DL, Sessler DI. Oral microbial and respiratory status of persons with mental retardation/intellectual and developmental disability: an observational cohort study. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod* 2009;108(5):722-31. Epub 2009 Sep 12.
142. Morgan JP, Minihan PM, Stark PC, Finkelman MD, Yantsides KE, Park A, et al. The oral health status of 4,732 adults with intellectual and developmental disabilities. *J Am Dent Assoc* 2012;143(8):838-46.
143. Finkelman MD, Stark PC, Tao W, Morgan JP. Relationship between duration of treatment and oral health in adults with intellectual and developmental disabilities. *Spec Care Dentist* 2014;34(4):171-5. Epub 2013 Oct 3.
144. Forster-Gibson C, Berg J. Health watch table: Down syndrome. In: Sullivan WF, Health Watch Tables Working Group, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 43-5. Available from: **surreyplace.ca/ddprimarycare/health-watch-tables/down-synrome**. Accessed 2017 Feb 25.
145. Forster-Gibson C, Berg J. Health watch table: Prader-Willi syndrome (PWS). In: Sullivan WF, Health Watch Tables Working Group, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 50-4. Available from: **surreyplace.ca/ddprimarycare/health-watch-tables/prader-willi-syndrome**. Accessed 2017 Oct 20.

146. Forster-Gibson C, Berg J. Health watch table: 22q11.2 deletion syndrome. In: Sullivan WF, Health Watch Tables Working Group, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 58-61. Available from: **surreyplace.ca/ddprimarycare/health-watch-tables/22q11.2del-syndrome**. Accessed 2017 Feb 18.
147. De Winter CF, van den Berge AP, Schoufour JD, Oppewal A, Evenhuis HM. A 3-year follow-up study on cardiovascular disease and mortality in older people with intellectual disabilities. *Res Dev Disabil* 2016;53-54:115-26. Epub 2016 Feb 11.
148. Morin D, Merineau-Cote J, Ouellette-Kuntz H, Tasse MJ, Kerr M. A comparison of the prevalence of chronic disease among people with and without intellectual disability. *Am J Intellect Dev Disabil* 2012;117(6):455-63.
149. Merrick J, Morad M. Cardiovascular disease. In: O'Hara J, McCarthy JM, Bouras N, editors. *Intellectual disability and ill health: a review of the evidence*. Cambridge, UK: Cambridge University Press; 2010. p. 73-7.
150. Preventive health care and health promotion. In: *Management guidelines: developmental disability*. 3rd ed. Melbourne, Aust: Therapeutic Guidelines Limited; 2012. p. 117-9.
151. Lunsky Y, Klein-Geltink JE, Yates EA. *Atlas on the primary care of adults in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013. Available from: **www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e**. Accessed 2015 Dec 8.
152. Freeman SB, Bean LH, Allen EG, Tinker SW, Locke AE, Druschel C, et al. Ethnicity, sex, and the incidence of congenital heart defects: a report from the National Down Syndrome Project. *Gen Med* 2008;10(3):173-80. Accessed 13 May 2008.
153. Colvin KL, Yeager ME. What people with Down syndrome can teach us about cardiopulmonary disease. *Eur Respir Rev* 2017;26(143):160098.
154. Webb GD, Williams RG. Care of the adult with congenital heart disease: introduction. *J Am Coll Cardiol* 2001;37(5):1166.
155. Silversides CK, Marelli A, Beauchesne L, Dore A, Kiess M, Salehian O, et al. Canadian Cardiovascular Society 2009 Consensus Conference on the Management of Adults with Congenital Heart Disease: executive summary. *Can J Cardiol* 2010;26(3):143-50.
156. Warnes CA, Williams RG, Bashore TM, Child JS, Connolly HM, Dearani JA, et al. ACC/AHA 2008 guidelines for the management of adults with congenital heart disease: executive summary: a report of the American College of Cardiology/American Heart Association Task Force on practice guidelines (writing committee to develop guidelines for the management of adults with congenital heart disease). *Circulation* 2008;118(23):2395-451. Epub 2008 Nov 7.
157. Canadian Congenital Heart Alliance [website]. *Find an adult CHD centre near you*. Oakville, ON: Canadian Congenital Heart Alliance; 2017. Available from: **www.cchaforlife.org/find-adult-chd-centre-near-you**. Accessed 2018 Feb 15.
158. Patja K, Molsa P, Iivanainen M. Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *J Intellect Disabil Res* 2001;45(Pt 1):30-40.
159. Chadwick DD, Jolliffe J. A descriptive investigation of dysphagia in adults with intellectual disabilities. *J Intellect Disabil Res* 2009;53(1):29-43. Epub 2008 Aug 28.
160. Marks JH. Pulmonary care of children and adolescents with developmental disabilities. *Pediatr Clin North Am* 2008;55(6):1299-314.
161. Rogers B, Stratton P, Msall M, Andres M, Champlain MK, Koerner P, et al. Long-term morbidity and management strategies of tracheal aspiration in adults with severe developmental disabilities. *Am J Ment Retard* 1994;98(4):490-8.
162. Thillai M. Respiratory diseases. In: O'Hara J, McCarthy JM, Bouras N, editors. *Intellectual disability and ill health: a review of the evidence*. Cambridge, UK: Cambridge University Press; 2010. p. 78-87.
163. McCaslin CA, Schuen JN. Pulmonology and sleep disordered breathing. In: Rubin IL, Merrick J, Greydanus DE, Patel D, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. Cham, Switz: Springer; 2016. p. 1325-46.
164. Perez CM, Ball SL, Wagner AP, Clare ICH, Holland AJ, Redley M. The incidence of healthcare use, ill health and mortality in adults with intellectual disabilities and mealtime support needs. *J Intellect Disabil Res* 2015;59(7):638-52. Epub 2014 Nov 3.
165. Lin E, Selick A, Balogh RS, Isaacs BJ, Ouellette-Kuntz HMJ, Klein-Geltink JE, et al. Prevalence, demographic and disease profiles. In: Lunsky Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013. p. 20-40. Available from: **www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e**. Accessed 8 Dec 2015.
166. Gale L, Naqvi H, Russ L. Asthma, smoking and BMI in adults with intellectual disabilities: a community-based survey. *J Intellect Disabil Res* 2009;53(9):787-96. Epub 2009 Jul 16.
167. Atay O. Gastrointestinal issues. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 1209-24.
168. Bohmer CJ, Klinkenberg-Knol EC, Niezen-de Boer, Meuwissen SG. Gastroesophageal reflux disease in intellectually disabled individuals: how often, how serious, how manageable? *Am J Gastroenterol* 2000;95(8):1868-72.
169. Bohmer CJ, Taminiau JA, Klinkenberg-Knol EC, Meuwissen SG. The prevalence of constipation in institutionalized people with intellectual disability. *J Intellect Disabil Res* 2001;45(Pt 3):212-8.
170. Kozlowski AM, Taylor T, Gonzalez ML, Girolami PA. Feeding disorders. In: Matson JL, Matson ML, editors. *Comorbid conditions in individuals with intellectual disabilities*. Dordrecht, Switz: Springer; 2015. p. 109-43.
171. Tracy JM, Wallace R. Presentations of physical illness in people with developmental disability: the example of gastro-oesophageal reflux. *Med J Aust* 2001;175(2):109-11.
172. Morad M, Nelson NP, Merrick J, Davidson PW, Carmeli E. Prevalence and risk factors of constipation in adults with intellectual disability in residential care centers in Israel. *Res Dev Disabil* 2007;28(6):580-6. Epub 2007 Mar 2.
173. Coleman J, Spurling G. Constipation in people with learning disability. *BMJ* 2010;340:c222.
174. Mishori R, McHale C. Pica: an age-old eating disorder that's often missed. *J Fam Pract* 2014;63(7):E1-4.
175. Williams DE, McAdam D. Assessment, behavioral treatment, and prevention of pica: clinical guidelines and recommendations for practitioners. *Res Dev Disabil* 2012;33(6):2050-7. Epub 2012 Jun 28.
176. Kitchens DH, Binkley CJ, Wallace DL, Darling D. *Helicobacter pylori* infection in people who are intellectually and developmentally disabled: a review. *Spec Care Dent* 2007;27(4):127-33.
177. Duff M, Scheepers M, Cooper M, Hoghton M, Baddeley P. *Helicobacter pylori:* has the killer escaped from the institution? A possible cause of increased stomach cancer in a population with intellectual disability. *J Intellect Disabil Res* 2001;45(Pt 3):219-25.
178. Wallace R, Schluter PJ, Duff M, Ouellette-Kuntz H, Webb PMSM. A review of the risk factors for, consequences, diagnosis, and management of *Helicobacter pylori* in adults with intellectual disabilities. *J Policy Pract Intellect Disabil* 2004;1(3-4):147-63.
179. Wallace RA, Schluter PJ, Webb PM. Recurrence of *Helicobacter pylori* infection in adults with intellectual disability. *Intern Med J* 2004;34(3):132-3.
180. Cockburn-Wells H. Managing constipation in adults with severe learning disabilities. *Learn Disabil Pract* 2014;17(9):16-22.
181. Vande Velde S, Van Biervliet S, Van Goethem G, De Looze D, Van Winckel M. Colonic transit time in mentally retarded persons. *Int J Colorectal Dis* 2010;25(7):867-71. Epub 2010 Mar 20.
182. Developmental Disabilities Primary Care Initiative. Bowel movement (B.M.)—monthly monitoring record (for people who have bowel problems). In: *Tools for caregivers: monitoring charts*. Toronto, ON: Surrey Place Centre; 2013. Available from: **surreyplace.ca/ddprimarycare/tools/physical-health/monitoring-charts/**. Accessed 2018 Feb 15.
183. Grover SR. Gynaecological issues in adolescents with disability. *J Paediatr Child Health* 2011;47(9):610-3.
184. Savasi I, Spitzer RF, Allen LM, Ornstein MP. Menstrual suppression for adolescents with developmental disabilities. *J Pediatr Adolesc Gynecol* 2009;22(3):143-9.
185. Van Schrojenstein Lantman-de Valk HMJ, Rook F, Maaskant MA. The use of contraception by women with intellectual disabilities. *J Intellect Disabil Res* 2011;55(4):434-40. Epub 2011 Mar 3.
186. Atkinson E, Bennett MJ, Dudley J, Grover S, Matthews K, Moore P, et al. Consensus statement: menstrual and contraceptive management in women with an intellectual disability. *Aust N Z J Obstet Gynaecol* 2003;43(2):109-10.
187. McCarthy M. Prescribing contraception to women with intellectual disabilities: general practitioners' attitudes and practices. *Sex Disab* 2011;29(4):339-49.
188. Kluge EH. After "Eve": whither proxy decision-making? *CMAJ* 1987;137(8):715-20.
189. Brown HK, Cobigo V, Lunsky Y, Vigod SN. Maternal and offspring outcomes in women with intellectual and developmental disabilities: a population-based cohort study. *BJOG* 2017;124(5):757-65. Epub 2016 May 24.
190. Brown HK, Kirkham YA, Cobigo V, Lunsky Y, Vigod SN. Labour and delivery interventions in women with intellectual and developmental disabilities: a population-based cohort study. *J Epidemiol Community Health* 2016;70(3):238-44. Epub 2015 Oct 8.
191. Brown HK, Lunsky Y, Wilton AS, Cobigo V, Vigod SN. Pregnancy in women with intellectual and developmental disabilities. *J Obstet Gynaecol Can* 2016;38(1):9-16.
192. Willis DS, Wishart JG, Muir WJ. Menopausal experiences of women with intellectual disabilities. *J Appl Res Intellect Disabil* 2011;24(1):74-85.
193. Stein S, Tepper M. Sexuality. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. Cham, Switz: Springer; 2016. p. 1365-81.
194. Abells D, Kirkham YA, Ornstein MP. Review of gynecologic and reproductive care for women with developmental disabilities. *Curr Opin Obstet Gynecol* 2016;28(5):350-8.
195. Haveman M, Heller T, Lee L, Maaskant M, Shooshtari S, Strydom A. Major health risks in aging persons with intellectual disabilities: an overview of recent studies. *J Policy Pract Intellect Disabil* 2010;7(1):59-69.
196. Pfister AA, Roberts AG, Taylor HM, Noel-Spaudling S, Damian MM, Charles PD. Spasticity in adults living in a developmental center. *Arch Phys Med Rehabil* 2003;84(12):1808-12.
197. Jenkins DW, Cooper K, Heigh EG. Prevalence of podiatric conditions seen in Special Olympics athletes: a comparison of USA data to an international population. *Foot (Edinb)* 2015;25(1):5-11. Epub 2014 Oct 5.
198. Marks B, Sisirak J, Heller T. *Health matters: the exercise, nutrition, and health education curriculum for people with developmental disabilities.* Baltimore, MD: Paul H. Brookes Pub Co; 2010.
199. Courtenay K, Murray A. Foot health and mobility in people with intellectual disabilities. *J Policy Practi Intellect Disabil* 2015;12(1):42-6.
200. Jenkins DW, Cooper K, O'Connor R, Watanabe L. Foot-to-shoe mismatch and rates of referral in Special Olympics athletes. *J Am Podiatr Med Assoc* 2012;102(3):187-97.
201. Balogh R, Wood J, Dobranowski K, Lin E, Wilton A, Jaglal SB, et al. Low-trauma fractures and bone mineral density testing in adults with and without intellectual and developmental disabilities: a population study. *Osteoporos Int* 2017;28(2):727-32. Epub 2016 Sep 9.
202. Petrone LR. Osteoporosis in adults with intellectual disabilities. *South Med J* 2012;105(2):87-92.
203. Dreyfus D, Lauer E, Wilkinson J. Characteristics associated with bone mineral density screening in adults with intellectual disabilities. *J Am Board Fam Med* 2014;27(1):104-14.
204. Jasien J, Daimon CM, Maudsley S, Shapiro BK, Martin B. Aging and bone health in individuals with developmental disabilities. *Int J Endocrin* 2012;2012:469235.
205. Jaffe JS, Timell AM, Elolia R, Thatcher SS. Risk factors for low bone mineral density in individuals residing in a facility for the people with intellectual disability. *J Intellect Disabil Res* 2005;49(6):457-62.

206. Robertson J, Hatton C, Emerson E, Baines S. Prevalence of epilepsy among people with intellectual disabilities: a systematic review. *Seizure* 2015;29:46-62. Epub 2015 Mar 30.
207. Robertson J, Hatton C, Emerson E, Baines S. Mortality in people with intellectual disabilities and epilepsy: a systematic review. *Seizure* 2015;29:123-33. Epub 2015 Apr 20.
208. National Institute for Health and Clinical Excellence. *The epilepsies: diagnosis and management—clinical guideline [CG137]*. London, UK: National Clinical Guideline Centre; 2012. Available from: **www.nice.org.uk/guidance/cg137**. Accessed 2016 Jun 26.
209. Chapman M, Iddon P, Atkinson K, Brodie C, Mitchell D, Parvin G, et al. The misdiagnosis of epilepsy in people with intellectual disabilities: a systematic review. *Seizure* 2011;20(2):101-6. Epub 2010 Nov 30.
210. Branford D, Bhaumik S, Kiani R. Epilepsy. In: Bhaumik S, Branford D, Barrett M, Gangadharan SK, editors. *The Frith prescribing guidelines for people with intellectual disability*. 3rd ed. Chichester, UK: John Wiley & Sons Inc; 2015.
211. Whitten E, Griffiths A. Implementing epilepsy guidelines within a learning disability service. *Seizure* 2007;16(6):471-8. Epub 2007 Apr 27.
212. Epilepsy Action [website]. *Primary care resource pack*. Leeds, UK: Epilepsy Action; 2017. Available from: **www.epilepsy.org.uk/professional/primary-care/resource-pack**. Accessed 2017 Mar 21.
213. Kapell D, Nightingale B, Rodriguez A, Lee JH, Zigman WB, Schupf N. Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Ment Retard* 1998;36(4):269-79.
214. Beange H, Lennox N, Parmenter TR. Health targets for people with intellectual disability. *J Intellect Dev Disabil* 1999;24(4):283-97.
215. Cazeau RA, Kamboj MK. Endocrine issues. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 1257-79.
216. Bhaumik S, Branford D, Barrett M, Gangadharan SK, editors. *The Frith prescribing guidelines for people with intellectual disability*. 3rd ed. Chichester, UK: John Wiley & Sons Inc; 2015.
217. Visser WE, de Rijke YB, van Toor H, Visser TJ. Thyroid status in a large cohort of patients with mental retardation: the TOP-R (thyroid origin of psychomotor retardation) study. *Clin Endocrinol* (Oxf) 2011;75(3):395-401.
218. Balogh RS, Lake JK, Lin E, Wilton A, Lunsky Y. Disparities in diabetes prevalence and preventable hospitalizations in people with intellectual and developmental disability: a population-based study. *Diabet Med* 2015;32(2):235-42. Epub 2014 Oct 7.
219. MacRae S, Brown M, Karatzias T, Taggart L, Truesdale-Kennedy M, Walley R, et al. Diabetes in people with intellectual disabilities: a systematic review of the literature. *Res Dev Disabil* 2015;47:352-74. Epub 2015 Oct 23.
220. Queensland Centre for Intellectual and Developmental Disability [website]. *Diabetes to the point*. Brisbane, Aust: University of Queensland; 2016. Available from: **https://qcidd.centre.uq.edu.au/resources/diabetes-point**. Accessed 2017 Mar 22.
221. Taggart L, Truesdale-Kennedy M, Scott J. Working with people with intellectual and developmental disabilities who have diabetes. *J Diabetes Nurs* 2015;19(5):190-4.
222. Cardol M, Rijken M, van Schrojenstein Lantman-de Valk H. People with mild to moderate intellectual disability talking about their diabetes and how they manage. *J Intellect Disabil Res* 2012;56(4):351-60. Epub 2011 Sep 29.
223. Burton C, Vaudry W, Moore D, Bettinger JA, Tran D, Halperin SA, et al. Burden of seasonal influenza in children with neurodevelopmental conditions. *Pediatr Infect Dis J* 2014;33(7):710-4.
224. Smith M, Peacock G, Uyeki TM, Moore C. Influenza vaccination in children with neurologic or neurodevelopmental disorders. *Vaccine* 2015;33(20):2322-7. Epub 2015 Mar 30.
225. Yen CF, Lin JD. Factors influencing administration of hepatitis B vaccine to community-dwelling teenagers aged 12-18 with an intellectual disability. *Res Dev Disabil* 2011;32(6):2943-9. Epub 2011 Jun 8.
226. Khasawneh R, Wallen J, Davies HD. Infectious diseases, immunizations and universal precautions. In: Rubin IL, Merrick J, Greydanus DE, Patel D, editors. *Health care for people with intellectual and developmental disabilities across the lifespan*. 3rd ed. Cham, Switz: Springer; 2016. p. 1711-28.
227. Wilson B, Jones KB, Weedon D, Bilder D. Care of adults with intellectual and developmental disabilities: Down syndrome. *FP Essent* 2015;439:20-5.
228. Public Health Agency of Canada. *Canadian immunization guide: part 3 vaccination of specific populations*. Ottawa, ON: Public Health Agency of Canada; 2016.
229. Severtson SG, Hedden SL, Martins SS, Latimer WW. Patterns of cognitive impairments among heroin and cocaine users: the association with self-reported learning disabilities and infectious disease. *J Learn Disabil* 2012;45(2):139-50. Epub 2010 Jun 23.
230. Cobigo V, Ouellette-Kuntz H, Balogh R, Leung F, Lin E, Lunsky Y. Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. *J Intellect Disabil Res* 2013;57(5):478-88. Epub 2013 Mar 19.
231. Ouellette-Kuntz H, Coo H, Cobigo V, Wilton AS. Uptake of colorectal cancer screening among Ontarians with intellectual and developmental disabilities. *PLoS One* 2015;10(2):e0118023.
232. Greenwood NW, Dreyfus D, Wilkinson J. More than just a mammogram: breast cancer screening perspectives of relatives of women with intellectual disability. *Intellect Dev Disabil* 2014;52(6):444-55.
233. Merten JW, Pomeranz JL, King JL, Moorhouse M, Wynn RD. Barriers to cancer screening for people with disabilities: a literature review. *Disabil Health J* 2015;8(1):9-16. Epub 2014 Jul 1.
234. Canadian Task Force on Preventive Health Care [website]. *CTFPHC guidelines*. Calgary, AB: Canadian Task Force on Preventive Health Care; 2016. Available from: **http://canadiantaskforce.ca/?content=pcp**. Accessed 2016 Nov 30.
235. Centre for Developmental Disability Health Victoria, Pap Screen Victoria. *Pap test: the plain facts*. Dandenong, Aust: Centre for Developmental Disability Health Victoria; 2011. Available from: **www.papscreen.org.au/downloads/resources/brochures/Pap_tests_the_plain_facts.pdf**. Accessed 2016 Nov 30.
236. Satgé D, Sauleau EA, Jacot W, Raffi F, Azéma B, Bouyat JC, et al. Age and stage at diagnosis: a hospital series of 11 women with intellectual disability and breast carcinoma. *BMC Cancer* 2014;14:150.
237. Canadian Breast Cancer Foundation [website]. *Be breast aware*. Toronto, ON: Canadian Cancer Society; 2016. Available from: **www.cbcf.org/ontario/AboutBreastHealth/BeBreastAware/Pages/default.aspx**. Accessed 2016 Nov 30.
238. Canadian Cancer Society [website]. *Signs and symptoms of breast cancer*. Toronto, ON: Canadian Cancer Society; 2016. Available from: **www.cancer.ca/en/cancer-information/cancer-type/breast/signs-and-symptoms/?region=on**. Accessed 2017 Oct 25.
239. Van de Wouw E, Evenhuis HM, Echteld MA. Prevalence, associated factors and treatment of sleep problems in adults with intellectual disability: a systematic review. *Res Dev Disabil* 2012;33(4):1310-32. Epub 2012 Mar 30.
240. Heussler HS. Management of sleep disorders in neurodevelopmental disorders and genetic syndromes. *Curr Opin Psychiatry* 2016;29(2):138-43.
241. Stores G. *Sleep and its disorders in children and adolescents with a neurodevelopmental disorder: a review and clinical guide*. Cambridge, UK: Cambridge University Press; 2014.
242. Wallace RA, Dalton AJ. Clinicians' guide to physical health problems of older adults with down syndrome. *J Dev Disabil* 2006;12(1 Suppl 1):1-92.
243. Lal C, White DR, Joseph JE, van Bakergem K, LaRosa A. Sleep-disordered breathing in Down syndrome. *Chest* 2015;147(2):570-9.
244. Hulbert-Williams L, Hastings R, Owen DM, Burns L, Day J, Mulligan J, et al. Exposure to life events as a risk factor for psychological problems in adults with intellectual disabilities: a longitudinal design. *J Intellect Disabil Res* 2014;58(1):48-60. Epub 2013 Apr 30.
245. Scott HM, Havercamp SM. Mental health for people with intellectual disability: the impact of stress and social support. *Am J Intellect Dev Disabil* 2014;119(6):552-64.
246. Lunsky Y, Bramston P. A preliminary study of perceived stress in adults with intellectual disabilities according to self-report and informant ratings. *J Intellect Dev Disabil* 2006;31(1):20-7.
247. Hartley SL, MacLean WE Jr. Depression in adults with mild intellectual disability: role of stress, attributions, and coping. *Am J Intellect Dev Disabil* 2009;114(3):147-60.
248. Gilmore L, Cuskelly M. Vulnerability to loneliness in people with intellectual disability: an explanatory model. *J Policy Pract Intellect Disabil* 2014;11(3):192-9.
249. Skotko BG, Levine SP, Goldstein R. Having a brother or sister with Down syndrome: perspectives from siblings. *Am J Med Genet A* 2011;155A(10):2348-59. Epub 2011 Sep 9.
250. Skotko BG, Levine SP, Goldstein R. Having a son or daughter with Down syndrome: perspectives from mothers and fathers. *Am J Med Genet A* 2011;155A(10):2335-47. Epub 2011 Sep 13.
251. Skotko BG, Levine SP, Goldstein R. Self-perceptions from people with Down syndrome. *Am J Med Genet A* 2011;155A(10):2360-9. Epub 2011 Sep 9.
252. National Institute for Health and Care Excellence. *Mental health problems in people with learning disabilities: prevention, assessment and management—methods, evidence and recommendations: final version*. London, UK: British Psychological Society, Royal College of Psychiatrists; 2016. Available from: **www.nice.org.uk/guidance/ng54/evidence/full-guideline-2612227933**. Accessed 2017 Jan 10.
253. Zeedyk SM, Rodriguez G, Tipton LA, Baker BL, Blacher J. Bullying of youth with autism spectrum disorder, intellectual disability, or typical development: victim and parent perspectives. *Res Autism Spectr Disord* 2014;8(9):1173-83.
254. Larkin P, Jahoda A, MacMahon K, Pert C. Interpersonal sources of conflict in young people with and without mild to moderate intellectual disabilities at transition from adolescence to adulthood. *J Appl Res Intellect Disabil* 2012;25(1):29-38. Epub 2011 Nov 3.
255. Hermans H, Evenhuis HM. Life events and their associations with depression and anxiety in older people with intellectual disabilities: results of the HA-ID study. *J Affect Disord* 2012;138(1-2):79-85. Epub 2012 Feb 2.
256. Wigham S, Hatton C, Taylor JL. The effects of traumatizing life events on people with intellectual disabilities: a systematic review. *J Ment Health Res Intellect Disabil* 2011;4(1):19-39.
257. Holland A. Disorders of intellectual development: historical, conceptual, epidemiological and nosological overview. In: Woodbury-Smith M, editor. *Clinical topics in disorders of intellectual development*. London, UK: Royal College of Psychiatrists Publications; 2015. p. 3-21.
258. Bradley E, Behavioural and Mental Health Working Group of the Developmental Disabilities Primary Care Initiative. Guide to understanding behavioural problems and emotional concerns in adults with developmental disabilities (DD) for primary care providers and caregivers. In: Sullivan W, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 67-75. Available from: **surreyplace.ca/ddprimarycare/tools/mental-health/guide-to-understanding-behaviour-abc/**. Accessed 2018 Feb 16.
259. Levitas AS, Gilson SF. Predictable crises in the lives of people with mental retardation. *Mental Health Aspects Dev Disabil* 2001;4(3):89-100.
260. Bradley E, Baroness Hollins S, Korossy M, Levitas A. Adjustment disorder in disorders of intellectual development. In: Casey P, editor. *Adjustment disorders: from controversy to clinical practice*. Oxford, UK: Oxford University Press; 2018.
261. Bradley EA, Goody R, McMillan S. A to Z of disciplines that may contribute to the multi- and interdisciplinary work as applied to mood and anxiety disorders. In: Hassiotis A, Barron DA, Hall I, editors. *Intellectual disability psychiatry: a practical handbook*. Chichester, UK: Wiley-Blackwell; 2009. p. 257-63.
262. Buckles J, Luckasson R, Keefe E. A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003-2010. *J Ment Health Res Intellect Disabil* 2013;6(3):181-207.
263. Alexander RT, Branford D, Devapriam J. *Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines*. London, UK: Royal College of Psychiatrists; 2016. Available from: **www.rcpsych.ac.uk/pdf/FR_ID_09_for_website.pdf**. Accessed 2016 Apr 22.

264. Sheehan R, Hassiotis A, Walters K, Osborn D, Strydom A, Horsfall L. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ* 2015;351:h4326.
265. Bradley E, Behavioural and Mental Health Working Group of the Developmental Disabilities Primary Care Initiative. Auditing psychotropic medication therapy. In: Sullivan WE, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 88-9. Available from: **surreyplace.ca/ddprimarycare/tools/mental-health/auditing-psychotropic-medication-therapy/**. Accessed 2018 Feb 16.
266. Branford D, Bhaumik S. Aggressive behaviour. In: Bhaumik S, Branford D, Barrett M, Gangadharan SK, editors. *The Frith prescribing guidelines for people with intellectual disability*. 3rd ed. Chichester, UK: John Wiley & Sons Inc; 2015. p. 147-52.
267. Branford D, Bhaumik S. Physical and health monitoring. In: Bhaumik S, Branford D, Barret M, editors. *The Frith prescribing guidelines for adults with learning disability*. 3rd ed. Chichester, UK: John Wiley & Sons Inc; 2015. p. 21-30.
268. Deb S, Kwok H, Bertelli M, Salvador-Carulla L, Bradley E, Torr J, et al. International guide to prescribing psychotropic medication for the management of problem behaviours in adults with intellectual disabilities. *World Psychiatry* 2009;8(3):181-6.
269. Glover G, Williams R, Branford D, Avery R, Chauhan U, Hoghton M, et al. *Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England*. London, UK: Public Health England, Clinical Practice Research Datalink; 2015. Available from: **webarchive.nationalarchives.gov.uk/20160805132945/http://www.nhsiq.nhs.uk/media/2671718/psychotropic_medication_and_people_with_learning_disabilities_or_autism__3_.pdf**. Accessed 2018 Feb 16.
270. Tyrer P, Oliver-Africano PC, Ahmed Z, Bouras N, Cooray S, Deb S, et al. Risperidone, haloperidol, and placebo in the treatment of aggressive challenging behaviour in patients with intellectual disability: a randomised controlled trial. *Lancet* 2008;371(9606):57-63.
271. Sheehan R, Hassiotis A. Reduction or discontinuation of antipsychotics for challenging behaviour in adults with intellectual disability: a systematic review. *Lancet Psychiatry* 2017;4(3):238-56. Epub 2016 Nov 10.
272. Lunsky Y, Khuu W, Tadrous M, Vigod S, Cobigo V, Gomes T. Antipsychotic use with and without comorbid psychiatric diagnosis among adults with intellectual and developmental disabilities. *Can J Psychiatry* 2017:706743717727240. Epub ahead of print.
273. Cooper SA, McLean G, Guthrie B, McConnachie A, Mercer S, Sullivan F, et al. Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Fam Pract* 2015;16:110.
274. Fletcher R, Barnhill J, Cooper S, editors. *Diagnostic manual—intellectual disability (DM-ID 2): a textbook of diagnosis of mental disorders in persons with Intellectual disability*. 2nd ed. Kingston, NY: NADD Press; 2017.
275. Royal College of Psychiatrists. *DC-LD (diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation)*. London, UK: Gaskell; 2001.
276. Bradley E, Lunsky Y, Palucka A, Homitidis S. Recognition of intellectual disabilities and autism in psychiatric inpatients diagnosed with schizophrenia and other psychotic disorders. *Adv Ment Health Intellect Disabil* 2011;5(6):4-18.
277. Cooper SA, Smiley E, Morrison J, Allan L, Williamson A, Finlayson J, et al. Psychosis and adults with intellectual disabilities. Prevalence, incidence, and related factors. *Soc Psychiatry Psychiatr Epidemiol* 2007;42(7):530-6. Epub 2008 Oct 29.
278. Lunsky Y, Bradley E, Durbin J, Koegl C. A comparison of patients with intellectual disability receiving specialised and general services in Ontario's psychiatric hospitals. *J Intellect Disabil Res* 2008;52(11):1003-12. Epub 2008 Mar 11.
279. Myers B. Psychotic disorders in people with mental retardation: diagnostic and treatment issues. *Ment Health Aspects Develop Disabil* 1999;2(1):1-11.
280. Myers R. *Recognizing psychosis in persons with intellectual disabilities who do not use speech*. Hertfordshire, UK: University of Hertfordshire; 2010. Available from: **www.intellectualdisability.info/diagnosis/articles/recognizing-psychosis-in-persons-with-intellectual-disabilities-who-do-not-use-speech**. Accessed 2016 Jan 7.
281. Mileviciute I, Hartley SL. Self-reported versus informant-reported depressive symptoms in adults with mild intellectual disability. *J Intellect Disabil Res* 2015;59(2):158-69.
282. Cuthill FM, Espie CA, Cooper SA. Development and psychometric properties of the Glasgow Depression Scale for people with a learning disability. Individual and carer supplement versions. *Br J Psychiatry* 2003;182:347-53.
283. Mindham J, Espie CA. Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *J Intellect Disabil Res* 2003;47(Pt 1):22-30.
284. Hodapp RM, Dankner NA, Dykens EM. Behavioural phenotypes/genetic syndromes. In: Hemmings C, Bouras N, editors. *Psychiatric and behavioral disorders in intellectual and developmental disabilities*. 3rd ed. Cambridge, UK: Cambridge University Press; 2016. p. 196-206.
285. Levitas A, Finucane B, Simon E, Schuster M, Kates W, Olszewski AK, et al. Behavioral phenotypes and neurodevelopmental disorders. In: Fletcher R, Barnhill J, Cooper S, editors. *Diagnostic manual—intellectual disability (DM-ID 2): a textbook of diagnosis of mental disorders in persons with intellectual disability*. 2nd ed. Kingston, NY: NADD Press; 2017. p. 35-74.
286. Bradley E, Loh A, Grier E, Korossy M, Cameron D. *Health watch table: autism spectrum disorder (ASD)*. Toronto, ON: Surrey Place Centre; 2014. Available from: **surreyplace.ca/ddprimarycare/health-watch-tables/austism-spectrum-disorder**. Accessed 2017 Oct 20.
287. Tao L, Temple V, Casson I, Kirkpatrick SML. *Health watch table: fetal alcohol spectrum disorder (FASD)*. Toronto, ON: Surrey Place Centre; 2013. Available from: **surreyplace.ca/ddprimarycare/health-watch-tables/fetal-alcohol-spectrum-disorder**. Accessed 2017 Oct 20.
288. Forster-Gibson C, Berg J. *Health watch table: Williams syndrome*. Toronto, ON: Surrey Place Centre; 2013. Available from: **surreyplace.ca/ddprimarycare/health-watch-tables/williams-syndrome**. Accessed 2017 Oct 20.
289. Hubert J, Hollins S. Men with severe learning disabilities and challenging behaviour in long-stay hospital care: qualitative study. *Br J Psychiatry* 2006;188:70-4.
290. Mevissen L, de Jongh A. PTSD and its treatment in people with intellectual disabilities. A review of the literature. *Clin Psychol Rev* 2010;30(3):308-16. Epub 2009 Dec 13.
291. McCarthy J, Blanco RA, Gaus VL, Razza NJ, Tomasulo DJ. Trauma- and stressor-related disorders. In: Fletcher R, Barnhill J, Cooper S, editors. *Diagnostic manual—intellectual disability (DM-ID 2): a textbook of diagnosis of mental disorders in persons with intellectual disability*. 2nd ed. Kingston, NY: NADD Press; 2017. p. 353-400.
292. Hemmings C. Schizophrenia spectrum disorders. In: Tsakanikos E, McCarthy JM, editors. *Handbook of psychopathology in intellectual disability: research, practice, and policy*. New York, NY: Springer; 2014.
293. Deb S, Matthews T, Holt G, Bouras N. *Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability*. Cheapside, UK: Pavilion; 2001. Available from: **www.slam.nhs.uk/media/199170/practiceguidelines.pdf**. Accessed 2018 Feb 16.
294. Bradley EA, Goody R, McMillan S, Levitas A. Common mental disorders (depression, anxiety, OCD, PTSD). In: Hassiotis A, Barron DA, Hall I, editors. *Intellectual disability psychiatry: a practical handbook*. Chichester, UK: Wiley-Blackwell; 2009. p. 51-66.
295. Summers J, Boyd K, Reid J, Adamson J, Habjan B, Gignac V, et al. The interdisciplinary mental health team. In: Griffiths DM, Stavrakaki C, Summers J, editors. *Dual diagnosis: an introduction to the mental health needs of persons with developmental disabilities*. Sudbury, ON: Habilitative Mental Health Resource Network; 2002. p. 325-57.
296. Read J, Fosse R, Moskowitz A, Perry B. The traumagenic neurodevelopmental model of psychosis revisited. *Neuropsychiatry* 2014;4(1):65-79.
297. Longden E, Madill A, Waterman MG. Dissociation, trauma, and the role of lived experience: toward a new conceptualization of voice hearing. *Psychol Bull* 2012;138(1):28-76. Epub 2011 Nov 14.
298. Linszen MMJ, Brouwer RM, Heringa SM, Sommer IE. Increased risk of psychosis in patients with hearing impairment: review and meta-analyses. *Neurosci Biobehav Rev* 2016;62:1-20. Epub 2015 Dec 30.
299. Boardman L, Bernal J, Hollins S. Communicating with people with intellectual disabilities: a guide for general psychiatrists. *Adv Psychiatr Treat* 2014;20(1):27-36.
300. Royal College of Speech and Language Therapists. *Five good communication standards*. London, UK: Royal College of Speech and Language Therapists; 2013. Available from: **www.rcslt.org/news/docs/good_comm_standards**. Accessed 2018 Feb 16.
301. Azimi K, Modi M, Hurlbut J, Lunsky Y. Occurrence of medical concerns in psychiatric outpatients with intellectual disabilities. *J Ment Health Res Intellect Disabil* 2016;9(1-2):24-35.
302. Melville CA, Johnson PC, Smiley E, Simpson N, Purves D, McConnachie A, et al. Problem behaviours and symptom dimensions of psychiatric disorders in adults with intellectual disabilities: an exploratory and confirmatory factor analysis. *Res Dev Disabil* 2016;55:1-13. Epub 2016 Mar 25.
303. Ji NY, Findling RL. Pharmacotherapy for mental health problems in people with intellectual disability. *Curr Opin Psychiatry* 2016;29(2):103-25.
304. Bradley E, Cheetham T. The use of psychotropic medication for the management of problem behaviours in adults with intellectual disabilities living in Canada. *Adv Ment Health Intellect Disabil* 2010;4(3):12-26.
305. Eady N, Courtenay K, Strydom A. Pharmacological management of behavioral and psychiatric symptoms in older adults with intellectual disability. *Drugs Aging* 2015;32(2):95-102.
306. Emerson E, Einfeld SL. Pharmacotherapy. In: Emerson E, Einfeld SL. *Challenging behaviour*. 3rd ed. Cambridge, UK; Cambridge University Press; 2011. p. 94-101.
307. Scheifes A, Walraven S, Stolker JJ, Nijman HL, Egberts TC, Heerdink ER. Adverse events and the relation with quality of life in adults with intellectual disability and challenging behaviour using psychotropic drugs. *Res Dev Disabil* 2016;49-50:13-21.
308. De Kuijper G, Mulder H, Evenhuis H, Visser F, Hoekstra PJ. Effects of controlled discontinuation of long-term used antipsychotics on weight and metabolic parameters in individuals with intellectual disability. *J Clin Psychopharmacol* 2013;33(4):520-4.
309. Glover G, Bernard S, Branford D, Holland A, Strydom A. Use of medication for challenging behaviour in people with intellectual disability. *Br J Psychiatry* 2014;205(1):6-7.
310. Balogh RS, Wood J, Lunsky Y, Ouellette-Kuntz HMJ, Wilton AS, Cobigo V, et al. Chronic disease management. In: Lunsky Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013. p. 92-116. Available from: **www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e**. Accessed 2015 Dec 8.
311. Bradley A, Lofchy J. Learning disability in the accident and emergency department. *Adv Psychiatr Treat* 2005;11(1):45-57.
312. Bell R. Does he have sugar in his tea? Communication between people with learning disabilities, their carers and hospital staff. *Tizard Learn Disabil Rev* 2012;17(2):57-63.
313. Hemmings C, Obousy S, Craig T. Mental health crisis information for people with intellectual disabilities. *Adv Ment Health Intellect Disabil* 2013;7(3):135-42.
314. Lunsky Y, Balogh R, Cairney J. Predictors of emergency department visits by persons with intellectual disability experiencing a psychiatric crisis. *Psychiatr Serv* 2012;63(3):287-90.
315. Bradley E, Behavioural and Mental Health Working Group of the Developmental Disabilities Primary Care Initiative. Crisis prevention and management plan. In: Sullivan W, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 77-81. Available from: **surreyplace.ca/ddprimarycare/tools/mental-health/crisis-prevention-and-management-plan/**. Accessed 2018 Feb 16.

316. Lunsky Y, Perry A, Lake J, Lee J. *Improving emergency care for adults with developmental disabilities: a toolkit for providers.* Toronto, ON: Portico Network, Centre of Addiction and Mental Health; 2016. Available from: **www.porticonetwork.ca/documents/38160/99698/Emergency+Care+Toolkit/3e3a9dca-6dc0-474e-aed3-34d8201656c7**. Accessed 2017 Apr 9.
317. Lin E, Balogh R, McGarry C, Selick A, Dobranowski K, Wilton AS, et al. Substance-related and addictive disorders among adults with intellectual and developmental disabilities (IDD): an Ontario population cohort study. *BMJ Open* 2016;6(9):e011638,2016-011638.
318. Van Duijvenbode N, VanDerNagel JE, Didden R, Engels RC, Buitelaar JK, Kiewik M, et al. Substance use disorders in individuals with mild to borderline intellectual disability: current status and future directions. *Res Dev Disabil* 2015;38:319-28. Epub 2015 Jan 9.
319. Pezzoni V, Kouimtsidis C. Screening for alcohol misuse within people attending a psychiatric intellectual disability community service. *J Intellect Disabil Res* 2015;59(4):353-9. Epub 2014 Oct 29.
320. To WT, Neirynck S, Vanderplasschen W, Vanheule S, Vandevelde S. Substance use and misuse in persons with intellectual disabilities (ID): results of a survey in ID and addiction services in Flanders. *Res Dev Disabil* 2014;35(1):1-9. Epub 2013 Nov 8.
321. Taggart L, Chaplin E. Substance misuse. In: Tsakanikos E, McCarthy JM, editors. *Handbook of psychopathology in intellectual disability: research, practice, and policy*. New York, NY: Springer; 2014. p. 205-23.
322. Public Health England. *Substance misuse and people with learning disabilities: making reasonable adjustments to services*. London, UK: Public Health England; 2017. Available from: **www.ndti.org.uk/uploads/files/Substance_Misuse_RA_Report.pdf**. Accessed 2017 Nov 13.
323. Slayter E, Steenrod SA. Addressing alcohol and drug addiction among people with mental retardation in nonaddiction settings: a need for cross-system collaboration. *J Soc Work Pract Addict* 2009;9(1):71-90.
324. Slayter EM. Understanding and overcoming barriers to substance abuse treatment access for people with mental retardation. *J Soc Work Disabil Rehabil* 2008;7(2):63-80.
325. Day C, Lampraki A, Ridings D, Currell K. Intellectual disability and substance use/misuse: a narrative review. *J Intellect Disabil Offending Behav* 2016;7(1):25-34.
326. Dodd K; Faculty for People with Intellectual Disabilities of the British Psychological Society Division of Clinical Psychology, Intellectual Disabilities Faculty of the Royal College of Psychiatrists. *Dementia and people with intellectual disabilities: guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia.* Leicester, UK: British Psychological Society; 2015. Available from: **www.bps.org.uk/system/files/Public%20files/rep77_dementia_and_id.pdf**. Accessed 2018 Feb 16.
327. Prasher VP. *Practical dementia care for adults with Down syndrome or with intellectual disabilities.* Hauppauge, NY: Nova Science Publishers, Inc; 2014.
328. Herron D. *Understanding dementia: people with learning disabilities finding out and raising awareness together.* West Midlands, UK: Black Country Partnership, NHS; 2014. Available from: **www.hee.nhs.uk/sites/default/files/documents/3%20-%20Understanding%20dementia%20for%20web.pdf**. Accessed 2018 Feb 16.
329. Sheehan R, Ali A, Hassiotis A. Dementia in intellectual disability. *Curr Opin Psychiatry* 2014;27(2):143-8.
330. Alvarez N. Dementia and people with intellectual and developmental disabilities. *Int J Child Health Hum Dev* 2015;8(4):449-69.
331. Gangadharan SK, Jesu AJM. Dementia in people with intellectual disability. In: Bhaumik S, Branford D, Barrett M, Gangadharan SK, editors. *The Frith prescribing guidelines for people with intellectual disability*. 3rd ed. Chichester, UK: John Wiley & Sons Inc; 2015. p. 63-75.
332. Jokinen N, Janicki MP, Keller SM, Mccallion P, Force LT. Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *J Policy Pract Intellect Disabil* 2013;10(1):1-24.
333. National Task Group on Intellectual Disabilities and Dementia Practices. *NTG-EDSD screening instrument.* Prospect, KY: American Academy of Developmental Medicine and Dentistry; 2013. Available from: **http://aadmd.org/sites/default/files/NTG-EDSD-ElectronicForm.pdf**. Accessed 2017 Oct 25.
334. Sullivan WF, editor. Special issue on primary care of adults with intellectual and developmental disabilities. *Can Fam Physician* 2018;64(Suppl 2):S1-78.

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