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# Primary care of adults with developmental disabilities

## Canadian consensus guidelines

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### Abstract

**Objective** To update the 2006 Canadian guidelines for primary care of adults with developmental disabilities (DD) and to make practical recommendations based on current knowledge to address the particular health issues of adults with DD.

**Quality of evidence** Knowledgeable health care providers participating in a colloquium and a subsequent working group discussed and agreed on revisions to the 2006 guidelines based on a comprehensive review of publications, feedback gained from users of the guidelines, and personal clinical experiences. Most of the available evidence in this area of care is from expert opinion or published consensus statements (level III).

**Main message** Adults with DD have complex health issues, many of them differing from those of the general population. Good primary care identifies the particular health issues faced by adults with DD to improve their quality of life, to improve their access to health care, and to prevent suffering, morbidity, and premature death. These guidelines synthesize general, physical, behavioural, and mental health issues of adults with DD that primary care providers should be aware of, and they present recommendations for screening and management based on current knowledge that practitioners can apply. Because of interacting biologic, psychoaffective, and social factors that contribute to the health and well-being of adults with DD, these guidelines emphasize involving caregivers, adapting procedures when appropriate, and seeking input from a range of health professionals when available. Ethical care is also emphasized. The guidelines are formulated within an ethical framework that pays attention to issues such as informed consent and the assessment of health benefits in relation to risks of harm.

**Conclusion** Implementation of the guidelines proposed here would improve the health of adults with DD and would minimize disparities in health and health care between adults with DD and those in the general population.

### Résumé

**Objectif** Mettre à jour les lignes directrices canadiennes de 2006 sur les soins primaires aux adultes ayant une déficience développementale (DD) et présenter des recommandations pratiques fondées sur les connaissances actuelles pour traiter des problèmes de santé particuliers chez des adultes ayant une DD.

**Qualité des preuves** Des professionnels de la santé expérimentés participant à un colloque et un groupe de travail subséquent ont discuté et convenu des révisions aux lignes directrices de 2006 en se fondant sur une recherche documentaire exhaustive, la rétroaction obtenue des utilisateurs

**KEY POINTS** As a group, adults with developmental disabilities (DD) have poorer health and greater difficulty accessing primary care than does the general population. They have different patterns of illness and complex interactions among comorbidities. These guidelines update the general, physical, behavioural, and mental health recommendations for adults with DD, especially for those conditions not screened for by routine health assessments of the general population. Ethical issues, such as informed consent and assessment of benefits in relation to risks, are addressed. Among the most important updates are consideration of atypical manifestations of pain and distress in adults with DD and a strong recommendation to avoid inappropriate long-term use of antipsychotic medications to address behavioural issues.

**POINTS DE REPÈRE** Collectivement, les adultes ayant des déficiences développementales (DD) sont en moins bonne santé et ont plus de difficultés à avoir accès aux soins primaires en comparaison de l'ensemble de la population. Les maladies évoluent différemment et présentent entre elles des interactions complexes chez ces personnes. Les lignes directrices font la mise en jour des recommandations pour la santé générale, physique, comportementale et mentale des adultes ayant une DD, en particulier pour les problèmes qui ne sont pas dépistés dans les évaluations systématiques de la santé dans la population en général. Elles traitent des questions d'ordre éthique, comme le consentement éclairé et l'évaluation des bienfaits par rapport aux risques. Parmi les mises à jour les plus importantes, on peut mentionner les manifestations atypiques de la douleur et de la détresse chez les adultes ayant une DD et une très forte recommandation d'éviter l'utilisation à long terme inappropriée des antipsychotiques pour les problèmes comportementaux.

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du guide de pratique et les expériences cliniques personnelles. La plupart des preuves disponibles dans ce domaine viennent de l'opinion d'experts ou de déclarations consensuelles publiées (niveau III).

**Message principal** Les adultes ayant une DD ont des problèmes de santé complexes, dont plusieurs diffèrent de ceux de la population en général. De bons soins primaires permettent d'identifier les problèmes de santé particuliers dont souffrent les adultes ayant une DD pour améliorer leur qualité de vie et leur accès aux soins de santé et prévenir la morbidité et le décès prématuré. Ces lignes directrices résument les problèmes de santé générale, physique, comportementale et mentale des adultes ayant une DD que devraient connaître les professionnels des soins primaires et présentent des recommandations pour le dépistage et la prise en charge en se basant sur les connaissances actuelles que les cliniciens peuvent mettre en pratique. En raison de l'interaction des facteurs biologiques, psychoaffectifs et sociaux qui contribuent à la santé et au bien-être des adultes ayant une DD, ces lignes directrices insistent sur la participation des aidants, l'adaptation des interventions, au besoin, et la consultation auprès de divers professionnels de la santé quand ils sont accessibles. Elles mettent aussi en évidence la nature éthique des soins. Les lignes directrices sont formulées dans le contexte d'un cadre éthique qui tient compte des questions comme le consentement éclairé et l'évaluation des bienfaits pour la santé par rapport aux risques de préjudice.

**Conclusion** La mise en œuvre des lignes directrices proposées ici améliorerait la santé des adultes ayant une DD et minimiserait les disparités sur les plans de la santé et des soins de santé entre les adultes ayant une DD et la population en général.

The terms *developmental disabilities* (DD) or *intellectual disabilities* are used synonymously in Canada (equivalent to *learning disabilities* in the United Kingdom) to refer to a range of conditions in which lifelong limitations in intellectual functioning and conceptual, social, and practical skills are noticeable before age 18 years.<sup>1</sup> Estimates of the prevalence of DD vary between 1% and 3% of Canadians. Most reside and receive health care in the community.<sup>2</sup> A growing proportion of them are living longer than in the past.<sup>2,3</sup> Their health needs and access to primary care vary individually with factors such as the etiology of their DD, coexisting physical and mental health characteristics, severity of functional limitations, quality of environment and social supports, and age.<sup>4</sup>

Health disorders in people with DD frequently differ from those encountered in the general population in terms of prevalence, age of onset, rate of progression, degree of severity, and presenting manifestations. These disorders are also more likely to be multiple and

complex in those with DD.<sup>3</sup> They therefore require the support of health professionals who are willing, knowledgeable, and skilled to address their particular challenges and vulnerabilities in maintaining health.

Various studies in Canada, the United States, the United Kingdom, and Australia have shown that people with DD, as a group, are poorly supported by health care systems.<sup>5</sup> The United Nations' *Convention on the Rights of Persons with Disabilities*,<sup>6</sup> which has been ratified by Canada, includes the right to health care. Primary care providers are the lynchpin in efforts to ameliorate health care for people with DD. Primary care providers are often the most consistently available health professionals involved in caring for people with DD and in interacting with regular caregivers. Their contribution is vital for disease prevention, early detection, and appropriate management. They can help to assess the need for referral to specialized and interdisciplinary health services when these are available. They also provide continuity and coordination of care. Reliable guidelines, however, are required to inform primary care providers about the particular health needs of people with DD and the best approaches to management.

There is an especially pressing need for such guidelines concerning adults with DD. Adulthood, usually after 18 years of age, is when people with DD are no longer deemed eligible for pediatric and adolescent services, although this age varies provincially in Canada. In the Canadian health care system, service gaps resulting from transition to the adult care system, which generally has fewer resources and is less specialized and more fragmented than the pediatric and adolescent care systems, present enormous challenges to adults with DD and their caregivers. These challenges are complicated by recent increases in life expectancy and the aging of people with DD, and by their integration into the community. Thus, while more people with DD are moving into the adult care system than in the past, there are insufficient numbers of knowledgeable and experienced primary care providers to support them. To compound the situation, there have been fewer publications addressing the screening, assessment, and management of health disorders and challenges of adults with DD, relative to such publications for infants and children with such disabilities.

In 2005, a consensus colloquium involving knowledgeable and experienced clinicians and researchers in DD from across Canada and abroad formulated the "Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities" (hereafter referred to as the *2006 Guidelines*).<sup>7</sup> Subsequent consultations with users of the 2006 Guidelines, as well as developments in research and practice, led to expanding and updating those guidelines, which remain, to our knowledge, the only comprehensive guidelines for the primary care of adults with

DD in Canada. References to various clinical tools that might help in applying the guidelines have also been added.

## Methods

A consensus development method was used to update the 2006 Guidelines. This consisted of 2 steps: meticulous electronic and manual searches for relevant publications and discussion of recommended changes to the 2006 Guidelines by knowledgeable and experienced Canadian clinicians and researchers on primary health care of adults with DD who participated in a consensus colloquium in March 2009 and in a subsequent working group.

A librarian familiar with research on DD undertook ongoing, comprehensive electronic searches in PubMed and PsycINFO for publications in English from 1990 to 2010 that were indexed under, or contained in their title, abstract, or text, the terms *mental retardation*, *intellectual disability (disabilities)*, or *developmental disability (disabilities)*. Publications from Great Britain were also searched for the terms *learning difficulties*, *learning disability (disabilities)*, or *learning disorders*. These were cross-referenced with a long list of physical and mental health key words relating to medical assessment, diagnosis, treatment, prognosis, health care access, need, planning, services, and delivery. The search was then expanded to include specific health issues highlighted in the 2006 Guidelines. In addition, the librarian undertook manual searches using cited references in Scopus and Internet searches for relevant publications that had not been indexed by any of the above-mentioned electronic databases.

Search results were downloaded to and organized in an electronic database management system known as RefWorks. Two family physicians, a psychologist, and a psychiatrist drew on this database and on comments regarding the 2006 Guidelines gained from various users and reviewers. They were each assigned a section of the 2006 Guidelines for which they were to propose revisions.

Participants who helped to formulate the 2006 Guidelines and others who had completed training courses on the guidelines between 2006 and 2009 were invited to a day-long colloquium in Toronto, Ont, in March 2009. Among the 39 participants were practitioners in family medicine, nursing, pediatrics, psychiatry, psychology, occupational therapy, and speech-language pathology. Before the colloquium, all had access to the librarian's entries into the RefWorks database and received a summary of feedback from users and reviewers of the 2006 Guidelines. The prepared proposals for revisions were discussed in small groups and in plenary sessions, and a summary of accepted revisions was presented and discussed at the end of the

colloquium in relation to the priority criteria adopted in the 2006 Guidelines (Table 1).<sup>8</sup> A working group consisting of 7 participants, with a family physician in the leading role, met monthly between March 2009 and March 2010 to draft the first version of the updated guidelines. They incorporated into the 2006 Guidelines the changes discussed and accepted during the colloquium. This working group also reviewed published supporting evidence for all the guidelines, including those from supplementary electronic and manual searches for publications undertaken after the colloquium to address particular issues that were not foreseen in the original literature searches. The working group judged the level of evidence supplied for any modified or new guidelines, using the classification scheme adopted in the 2006 Guidelines (Table 2).

The first draft of the updated guidelines was circulated for review by participants in the colloquium as well as several invited consultants who were unable to attend the colloquium. Based on the feedback received, the working group prepared the second and final draft between March and October of 2010. This version was sent to participants in the colloquium and review process for their approval; it was then submitted for review for publication.

**Table 1. Guideline priority criteria**

CRITERIA	EXPLANATION
Importance	Guidelines that address the most prevalent health issues for people with developmental disabilities, especially the leading causes of ill health and death
Disparity	Guidelines that address an issue that would not be identified by public health initiatives or illness prevention measures that target the general population
Usefulness	Guidelines that can be practically implemented and evaluated; these refer to health problems that are easy to detect, for which the means of prevention and care are readily available, and which have health outcomes that can be monitored
Information	Guidelines that are supported by reliable clinical information and research evidence

Adapted from the POMONA Partnership.<sup>8</sup>

**Table 2. Criteria for assigning levels of evidence**

LEVEL	CRITERIA
I	At least 1 properly conducted randomized controlled trial, systematic review, or meta-analysis
II	Other comparison trials, non-randomized, cohort, case control, or epidemiologic studies, and preferably more than 1 study
III	Expert opinion or consensus statements

## Practice guidelines

The updated guidelines are presented in their entirety in **Table 3**.<sup>1,2,9-180</sup>

## Discussion

**Improving clarity.** On the whole, there has been substantial elaboration and rewording of most of the 2006 Guidelines, with attention paid to rendering the considerations and recommendations easier to understand and apply.

Compared with the 2006 Guidelines, the focus of the updates is more clearly on health conditions and needs of adults with DD that diverge from those of

the general population. Although primary care guidelines that have been found effective for preventing diseases in the general population should normally also be applied to people with DD, the guidelines in **Table 3**<sup>1,2,9-180</sup> provide additional recommendations and appropriate modifications to standard practice that are relevant for adults with DD. However, some recommendations that apply to the general population have been included in the updated guidelines either because they pertain to tests and other interventions from which adults with DD tend to be excluded or because there is inadequate evidence-based guidance specific to adults with DD.

**Table 3. Preventive care checklist for adults with developmental disabilities: The level of evidence is indicated for each recommendation and is based on the cited reference or references.**

CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
<b>GENERAL ISSUES IN PRIMARY CARE OF ADULTS WITH DD</b>		
1. Disparities in primary care exist between adults with DD and the general population. The former often have poorer health, increased morbidity, and earlier mortality. <sup>2</sup> Assessments that attend to the specific health issues of adults with DD can improve their primary care. <sup>9</sup>	a. Apply age- and sex-specific guidelines for preventive health care as for adults in the general population. <sup>10,11</sup> Perform an annual comprehensive preventive care assessment including physical examination and use guidelines and tools adapted for adults with DD. <sup>9</sup>	I
2. Etiology of DD is useful to establish, whenever possible, as it often informs preventive care or treatment. <sup>12-14</sup>	a. Contact a genetics centre for referral criteria and testing protocols concerning etiologic assessment of adults whose DD is of unknown or uncertain origin. <sup>15-17</sup>	III
Advances in genetic knowledge continue to enhance detection of etiology. <sup>13,18</sup>	b. Consider reassessment periodically if a previous assessment was inconclusive, according to the criteria of the genetics centre. <sup>19</sup>	III
3. Adaptive functioning can decline or improve in some adults with DD. A current assessment of intellectual and adaptive functioning helps to determine necessary care and supports, and establishes a baseline for future assessment. <sup>1,20,21</sup>	a. Refer to a psychologist for assessment of functioning if the patient has never been assessed during adolescence or adulthood, or if a considerable life transition is expected (eg, cessation of schooling or transition from middle to old age).	III
	b. Consider reassessment if indicated, comprehensively or in specific areas, to determine contributing factors to problem behaviour (see guideline 22). <sup>22</sup>	III
4. Pain and distress, often unrecognized, <sup>23</sup> might present atypically in adults with DD, particularly those who have difficulty communicating. Nonspecific changes in behaviour might be the only indicator of medical illness or injury. <sup>24,25</sup>	a. Be attentive to atypical physical cues of pain and distress using an assessment tool adapted for adults with DD. <sup>26,27</sup>	III
Evaluation tools are available to assess the presence and intensity of pain in adults with DD. <sup>27-29</sup>	b. Consider medical causes of changes in behaviour (eg, urinary tract infection, dysmenorrhea, constipation, dental disease). <sup>30</sup>	III
5. Multiple or long-term use of some medications by adults with DD can cause harm that is preventable. <sup>31</sup>	a. Review the date of initiation, indications, dosages, and effectiveness of all medications regularly (eg, every 3 mo). <sup>32</sup>	III
	b. Determine patient adherence capacity and recommend dosettes, blister-packs, and other aids if necessary.	III
	c. Watch for both typical and atypical signs of adverse effects. <sup>33</sup> Regularly monitor potentially toxic medications or interactions of medications (eg, liver function tests or serum drug levels) at the recommended interval for each medication. <sup>34</sup>	III
	d. Ensure that patient and staff or caregivers are educated about appropriate use of medications, including over-the-counter, alternative, and as-needed medications.	III
6. Abuse and neglect of adults with DD occur frequently and are often perpetrated by people known to them. <sup>35-39</sup> Behavioural indicators that might signal abuse or neglect include unexplained change in weight, noncompliance, aggression, withdrawal, depression, avoidance, poor self-esteem, inappropriate attachment or sexualized behaviour, sleep or eating disorders, and substance abuse. <sup>35</sup>	a. Screen annually for risk factors (eg, caregiver stress) and possible behavioural indicators of abuse or neglect. <sup>35</sup>	III
	b. When abuse or neglect is suspected, report to the police or other appropriate authority and address any consequent health issues (eg, through appropriate counseling). <sup>35</sup>	III

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CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
<p><b>7. Capacity for voluntary and informed consent</b> varies with the complexity and circumstances of decision making. The limited range of life experiences of some adults with DD, level of intellectual functioning, learned helplessness, and some mental health issues might impair capacity to give informed or voluntary consent. An adult with DD assessed as incapable of some aspects of decision making (eg, understanding or judging consequences) might still be able to convey, through verbal or other means, perspectives that can inform the judgment of a substitute decision maker.<sup>40</sup></p>	a. Always assess capacity for consent when proposing investigations or treatments for which consent is required. <sup>41</sup>	III
<p>Communicating appropriately with adults with DD is necessary for assessing their capacity to consent and for seeking this consent.<sup>42</sup></p>	b. Adapt the level and means of communicating to the patient's level of intellectual and adaptive functioning. <sup>43</sup>	III
<p>Although some adults with DD might be incapable of giving consent, they might be able to contribute to decision making (eg, understanding information, expressing perspectives, giving assent) with appropriate support from regular caregivers. Caregivers can also contribute to decision making. They may consent to or refuse treatment on behalf of an adult with DD who is assessed to be incapable of providing informed consent, if they are the most appropriate and available substitute decision makers according to the law.<sup>40</sup></p>	c. Always consider the best interests of the adult with DD, including his or her perspective in pursuing or forgoing any health care intervention. Support whatever decision-making capacity is possible in adults with DD. Involve family or other caregivers to facilitate communication with, and understanding of, the adult with DD, but also be attentive to inappropriate taking over of decision making. <sup>42,44</sup>	III
<p><b>8. Advance care planning</b> can often make a positive difference to the outcome of difficult life transitions and crises, and for end-of-life care.<sup>40,43,45</sup></p>	a. Discuss advance care plans with adults with DD and their caregivers, especially to determine their preference of a substitute decision maker. <sup>41</sup>	III
	b. Record advance care plans and review them annually, or sooner in the context of a health crisis, for appropriateness to the adult with DD's present situation and for what needs to be implemented. <sup>43</sup>	III
<p><b>9. Interdisciplinary health care</b> is effective in addressing the complex needs of adults with DD. Ideally this would involve a family physician, nurse, and other health practitioners as required, with a coordinator, who might be the family physician, to ensure continuity of care.<sup>46,47</sup></p>	a. Involve other available health professionals as needed. <sup>46</sup> To address complex physical, behavioural or mental health needs, consult available regional service coordination agencies or specialized interdisciplinary teams. <sup>48,49</sup>	III
<p><b>PHYSICAL HEALTH GUIDELINES FOR ADULTS WITH DD</b></p>		
<p><b>10. Physical inactivity and obesity</b> are prevalent among adults with DD and are associated with adverse outcomes, including cardiovascular disease, diabetes, osteoporosis, constipation, and early mortality.<sup>50,51</sup> Being underweight, with its attendant health risks, is also common.<sup>52</sup></p>	a. Monitor weight and height regularly and assess risk status using body mass index, waist circumference, or waist-hip ratio measurements. <sup>53,54</sup>	II
<p>A health promotion program can improve attitudes toward physical activity and satisfaction with life.<sup>55,56</sup></p>	b. Counsel patients and their caregivers annually or more frequently, if indicated, regarding guidelines for nutrition and physical fitness and how to incorporate regular physical activity into daily routines. Refer to dietitian if indicated. <sup>56-59</sup>	II
<p><b>11. Vision and hearing impairments</b> among adults with DD are often underdiagnosed and can result in substantial changes in behaviour and adaptive functioning.<sup>60-64</sup></p>	a. Perform office-based screening of vision and hearing (eg, Snellen eye chart, whispered voice test) annually as recommended for average-risk adults, and when symptoms or signs of visual or hearing problems are noted, including changes in behaviour and adaptive functioning. <sup>33,65</sup>	III
	b. Refer for vision assessment to detect glaucoma and cataracts every 5 y after age 45. <sup>65</sup>	III
	c. Refer for hearing assessment if indicated by screening and for age-related hearing loss every 5 y after age 45. <sup>65</sup>	III
	d. Screen for and treat cerumen impaction every 6 mo. <sup>66,67</sup>	III
<p><b>12. Dental disease</b> is among the most common health problems in adults with DD owing to their difficulties in maintaining oral hygiene routines and accessing dental care. Changes in behaviour can be the result of discomfort from dental disease.<sup>33,68</sup></p>	a. Promote regular oral hygiene practices and other preventive care (eg, fluoride application) by a dental professional. <sup>69-72</sup>	I
<p><b>13. Cardiac disorders</b> are prevalent among adults with DD. Risk factors for coronary artery disease include physical inactivity, obesity, smoking, and prolonged use of some psychotropic medications.<sup>51,73,74</sup></p>	a. When any risk factor is present, screen for cardiovascular disease earlier and more regularly than in the general population and promote prevention (eg, increasing physical activity, reducing smoking). <sup>73</sup>	III
<p>Some adults with DD have congenital heart disease and are susceptible to bacterial endocarditis.</p>	b. Refer to a cardiologist or adult congenital heart disease clinic. <sup>75</sup>	III
	c. Follow guidelines for antibiotic prophylaxis for those few patients who meet revised criteria. <sup>76</sup>	II

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CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
<p>14. <b>Respiratory disorders</b> (eg, aspiration pneumonia) are among the most common causes of death for adults with DD. Swallowing difficulties are prevalent in those patients with neuromuscular dysfunction or taking certain medications with anticholinergic side effects, and they might result in aspiration or asphyxiation.<sup>77-79</sup></p>	a. Screen at least annually for possible signs of swallowing difficulty and overt or silent aspiration (eg, throat clearing after swallowing, coughing, choking, drooling, long mealtimes, aversion to food, weight loss, frequent chest infections). Refer as appropriate. <sup>80</sup>	III
<p>15. <b>Gastrointestinal and feeding problems</b> are common among adults with DD. Presenting manifestations are often different than in the general population and might include changes in behaviour or weight.<sup>81-83</sup></p>	<p>a. Screen annually for manifestations of GERD and manage accordingly. If introducing medications that can aggravate GERD, monitor more frequently for related symptoms.<sup>83,84</sup></p> <p>b. If there are unexplained gastrointestinal findings or changes in behaviour or weight, investigate for constipation, GERD, peptic ulcer disease, and pica.<sup>82,84</sup></p>	III II
<p>Adults with DD might have an increased risk of <i>Helicobacter pylori</i> infection related to factors such as having lived in a group home, rumination, or exposure to saliva or feces due to personal behaviour or environmental contamination.<sup>83,85,86</sup></p>	<p>c. Screen for <i>H pylori</i> infection in symptomatic adults with DD or asymptomatic ones who have lived in institutions or group homes. Consider retesting at regular intervals (eg, 3-5 y).<sup>83</sup></p> <p>d. Consider urea breath testing, fecal antigen testing, or serologic testing depending on the indication, availability, and tolerability of the test.<sup>83,85</sup></p>	III III
<p>16. <b>Sexuality</b> is an important issue that is often not considered in the primary care of adolescents and adults with DD.<sup>87,88</sup></p>	a. Discuss the patient's or caregiver's concerns about sexuality (eg, menstruation, masturbation, fertility and genetic risks, contraception, menopause) and screen for potentially harmful sexual practices or exploitation. Offer education and counseling services adapted for those with DD. <sup>89,90</sup>	III
<p>17. <b>Musculoskeletal disorders</b> (eg, scoliosis, contractures, and spasticity, which are possible sources of unrecognized pain) occur frequently among adults with DD and result in reduced mobility and activity, with associated adverse health outcomes.<sup>51,91</sup></p>	<p>a. Promote mobility and regular physical activity.<sup>56,92</sup></p> <p>b. Consult a physical or occupational therapist regarding adaptations (eg, wheelchair, modified seating, splints, orthotic devices) and safety.<sup>92</sup></p>	III III
<p>Osteoporosis and osteoporotic fractures are more prevalent and tend to occur earlier in adults with DD than in the general population.<sup>93</sup> In addition to aging and menopause, risk factors include severity of DD, low body weight, reduced mobility, increased risk of falls, smoking, hypogonadism, hyperprolactinemia, the presence of particular genetic syndromes (eg, Down and Prader-Willi),<sup>91,94-96</sup> and long-term use of certain drugs (eg, glucocorticoids, anticonvulsants, injectable long-acting progesterone in women).<sup>34,97</sup> Diagnosis and management of osteoporosis related to the side effects of current treatments can be challenging in adults with DD.</p>	<p>c. Periodically assess risk of developing osteoporosis in all age groups of male and female patients with DD. Those at high risk warrant regular screening starting in early adulthood.<sup>94,96</sup></p> <p>d. Recommend early and adequate intake or supplementation of calcium and vitamin D unless contraindicated (eg, in Williams syndrome).<sup>94</sup></p>	III III
<p>Osteoarthritis is becoming more common with increasing life expectancy and weight gain, posing diagnostic and treatment difficulties.<sup>51,98</sup></p>	e. Be aware of osteoarthritis as a possible source of pain. <sup>51</sup>	III
<p>18. <b>Epilepsy</b> is prevalent among adults with DD and increases with the severity of the DD. It is often difficult to recognize, evaluate, and control.<sup>99-101</sup> and has a pervasive effect on the lives of affected adults and their caregivers.<sup>102</sup></p>	<p>a. Refer to guidelines for management of epilepsy in adults with DD.<sup>101</sup></p> <p>b. Review seizure medication regularly (eg, every 3-6 mo). Consider specialist consultation regarding alternative medications when seizures persist, and possible discontinuation of medications for patients who become seizure-free.<sup>101</sup></p> <p>c. Educate patients and caregivers about acute management of seizures and safety-related issues.<sup>103</sup></p>	III III III
<p>19. <b>Endocrine disorders</b> (eg, thyroid disease, diabetes, and low testosterone) can be challenging to diagnose in adults with DD.<sup>33,104-106</sup> Adults with DD have a higher incidence of thyroid disease compared with the general population.<sup>107</sup></p>	<p>a. Monitor thyroid function regularly. Consider testing for thyroid disease in patients with symptoms (including changes in behaviour and adaptive functioning) and at regular intervals (eg, 1-5 y) in patients with elevated risk of thyroid disease (eg, Down syndrome).<sup>33</sup></p> <p>b. Establish a thyroid baseline and test annually for patients taking lithium or atypical or second-generation antipsychotic drugs.<sup>34</sup></p>	III III
<p>Currently there is no clear evidence of increased prevalence of diabetes in adults with DD, with some exceptions (eg, Down syndrome).<sup>108,109</sup> Diabetes management guidance has been developed for adults with DD and their care providers.<sup>110,111</sup></p>	c. Consider screening for diabetes in adults with DD who are obese or who have sedentary lifestyles or hyperlipidemia.	III
<p>Limited available data suggest that hypogonadism is common among men with DD.<sup>106</sup> Substantial data are available on hypogonadism associated with specific syndromes (eg, Prader-Willi syndrome).<sup>112</sup></p>	d. Consider screening for hypogonadism and testosterone level at least once after full puberty is achieved, ideally at around age 18 y, and refer as appropriate if low levels are found. <sup>105,106</sup>	III

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CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
<p><b>20. Infectious disease prevention and screening.</b> Even though immunization is a crucial component of preventive care, adults with DD might have limited awareness of immunizations.<sup>9,33,113</sup></p> <p>It is important to screen for infectious diseases (eg, hepatitis B, HIV, and <i>H pylori</i>) in adults with DD. Some adults with DD have an increased risk of exposure to infectious diseases (eg, hepatitis A and B).<sup>118,119</sup></p>	a. Follow guidelines for routine immunization of adults. <sup>114,115</sup>	III
	b. Ensure influenza and <i>Streptococcus pneumoniae</i> vaccinations are current and offered when appropriate. <sup>116</sup>	III
	c. Discuss the human papillomavirus vaccine with female patients with DD between the ages of 9 and 26 y and, if appropriate, their substitute decision makers. <sup>117</sup>	III
	d. Screen for infectious diseases based on the patient's risk factors for exposure (for <i>H pylori</i> see 15c, 15d).	III
	e. Offer hepatitis A and B screening and immunization to all at-risk adults with DD, <sup>117-119</sup> including those who take potentially hepatotoxic medications or who have ever lived in institutions or group homes. <sup>115</sup>	III
<p><b>21. Cancer screening</b> is an essential aspect of preventive care. However, adults with DD are less likely than those in the general population to be included in preventive screening programs such as cervical screening,<sup>113</sup> breast examination, mammography, and digital rectal examination.<sup>2</sup> They are also less likely to do self-examination or to report abnormalities. Colorectal cancer risk is considerably greater for women than for men with DD.<sup>120</sup></p>	a. Perform regular cervical screening for all women who have been sexually active. <sup>121</sup>	I
	b. Perform annual breast screening, including mammography, for female patients with DD aged 50-69 y. <sup>122</sup>	III
	c. Perform an annual testicular examination for all male patients with DD. <sup>123</sup>	III
	d. Screen for prostate cancer annually using digital rectal examination from age 45 y for all male patients with DD. <sup>124</sup>	II
	e. Screen for colon cancer regularly in all adult patients with DD older than 50 y. <sup>120,125</sup>	I
<b>BEHAVIOURAL AND MENTAL HEALTH GUIDELINES FOR ADULTS WITH DD</b>		
<p><b>22. Problem behaviour</b>, such as aggression and self-injury, is not a psychiatric disorder but might be a symptom of a health-related disorder or other circumstance (eg, insufficient supports).<sup>25,126,127</sup></p> <p>Problem behaviours sometimes occur because environments do not meet the developmental needs of the adult with DD.<sup>128</sup></p> <p>Despite the absence of an evidence base, psychotropic medications are regularly used to manage problem behaviours among adults with DD.<sup>129,130</sup> Antipsychotic drugs should no longer be regarded as an acceptable routine treatment of problem behaviours in adults with DD.<sup>131</sup></p>	a. Before considering a psychiatric diagnosis, assess and address sequentially possible causes of problem behaviour, including physical (eg, infections, constipation, pain), environmental (eg, changed residence, reduced supports), and emotional factors (eg, stress, trauma, grief). <sup>127</sup>	II
	b. Facilitate "enabling environments" to meet these unique developmental needs as they will likely diminish or eliminate these problem behaviours. <sup>128</sup>	III
	c. Regularly audit the use of prescribed psychotropic medication, including those used as needed. <sup>132</sup> Plan for a functional analysis (typically performed by a behavioural therapist or psychologist) and interdisciplinary understanding of problem behaviours. Review with care providers psychological, behavioural, and other nonmedication interventions to manage problem behaviours. Consider reducing and stopping, at least on a trial basis, medications not prescribed for a specific psychiatric diagnosis. <sup>133</sup>	III
<p><b>23. Psychiatric disorders</b> and emotional disturbances are substantially more common among adults with DD, but their manifestations might mistakenly be regarded as typical for people with DD (ie, "diagnostic overshadowing"). Consequently, coexisting mental health disturbances might not be recognized or addressed appropriately.<sup>21,134,135</sup></p> <p>Increased risk of particular developmental, neurologic, or behavioural manifestations and emotional disturbances (ie, "behavioural phenotypes") is associated with some DD syndromes.<sup>140,141</sup></p>	a. When screening for psychiatric disorder or emotional disturbance, use tools developed for adults with DD according to their functioning level (eg, Aberrant Behaviour Checklist-Community [ABC-C]; Psychiatric Assessment Schedule for Adults with DD [PAS-ADD]). <sup>136-139</sup>	III
	b. Consult available information on behavioural phenotypes in adults with DD due to specific syndromes. <sup>142,143</sup>	III
<p>Establishing a diagnosis of a psychiatric disorder in adults with DD is often complex and difficult, as these disorders might be masked by atypical symptoms and signs.<sup>21,135</sup> In general, mood, anxiety, and adjustment disorders are underdiagnosed<sup>144</sup> and psychotic disorders are overdiagnosed in adults with DD.<sup>145,146</sup></p> <p><b>24. Psychotic disorders</b> are very difficult to diagnose when delusions and hallucinations cannot be expressed verbally.<sup>145</sup> Developmentally appropriate fantasies and imaginary friends might be mistaken for delusional ideation, and self-conversation for hallucination.<sup>145,147,148</sup></p> <p><b>25. Input and assistance from adults with DD and their caregivers</b> are vital for a shared understanding of the basis of problem behaviours, emotional disturbances, and psychiatric disorders, and for effectively developing and implementing treatment and interventions.<sup>127,151,152</sup></p>	c. When psychiatric disorder is suspected, seek interdisciplinary consultation from clinicians knowledgeable and experienced in DD.	III
	a. Seek interdisciplinary input from specialists in psychiatry, psychology, and speech-language pathology with expertise in DD to help clarify diagnoses in patients with limited or unusual use of language. <sup>144,149,150</sup>	III
	a. Establish a shared way of working with patients and caregivers. Seek input, agreement, and assistance in identifying target symptoms and behaviours that can be monitored.	III
	b. Use tools (eg, sleep charts, antecedent-behaviour-consequence [ABC] charts) to aid in assessing and monitoring behaviour and intervention outcomes. <sup>153,154</sup>	III

Continued on page 548



Table 3 *continued from page 547*

CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
<p><b>26. Interventions other than medication</b> are usually effective for preventing or alleviating problem behaviours.<sup>133,144,155</sup></p>	a. To reduce stress and anxiety that can underlie some problem behaviours, emotional disturbances, and psychiatric disorders, consider such interventions as addressing sensory issues (eg, underarousal, overarousal, hypersensitivity), environmental modification, education and skill development, communication aids, psychological and behaviour therapies, and caregiver support. <sup>144</sup>	III
	b. Cognitive behavioural therapy can be effective in decreasing anger and treating anxiety and depression in adults with DD. <sup>156,157</sup>	III
	c. There is increasing evidence of the efficacy of psychotherapy for emotional problems (eg, related to grief, abuse, trauma) that might underlie aggression, anxiety, and other such states. <sup>158-162</sup>	III
<p><b>27. Psychotropic medications</b> (eg, antidepressants) are effective for robust diagnoses of psychiatric disorders in adults with DD<sup>163</sup> as in the general population.<sup>164</sup></p> <p>Psychotropic medications, however, can be problematic for adults with DD and should therefore be used judiciously. Patients might be taking multiple medications and can thus be at increased risk of adverse medication interactions. Some adults with DD might have atypical responses or side effects at low doses. Some cannot describe harmful or distressing effects of the medications that they are taking.<sup>34,166</sup></p>	a. When psychiatric diagnosis is confirmed after comprehensive assessment, consider psychotropic medication along with other appropriate interventions as outlined in guideline 26. <sup>165</sup>	III
	b. "Start low, go slow" in initiating, increasing, or decreasing doses of medications. <sup>167</sup>	III
	c. Arrange to receive regular reports from patients and their caregivers during medication trials in order to monitor safety, side effects, and effectiveness. <sup>133</sup>	III
	d. In addition to reviews every 3 mo (see guideline 5), also review the psychiatric diagnosis and the appropriateness of prescribed medications for this diagnosis whenever there is a behavioural change. <sup>34,133</sup>	III
When unable to pinpoint a specific psychiatric diagnosis, behaviours of concern might serve as index behaviours against which to conduct a trial of medications. <sup>133,167</sup>	e. Having excluded physical, emotional, and environmental contributors to the behaviours of concern, a trial of medication appropriate to the patient's symptoms might be considered.	III
<p><b>28. Antipsychotic medications</b> are often inappropriately prescribed for adults with behaviour problems and DD.<sup>168</sup> In the absence of a robust diagnosis of psychotic illness, antipsychotic medications should not be regarded as routine treatments of problem behaviours in adults with DD.<sup>131</sup></p> <p>Antipsychotic medications increase risk of metabolic syndrome and can have other serious side effects (eg, akathisia, cardiac conduction problems, swallowing difficulties, bowel dysfunction).<sup>34,166</sup></p>	a. Do not use antipsychotic medication as a first-line treatment of problem behaviours without a confirmed robust diagnosis of schizophrenia or other psychotic disorder. <sup>131</sup>	III
	b. Carefully monitor for side effects of antipsychotic medication, including metabolic syndrome. Educate patients and caregivers to incorporate a healthy diet and regular exercise into their lifestyle. <sup>34</sup>	III
	c. Reassess the need for ongoing antipsychotic medications at regular intervals and consider dose reduction or discontinuation when appropriate (also see guidelines 5 and 27). <sup>34</sup>	III
<p><b>29. Behavioural crises</b> can occasionally arise that might need management in an emergency department.<sup>169-173</sup></p>	a. When psychotropic medications are used to ensure safety during a behavioural crisis, ideally such use should be temporary (no longer than 72 h).	III
	b. Debrief with care providers in order to minimize the likelihood of recurrence. This should include a review of crisis events and responses (eg, medication, de-escalation measures), and identification of the possible triggers and underlying causes of the behavioural crisis. <sup>133,174</sup>	III
	c. If the patient is at risk of recurrent behavioural crises, involve key stakeholders, including local emergency department staff, to develop a proactive, integrated emergency response plan. <sup>174</sup>	III
<p><b>30. Alcohol or drug abuse</b> is less common among adults with DD than in the general population, but the former might have more difficulty moderating their intake and experience more barriers to specialized rehabilitation services.<sup>175-177</sup></p>	a. Screen for alcohol and drug abuse as part of the annual health examination.	III
<p><b>31. Dementia</b> is important to diagnose early, especially in adults with Down syndrome who are at increased risk.<sup>178</sup> Diagnosis might be missed because changes in emotion, social behaviour, or motivation can be gradual and subtle. A baseline of functioning against which to measure changes is needed.</p> <p>Differentiating dementia from depression and delirium can be especially challenging.<sup>180</sup></p>	a. For patients at risk of dementia, assess or refer for psychological testing to establish a baseline of cognitive, adaptive, and communicative functioning. Monitor with appropriate tools. <sup>179</sup>	III
	b. Educate family and other care providers about early signs of dementia. When signs are present, investigate for potential reversible causes of dementia.	III
	c. Consider referral to the appropriate specialist (ie, psychiatrist, neurologist) if it is unclear whether symptoms and behaviour are due to emotional disturbance, psychiatric disorder, or dementia. <sup>179</sup>	III

DD—developmental disabilities, GERD—gastroesophageal reflux disease.

**Promoting ethical practices.** Many disparities and challenges encountered by adults with DD in primary care stem not only from the paucity of information available to care providers but also from attitudes and practices that fall short of respecting the dignity of people with DD. The selection of updates was guided by the ethical framework adopted for the 2006 Guidelines, which emphasized respect for the dignity of adults with DD throughout their lives, the importance of their caregiving relationships and communities, and the need to take into account the health issues particular to them, individually and as a group. Thus, the 2006 Guidelines regarding informed and voluntary consent (guideline 7 in **Table 3**)<sup>1,2,9-180</sup> and advanced care planning (guideline 8) were amplified. The value of consulting, educating, and enlisting the support of caregivers underlies many updated recommendations. In making recommendations for management of particular health conditions of adults with DD, consideration was given to what would most likely benefit the overall health and well-being of these adults while involving the least possible risk of restrictions, harmful side effects, distress, and other burdens. This framework was relevant, for example, when considering decreasing the recommended frequency of tests in the 2006 Guidelines, such as those for glaucoma and thyroid disorder (in guidelines 11b and 19a), when it was unlikely to result in any substantial difference in detection rates. In other cases, references to tools that improve communication, adapt standard test procedures, or minimize the distress from interventions experienced by adults with DD were added to specific recommendations.

**New guidelines.** A new guideline on detecting pain and distress (guideline 4) was added, as pain and distress can manifest in atypical ways in adults with DD (eg, different physical cues or changes in behaviour).

Furthermore, new guidelines were included for screening and prevention of infectious diseases (guideline 20), cancer (guideline 21), and alcohol or drug abuse (guideline 30), because it has been shown that adults with DD are less likely than those in the general population to be included in preventive screening programs, to do self-examinations, or to report abnormalities or difficulties in these areas.<sup>4</sup>

The behavioural and mental health guidelines contain substantially more detail than in the 2006 Guidelines, with new categories added to address nonpharmaceutical interventions (guideline 26) and psychotropic and antipsychotic medications (guidelines 27 and 28). An important new recommendation (guideline 28a) rejects the routine use of antipsychotic medications for problem behaviour, specifically aggressive challenging behaviour, without a confirmed robust diagnosis of schizophrenia or other psychotic disorder.<sup>131</sup>

**Limitations and implications for future research.** The aim of these guidelines is to inform primary care providers of the most prevalent health issues of adults with DD as a group and of the best approaches to management. However, any such set of guidelines will always be limited in their application by the reality that adults with DD are not a homogeneous group nor do they experience health disorders in the same way. These guidelines are not meant to replace attentive observation and prudent clinical decisions. The most appropriate care for an adult with DD takes into account relevant factors in his or her particular circumstances. Furthermore, although these guidelines are generally applicable to adults with DD, primary care providers will need to address additional specific health issues when there is a known cause of DD.

The division of these guidelines into distinct physical, behavioural, and mental health categories was intended to facilitate their application. Several guidelines, however, address the interaction of physical factors with behavioural and mental health ones, and between these and environmental factors and other determinants of health. More research is needed into such interactions and their implications for the deployment of an interdisciplinary and holistic approach to primary care of adults with DD. A helpful advance for researchers has been the POMONA Project's identification of 18 measurable health indicators and the development of a survey tool for gathering health data for adults with DD across 14 European countries.<sup>181,182</sup>

Some of these updated guidelines recommend the use of resources and specialized services that, while generally available in Canada, might be lacking or inaccessible in some regional health service systems. In such circumstances, it is necessary to adapt these guidelines to allow primary care providers to provide a reasonable standard of care and to develop practical resource-sharing strategies (eg, using clinical videoconferencing).

Further study of the effect of the guidelines on improving primary care of adults with DD and their health outcomes is essential. The extent to which they are applied must be assessed, and when they are not used the reasons need to be determined. It is likely that a comprehensive approach involving the training of primary care providers in the content and use of these guidelines, developing clinical tools to help apply them, and establishing clinical support networks could work in concert to increase the use of these guidelines. Since 2005, the Ontario Ministry of Community and Social Services, the Ministry of Health and Long-Term Care, and Surrey Place Centre have been co-sponsoring the Developmental Disabilities Primary Care Initiative, which aims to integrate these various components. Evaluation of this initiative is being undertaken and should shed light on whether this comprehensive approach

promotes the application of these guidelines by primary care providers of adults with DD, changes their practices, and improves health outcomes.

People with disabling conditions, including those with DD, have been aptly described as being at risk of a double disadvantage. Having a debilitating health condition in many studies renders likely study participants ineligible, and research on DD is generally a low priority for researchers.<sup>183</sup> Most of the recommendations specifically concerning adults with DD in the updated guidelines are supported by level III evidence based on expert opinion or published consensus statements. Three are based on randomized controlled trials, systematic reviews, or meta-analysis (level I evidence), and 7 are based on less methodologically rigorous studies (level II). Even when level I or II evidence for recommendations for the general population was found, but no level I or II evidence relating specifically to people with DD, it was thought prudent, in view of differences between these 2 groups, to reject, adapt, or formulate new guidelines based on expert opinion (level III evidence) for these guidelines.

Ethical and practical difficulties in conducting research on people with DD have been discussed in some recent studies.<sup>184,185</sup> Because of the vulnerabilities of adults with DD, the ethical management of research involving their participation requires careful attention to the likelihood of benefit and of risks of substantial harm; issues surrounding consent, privacy, and confidentiality; and access to the benefits of the research findings.

## Conclusion

In order to remain relevant and useful clinically, guidelines for the primary care of adults with DD in Canada should be updated regularly in light of new findings in practice and research. As knowledge and experience are gained from primary care providers caring for adults with DD who are living longer and residing in greater numbers in the community, expert opinion and consensus will continue to be helpful in updating the guidelines. Ethical and high-quality research on primary care of adults with DD, however, remains an urgent priority.

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### Contributors

**Dr Sullivan** was the project lead and was responsible for the development of the initial concept as well as all aspects of the guideline development and revision. **Dr Berg** provided expert clinical and scholarly input throughout the development of the guidelines. **Dr Bradley** led the revision process of the behavioural and mental health section. **Dr Cheetham** provided expert clinical and editorial input during the revision process, including extensive review of published evidence. **Dr Denton** led the revision discussions surrounding the general guidelines, contributed to the guideline revision process, and provided input on final editorial decisions. **Mr Heng** played a lead role in all aspects of the project, including the draft and final revision process. **Dr Hennen** played a lead role in all aspects of the project. **Dr Joyce** led the revision discussions surrounding the physical health guidelines, reviewed the full text of all cited references, and provided substantial editorial input throughout the revision process. **Ms Kelly** provided critical coordination of the project and contributed substantially to all aspects of the revision process. **Ms Korossy** searched and screened the published literature, set up and organized the RefWorks database housing published evidence, and participated in all stages of the revision and editorial process. **Dr Lunskey** was co-lead of the revision process on the behavioural and mental health section from a psychology perspective. **Ms McMillan** contributed expert input throughout the revision process from a nursing perspective. All authors approved the final version for publication.

### Competing interests

None declared

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