

# Primary care of adults with developmental disabilities

## Canadian consensus guidelines

William F. Sullivan MD CCFP PhD Joseph M. Berg MBBCh MSc FRCPSych FCCMG Elspeth Bradley PhD MBBS FRCPC FRCPSych

Tom Cheetham MD CCFP Richard Denton MD CCFP FCFP FRRMS John Heng MA Brian Hennen MA MD CCFP

David Joyce MD CCFP Maureen Kelly RN MPA Marika Korossy Yona Lunsky PhD CPsych Shirley McMillan RN MN CDDN

### 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.

This article has been peer reviewed.  
Cet article a fait l'objet d'une révision par des pairs.  
*Can Fam Physician* 2011;57:541-53

La traduction en français de cet article se trouve à [www.cfp.ca](http://www.cfp.ca) dans la table des matières du numéro de mai 2011 à la page e154.

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

Continued on page 545

**Table 3** *continued from page 544*

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>	<p>a. Always assess capacity for consent when proposing investigations or treatments for which consent is required.<sup>41</sup></p>	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>	<p>b. Adapt the level and means of communicating to the patient's level of intellectual and adaptive functioning.<sup>43</sup></p>	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>	<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></p>	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>	<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></p>	III
	<p>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></p>	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>	<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></p>	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>	<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></p>	II
<p>A health promotion program can improve attitudes toward physical activity and satisfaction with life.<sup>55,56</sup></p>	<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></p>	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>	<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></p>	III
	<p>b. Refer for vision assessment to detect glaucoma and cataracts every 5 y after age 45.<sup>65</sup></p>	III
	<p>c. Refer for hearing assessment if indicated by screening and for age-related hearing loss every 5 y after age 45.<sup>65</sup></p>	III
	<p>d. Screen for and treat cerumen impaction every 6 mo.<sup>66,67</sup></p>	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>	<p>a. Promote regular oral hygiene practices and other preventive care (eg, fluoride application) by a dental professional.<sup>69-72</sup></p>	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>	<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></p>	III
<p>Some adults with DD have congenital heart disease and are susceptible to bacterial endocarditis.</p>	<p>b. Refer to a cardiologist or adult congenital heart disease clinic.<sup>75</sup></p>	III
	<p>c. Follow guidelines for antibiotic prophylaxis for those few patients who meet revised criteria.<sup>76</sup></p>	II

*Continued on page 546*

Table 3 continued from page 545

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>	<p>III</p> <p>II</p>
<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>	<p>III</p> <p>III</p>
<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>	<p>III</p> <p>III</p>
<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>	<p>III</p> <p>III</p>
<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>	<p>III</p> <p>III</p> <p>III</p>
<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>	<p>III</p> <p>III</p>
<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

Continued on page 547

Table 3 continued from page 546

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.

**Dr Sullivan** is a family physician at St Michael's Hospital and Surrey Place Centre in Toronto, Ont, Associate Professor at the University of Toronto, and a bioethicist. **Dr Berg** is Professor Emeritus in the Faculty of Medicine at the University of Toronto and a medical consultant at Surrey Place Centre. **Dr Bradley** is an intellectual disabilities psychiatrist, Associate Professor in the Department of Psychiatry at the University of Toronto, and Psychiatrist-in-Chief at Surrey Place Centre. **Dr Cheetham** is a family physician at Surrey Place Centre. **Dr Denton** is a family physician in Kirkland Lake, Ont, and Assistant Professor in Clinical Science in the Department of Family Medicine at the Northern Ontario School of Medicine. **Mr Heng** is a bioethicist who teaches philosophy and thanatology at King's University College at the University of Western Ontario in London, Ont. **Dr Hennen** is Professor of Family Medicine at Dalhousie University in Halifax, NS. **Dr Joyce** is a family physician and clinical investigator in the Department of Family Medicine at the University of British Columbia in Vancouver, BC. **Ms Kelly** is Project Coordinator of the Developmental Disabilities Primary Care Initiative at Surrey Place Centre. **Ms Korossy** is the librarian at Surrey Place Centre. **Dr Lunskey** is Clinician

Scientist at the Centre for Addiction and Mental Health in Toronto, Adjunct Scientist at the Institute for Clinical and Evaluative Sciences, and Associate Professor at the University of Toronto. **Ms McMillan** is Mental Health Nurse Specialist at Surrey Place Centre.

### Acknowledgment

These updated guidelines are a product of the Colloquium on Guidelines for the Primary Health Care of Adults with Developmental Disabilities held on March 20, 2009, in Toronto, Ont, and attended by the following participants: **R. Balogh, M. Bissell, E. Bradley, T. Broda, S. Campbell, D. Champ, T. Cheetham, K. Cowan, R. Denton, L. Dunn, A. Fewster, C. Forster-Gibson, E. Ghazal, G. Gillis, E. Grier, J. Heng, B. Hennen, B. Isaacs, J. Jones, D. Joyce, M. Kelly, M. Korossy, M. Limbos, D. Lougheed, J. Ludlow, Y. Lunskey, S. McMillan, S. Morris, J. Nachshen, T. O'Driscoll, H. Ouellette-Kuntz, S. Perreault, J. Rao, S. Stemp, L. Tao, V. Temple, A. Veltman, and M. Westerhof.** The project was supported by the Ontario Ministry of Community and Social Services, the Ministry of Health and Long-Term Care, Surrey Place Centre, and the Surrey Place Centre Foundation.

### 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

### Correspondence

**Dr William Sullivan**, Surrey Place Centre, 2 Surrey Place, Toronto, ON M5S 2C2; fax 416 923-8476; e-mail [bill.sullivan@surreyplace.on.ca](mailto:bill.sullivan@surreyplace.on.ca)

### References

1. The AAIDD Ad Hoc Committee on Terminology and Classification, editor. *Intellectual disability: definition, classification, and systems of supports*. 11th ed. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2010.
2. Ouellette-Kuntz H, Garcin N, Lewis ME, Minnes P, Martin C, Holden JJ. Addressing health disparities through promoting equity for individuals with intellectual disability. *Can J Public Health* 2005;96(Suppl 2):S8-22.
3. Haveman MJ, Heller T, Lee LA, Maaskant MA, Shoostari S, Stydom A. *Report of the state of science on health risks and ageing in people with intellectual disabilities*. Dortmund, Germany: IASSID Special Interest Research Group on Ageing and Intellectual Disabilities, Faculty of Rehabilitation Sciences, University of Dortmund; 2009. Available from: [www.iaassid.org/pdf/SSCA\\_on\\_Health\\_Risks\\_report\\_final.pdf](http://www.iaassid.org/pdf/SSCA_on_Health_Risks_report_final.pdf). Accessed 2009 Jul 2.
4. Iacono T, Sutherland G. Health screening and developmental disabilities. *J Policy Pract Intell Disabil* 2006;3(3):155-63.
5. Scheepers M, Kerr M, O'Hara D, Bainbridge D, Cooper S, Davis R, et al. Reducing health disparity in people with intellectual disabilities: a report from Health Issues Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *J Policy Pract Intell Disabil* 2005;2(3-4):249-55.
6. United Nations. *Convention on the rights of persons with disabilities*. New York, NY: United Nations; 2006. Available from: [www.un.org/disabilities/default.asp?navid=13&pid=150](http://www.un.org/disabilities/default.asp?navid=13&pid=150). Accessed 2010 Sep 14.
7. Sullivan WF, Heng J, Cameron D, Lunskey Y, Cheetham T, Hennen B, et al. Consensus guidelines for primary health care of adults with developmental disabilities. *Can Fam Physician* 2006;52(11):1410-8.
8. POMONA Partnership. *POMONA II. Health indicators for people with intellectual disability: using an indicator set (final report)*. POMONA Partnership; 2008. Available from: [www.pomonaproject.org](http://www.pomonaproject.org). Accessed 2011 Apr 7.
9. Lennox N, Bain C, Rey-Conde T, Purdie D, Bush R, Pandeya N. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *Int J Epidemiol* 2007;36(1):139-46. Epub 2007 Jan 11.
10. Dubev V, Mathew R, Iglar K, Moineddin R, Glazier R. Improving preventive service delivery at adult complete health check-ups: the Preventive Health Evidence-based Recommendation Form (PERFORM) cluster randomized controlled trial. *BMC Fam Pract* 2006;7:44.
11. Iglar K, Katyal S, Mathew R, Dubev V. Complete health checkup for adults: update on the Preventive Care Checklist Form. *Can Fam Physician* 2008;54:84-8.
12. Cassidy SB, Allanson JE, editors. *Management of genetic syndromes*. 3rd ed. New York, NY: Wiley-Blackwell; 2010.

13. Lopez-Rangel E, Mickelson EC, Lewis ME. The value of a genetic diagnosis for individuals with intellectual disabilities: optimising healthcare and function across the lifespan. *Br J Dev Disabil* 2008;54(2):69-82.
14. Baty BJ, Carey JC, McMahon WM. Neurodevelopmental disorders and medical genetics. In: Goldstein S, Reynolds CR, editors. *Handbook of neurodevelopmental and genetic disorders in adults*. New York, NY: Guilford Press; 2005. p. 50-1.
15. Curry CJ, Stevenson RE, Aughton D, Byrne J, Carey JC, Cassidy S, et al. Evaluation of mental retardation: recommendations of a Consensus Conference: American College of Medical Genetics. *Am J Med Genet* 1997;72(4):468-77.
16. Diraimo J, Provincial IODE Genetics Resource Centre, London Health Sciences Centre. *Genetic resources Ontario* [website]. London, ON: London Health Sciences Centre; 2009. Available from: [www.geneticresourcesontario.ca](http://www.geneticresourcesontario.ca). Accessed 2009 Apr 28.
17. University of Washington. *GeneReviews: medical genetics information resource* [database online]. Seattle, WA: University of Washington; 1993. Available from: [www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=gene](http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=gene). Accessed 2009 Apr 14.
18. Dawson AJ, Riordan D, Tomiuk M, Konklin D, Anderson T, Bocangel P, et al. Cytogenetic microarrays in Manitoba patients with developmental delay. *Clin Genet* 2009;75(5):498-500.
19. Moeschler JB. Genetic evaluation of intellectual disabilities. *Semin Pediatr Neurol* 2008;15(1):2-9.
20. Borthwick-Duffy SA. Adaptive behavior. In: Jacobson JW, Mulick JA, Rojahn J, editors. *Handbook of intellectual and developmental disabilities*. New York, NY: Springer; 2007. p. 279-93.
21. Fletcher R, Loschen E, Stavrakaki C, First M, editors. *DM-ID: diagnostic manual—intellectual disability: a textbook of diagnosis of mental disorders in persons with intellectual disability*. Kingston, NY: NADD Press; 2007.
22. The AAIDD Ad Hoc Committee on Terminology and Classification. Adaptive behavior and its assessment. In: *Intellectual disability: definition, classification, and systems of supports*. 11th ed. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2010. p. 43-55.
23. Breau LM, Camfield CS, McGrath PJ, Finley GA. The incidence of pain in children with severe cognitive impairments. *Arch Pediatr Adolesc Med* 2003;157(12):1219-26.
24. Bodfish JW, Harper VN, Deacon JM, Deacon JR, Symons FJ. Issues in pain assessment for adults with severe to profound mental retardation: from research to practice. In: Oberlander TF, Symons FJ, editors. *Pain in children and adults with developmental disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co; 2006. p. 173-92.
25. Jones S, Cooper SA, Smiley E, Allan L, Williamson A, Morrison J. Prevalence of, and factors associated with, problem behaviors in adults with intellectual disabilities. *J Nerv Ment Dis* 2008;196(9):678-86.
26. Regnard D, Matthews D, Gibson L. Learning Disability and Palliative Care Team at Northgate Hospital. *DisDAT: Disability Distress Assessment Tool*. Northumberland, UK: Northumberland Tyne & Wear Trust, St Oswald's Hospice; 2008. Available from: [www.disdat.co.uk](http://www.disdat.co.uk). Accessed 2009 May 14.
27. 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.
28. Lotan M, Ljunggren EA, Johnsen TB, Defrin R, Pick CG, Strand LI. A modified version of the Non-Communicating Children Pain Checklist-Revised, adapted to adults with intellectual and developmental disabilities: sensitivity to pain and internal consistency. *J Pain* 2009;10(4):398-407. Epub 2009 Feb 8.
29. 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(4):735-45. Epub 2008 Nov 25.
30. Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *J Intellect Disabil Res* 2007;51(Pt 4):277-92.
31. Van der Heide DC, van der Putten AA, van den Berg PB, Taxis K, Vlaskamp C. The documentation of health problems in relation to prescribed medication in people with profound intellectual and multiple disabilities. *J Intellect Disabil Res* 2009;53(2):161-8. Epub 2008 Dec 10.
32. Lennox N. Developmental Disability Steering Group. Preventive health care and health promotion. In: *Management guidelines: developmental disability*. Version 2. Melbourne, Australia: Therapeutic Guidelines; 2005. p. 95-9.
33. Beange H, Lennox N, Parmenter TR. Health targets for people with an intellectual disability. *J Intellect Dev Disabil* 1999;24(4):283-97.
34. Bhaumik S, Branford D. Prescribing practice and physical monitoring. In: *The Frith prescribing guidelines for adults with intellectual disability*. 2nd ed. London, UK: HealthComm UK Ltd; 2008. p. 7-32.
35. 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 Co; 2007. p. 467-87.
36. Horner-Johnson W, Drum CE. Prevalence of maltreatment of people with intellectual disabilities: a review of recently published research. *Ment Retard Dev Disabil Res Rev* 2006;12(1):57-69.
37. McCarthy M. Sexuality. In: Walsh P, Heller T, editors. *Health of women with intellectual disabilities*. Oxford, UK: Blackwell Science; 2002. p. 90-102.
38. McCormack B, Kavanagh D, Caffrey S, Power A. Investigating sexual abuse: findings of a 15-year longitudinal study. *J Appl Res Intellect Disabil* 2005;18(3):217-27.
39. Sobsey D. *Family violence and people with intellectual disabilities*. Ottawa, ON: National Clearinghouse on Family Violence, Public Health Agency of Canada; 2002. Available from: [www.phac-aspc.gc.ca/ncfv-cnivf/pdfs/fv-intellectu\\_e.pdf](http://www.phac-aspc.gc.ca/ncfv-cnivf/pdfs/fv-intellectu_e.pdf). Accessed 2009 Jul 21.
40. Heng J, Sullivan WF. Ethics of consent in people with intellectual and developmental disabilities. In: Brown I, Percy M, editors. *A comprehensive guide to intellectual and developmental disabilities*. Baltimore, MD: Paul H. Brookes Publishing; 2007. p. 619-27.
41. Friedman RI. Use of advance directives: facilitating health care decisions by adults with mental retardation and their families. *Ment Retard* 1998;36(6):444-56.
42. Tuffrey-Wijne I, McEnhill L. Communication difficulties and intellectual disability in end-of-life care. *Int J Palliat Nurs* 2008;14(4):189-94.
43. Van Schroyen Lantman-de Valk HM, Walsh PN. Managing health problems in people with intellectual disabilities. *BMJ* 2008;337:a2507.
44. Rush AJ, Frances A. Guideline 2: informed consent. Expert Consensus Guideline Series: treatment of psychiatric and behavioral problems in mental retardation. *Am J Ment Retard* 2000;105(3):169.
45. Friedman SL, Helm DT, editors. *End-of-life care for children and adults with intellectual and developmental disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities; 2010.
46. Crocker AC. Systems of medical care delivery. In: Rubin IL, Crocker AC, editors. *Medical care for children and adults with developmental disabilities*. 2nd ed. Baltimore, MA: Paul H. Brookes Publishing Co; 2006. p. 57-9.
47. Drotar DD, Sturm LA. Interdisciplinary collaboration in the practice of mental retardation. In: Jacobson JW, Mulick JA, editors. *Manual of diagnosis and professional practice in mental retardation*. Washington, DC: American Psychological Association; 1996. p. 393-401.
48. Ministry of Community and Social Services [website]. *Our regional offices. Programs for adults with a developmental disability*. Toronto, ON: Ministry of Community and Social Services; 2008. Available from: [www.mcsc.gov.on.ca/en/mcsc/regionalMap/index.aspx](http://www.mcsc.gov.on.ca/en/mcsc/regionalMap/index.aspx). Accessed 2009 Sep 17.
49. Ministry of Community and Social Services [website]. *Community Networks of Specialized Care*. Toronto, ON: Community Networks of Specialized Care; 2009. Available from: [www.community-networks.ca](http://www.community-networks.ca). Accessed 2009 Jul 21.
50. Rimmer JH, Yamaki K. Obesity and intellectual disability. *Ment Retard Dev Disabil Res Rev* 2006;12(1):22-7.
51. Haveman M, Heller T, Lee L, Maaskant M, Shoostari S, Strydom A. Major health risks in aging persons with intellectual disabilities: an overview of recent studies. *J Policy Pract Intell Disabil* 2010;7(1):59-69.
52. Emerson E. Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *J Intellect Disabil Res* 2005;49(Pt 2):134-43.
53. Health Canada. *Canadian guidelines for body weight classification in adults*. Ottawa, ON: Health Canada; 2003. Available from: [www.hc-sc.gc.ca/fn-an/nutrition/weights-poids/guide-ld-adult/weight\\_book\\_tc-livres\\_des\\_poids\\_tm-eng.php](http://www.hc-sc.gc.ca/fn-an/nutrition/weights-poids/guide-ld-adult/weight_book_tc-livres_des_poids_tm-eng.php). Accessed 2009 Jul 14.
54. Bhaumik S, Watson JM, Thorp CF, Tyrer F, McGrother CW. Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study. *J Intellect Disabil Res* 2008;52(Pt 4):287-98.
55. Heller T, Hsieh K, Rimmer JH. Attitudinal and psychosocial outcomes of a fitness and health education program on adults with Down syndrome. *Am J Ment Retard* 2004;109(2):175-85.
56. Marks B, Sisirak J, Heller T. *Health matters: the exercise, nutrition, and health education curriculum for people with developmental disabilities* [CD-ROM with instructor references and participant handouts]. Baltimore, MD: Paul H. Brookes Publishing Co; 2010.
57. Healthy Living Unit, Public Health Agency of Canada. *Canada's physical activity guide*. Ottawa, ON: Public Health Agency of Canada; 2003. Available from: [www.phac-aspc.gc.ca/hp-ps/hl-mvs-pag-gap/downloads-eng.php](http://www.phac-aspc.gc.ca/hp-ps/hl-mvs-pag-gap/downloads-eng.php). Accessed 2009 Jul 14.
58. Hamilton S, Hankey CR, Miller S, Boyle S, Melville CA. A review of weight loss interventions for adults with intellectual disabilities. *Obes Rev* 2007;8(4):339-45.
59. Henderson CM, Robinson LM, Davidson PW, Haveman M, Janicki MP, Albertini G. Overweight status, obesity, and risk factors for coronary heart disease in adults with intellectual disability. *J Policy Pract Intell Disabil* 2008;5(3):174-7.
60. Evenhuis HM, Sjoukes L, Koot HM, Kooijman AC. Does visual impairment lead to additional disability in adults with intellectual disabilities? *J Intellect Disabil Res* 2009;53(1):19-28. Epub 2008 Sep 3.
61. Van Splunder J, Stijma JS, Bernsen RM, Evenhuis HM. Prevalence of ocular diagnoses found on screening 1539 adults with intellectual disabilities. *Ophthalmology* 2004;111(8):1457-63.
62. Van Splunder J, Stijma JS, Bernsen RM, Evenhuis HM. Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study. *Eye (Lond)* 2006;20(9):1004-10. Epub 2005 Sep 9.
63. Warburg M. Visual impairment in adult people with intellectual disability: literature review. *J Intellect Disabil Res* 2001;45(Pt 5):424-38.
64. Warburg M. Visual impairment in adult people with moderate, severe, and profound intellectual disability. *Acta Ophthalmol Scand* 2001;79(5):450-4.
65. Evenhuis HM, Natzgaam LM. *IASSID international consensus statement: early identification of hearing and visual impairment in children and adults with an intellectual disability*. Leiden, The Netherlands: International Association of Scientific Studies on Intellectual Disability, Special Interest Group on Health Issues; 1997. Available from: [www.iassid.org/pdf/consensir.alg.doc](http://www.iassid.org/pdf/consensir.alg.doc). Accessed 2008 Jul 10.
66. 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.
67. Roland PS, Smith TL, Schwartz SR, Rosenfeld RM, Ballachanda B, Earll JM, et al. Clinical practice guideline: cerumen impaction. *Otolaryngol Head Neck Surg* 2008;139(3 Suppl 2):S1-21.
68. Owens PL, Kerker BD, Zigler E, Horwitz SM. Vision and oral health needs of individuals with intellectual disability. *Ment Retard Dev Disabil Res* 2006;12(1):28-40.
69. Ismail AI, Lewis DW, Dingle JL. Prevention of periodontal disease. In: Canadian Task Force on the Periodic Health Examination, editor. *Canadian guide to clinical preventive health care*. Ottawa, ON: Health Canada; 1994. p. 420-31. Available from: [www.phac-aspc.gc.ca/publicat/clinic-clinique/pdf/s4c37e.pdf](http://www.phac-aspc.gc.ca/publicat/clinic-clinique/pdf/s4c37e.pdf). Accessed 2009 Aug 6.
70. Lewis DW, Ismail AI. Prevention of dental caries. In: Canadian Task Force on the Periodic Health Examination, editor. *Canadian guide to clinical preventive health care*. Ottawa, ON: Health Canada; 1994. p. 407-17. Accessed 2009 Aug 6.
71. Dougherty N, MacRae R. Providing dental care to patients with developmental disabilities. An introduction for the private practitioner. *N Y State Dent J* 2006;72(2):29-32. Available from: [www.nysdental.org/publications/archive-popup.cfm?ID=25](http://www.nysdental.org/publications/archive-popup.cfm?ID=25). Accessed 2011 Apr 7.
72. Glassman P, Miller C. Dental disease prevention and people with special needs. *J Calif Dent Assoc* 2003;31(2):149-60. Available from: [www.cda.org/library/cda\\_member/pubs/journal/jour0203/glassman.htm](http://www.cda.org/library/cda_member/pubs/journal/jour0203/glassman.htm). Accessed 2011 Apr 7.
73. Wallace RA, Schluter P. Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *J Intellect Dev Disabil* 2008;33(1):48-58.
74. Draheim CC. Cardiovascular disease prevalence and risk factors of persons with mental retardation. *Ment Retard Dev Disabil Res Rev* 2006;12(1):3-12.
75. Canadian Adult Congenital Health Network [website]. *Find a centre*. Mississauga, ON: CACH Network; 2009. Available from: [www.cachnet.org/centres.shtml](http://www.cachnet.org/centres.shtml). Accessed 2009 Sep 24.

76. Wilson W, Taubert KA, Gewitz M, Lockhart PB, Baddour LM, Levison M, et al. Prevention of infective endocarditis: guidelines from the American Heart Association: a guideline from the American Heart Association Rheumatic Fever, Endocarditis and Kawasaki Disease Committee, Council on Cardiovascular Disease in the Young, and the Council on Clinical Cardiology, Council on Cardiovascular Surgery and Anesthesia, and the Quality of Care and Outcomes Research Interdisciplinary Working Group. *J Am Dent Assoc* 2007;138(6):739-45, 747-60.
77. 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.
78. Waltz DA, Katz ES. Pulmonology. In: Rubin IL, Crocker AC, editors. *Medical care for children and adults with developmental disabilities*. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co; 2006. p. 325-42.
79. Patja K, Mölsä 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.
80. Chadwick DD, Jolliffe J. A descriptive investigation of dysphagia in adults with intellectual disabilities. *J Intellect Disabil Res* 2009;53(11):29-43. Epub 2008 Aug 28.
81. Lennox N; Developmental Disability Steering Group. Gastrointestinal problems. In: *Management guidelines: developmental disability*. Version 2. Melbourne, Australia: Therapeutic Guidelines; 2005. p. 65-71.
82. 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.
83. Wallace R, Schluter PJ, Duff M, Ouellette-Kuntz H, Webb PM. A review of the risk factors for, consequences, diagnosis, and management of Helicobacter pylori in adults with intellectual disabilities. *J Policy Pract Intell Disabil* 2004;1(3-4):147-63.
84. Böhmer CJ, Klinkenberg-Knol EC, Niezen-de Boer MC, Meuwissen SG. Gastroesophageal reflux disease in intellectually disabled individuals: how often, how serious, how manageable? *Am J Gastroenterol* 2000;95(8):1868-72.
85. Bourke B, Ceronis P, Chiba N, Czinn S, Ferraro R, Fischbach L, et al. Canadian Helicobacter Study Group Consensus Conference: update on the approach to Helicobacter pylori infection in children and adolescents—an evidence-based evaluation. *Can J Gastroenterol* 2005;19(7):399-408. Erratum in: *Can J Gastroenterol* 2005;19(8):478.
86. Kitchens DH, Binkley CJ, Wallace DL, Darling D. Helicobacter pylori infection in people who are intellectually and developmentally disabled: a review. *Spec Care Dentist* 2007;27(4):127-33.
87. Griffiths D. Sexuality and people who have intellectual disabilities. In: Brown I, Percy M, editors. *A comprehensive guide to intellectual and developmental disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co; 2007. p. 573-83.
88. The Children's Learning Disability Nursing Team, Leeds. *Puberty & sexuality for children and young people with learning disabilities*. Leeds, UK: NHS Leeds; 2009. Available from: [www.sexualhealthsheffield.nhs.uk/resources/pubertyandsexualitypack.pdf](http://www.sexualhealthsheffield.nhs.uk/resources/pubertyandsexualitypack.pdf). Accessed 2010 Feb 25.
89. Wilkinson JE, Cerreto MC. Primary care for women with intellectual disabilities. *J Am Board Fam Med* 2008;21(3):215-22.
90. Cox RL, Signore C, Quint E. *Interactive site for clinicians serving women with disabilities* [website]. Washington, DC: American Congress of Obstetricians and Gynecologists; 2011. Available from: [www.acog.org/departments/dept\\_notice.cfm?recno=38&bulletin=4526](http://www.acog.org/departments/dept_notice.cfm?recno=38&bulletin=4526). Accessed 2010 May 11.
91. 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.
92. O'Neil ME, Fragala-Pinkham MA, Westcott SL, Martin K, Chiarello LA, Valvano J, et al. Physical therapy clinical management recommendations for children with cerebral palsy—spastic diplegia: achieving functional mobility outcomes. *Pediatr Phys Ther* 2006;18(1):49-72.
93. Leslie WD, Pahlavan PS, Roe EB, Dittberner K. Bone density and fragility fractures in patients with developmental disabilities. *Osteoporos Int* 2009;20(3):379-83. Epub 2008 Jul 16.
94. Brown JP, Josse RG; Scientific Advisory Council of the Osteoporosis Society of Canada. 2002 clinical practice guidelines for the diagnosis and management of osteoporosis in Canada. *CMAJ* 2002;167(10 Suppl):S1-34. Errata in: *CMAJ* 2002;167(4):400, *CMAJ* 2002;167(5):544, *CMAJ* 2002;167(6):676.
95. 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(Pt 6):457-62.
96. Zylstra RG, Porter LL, Shapiro JL, Prater CD. Prevalence of osteoporosis in community-dwelling individuals with intellectual and/or developmental disabilities. *J Am Med Dir Assoc* 2008;9(2):109-13.
97. McCarthy M. I have the job so I can't be blamed for getting pregnant': contraception and women with learning disabilities. *Womens Stud Int Forum* 2009;32(3):198-208.
98. Janicki MP, Davidson PW, Henderson CM, McCallion P, Taets JD, Force LT, et al. Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *J Intellect Disabil Res* 2002;46(Pt 4):287-98.
99. Alvarez N. Epilepsy. In: Rubin IL, Crocker AC, editors. *Medical care for children and adults with developmental disabilities*. 2nd ed. Baltimore, MD: Paul H. Brookes Publishing Co; 2006. p. 255-71.
100. Burnham WM. Epilepsy. In: Brown I, Percy M, editors. *A comprehensive guide to intellectual and developmental disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co; 2007. p. 287-94.
101. Kerr M, Scheepers M, Arvio M, Beavis J, Brandt C, Brown S, et al. Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *J Intellect Disabil Res* 2009;53(8):687-94.
102. Prasher VP, Kerr MP, editors. *Epilepsy and intellectual disabilities*. New York, NY: Springer; 2008.
103. Epilepsy Canada [website]. *Coping*. Toronto, ON: Epilepsy Canada. Available from: [www.epilepsy.ca/eng/mainSet.html](http://www.epilepsy.ca/eng/mainSet.html). Accessed 2009 Sep 29.
104. Prasher V, Gomez G. Natural history of thyroid function in adults with Down syndrome—10-year follow-up study. *J Intellect Disabil Res* 2007;51(Pt 4):312-7.
105. McElduff A, Beange H. Men's health and well-being: testosterone deficiency. *J Intellect Dev Disabil* 2003;28(2):211-3.
106. McElduff A, Center J, Beange H. Hypogonadism in men with intellectual disabilities: a population study. *J Intellect Dev Disabil* 2003;28(2):163-70.
107. 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.
108. McDermott S, Moran R, Platt T, Dasari S. Prevalence of diabetes in persons with disabilities in primary care. *J Dev Phys Disabil* 2007;19(3):263-71.
109. McDermott S, Moran RR, Platt T. Diabetes. In: *The epidemiology of common health conditions among adults with developmental disabilities in primary care*. New York, NY: Nova Biomedical Books; 2008. p. 42-50.
110. Lennox N, Edie G, Taylor M, Rey-Conde T, McPhee J. Diabetes, to the point: designing a website about diabetes for adults with intellectual disability and carers. *Technol Disabil* 2009;21(1-2):11-8.
111. Queensland Centre for Intellectual and Developmental Disability. *Diabetes to the point*. Brisbane, Australia: University of Queensland. Available from: [www2.som.uq.edu.au/som/Research/ResearchCentres/qcidd/DiabetesToThePoint/Pages/default.aspx](http://www2.som.uq.edu.au/som/Research/ResearchCentres/qcidd/DiabetesToThePoint/Pages/default.aspx). Accessed 2010 Aug 4.
112. Sode-Carlsen R, Farholt S, Rabben KF, Bollerslev J, Schreiner T, Jurik AG, et al. Body composition, endocrine and metabolic profiles in adults with Prader-Willi syndrome. *Growth Horm IGF Res* 2010;20(3):179-84. Epub 2010 Mar 3.
113. Lewis MA, Lewis CE, Leake B, King BH, Lindemann R. The quality of health care for adults with developmental disabilities. *Public Health Rep* 2002;117(2):174-84.
114. Langley JM, Faughnan ME; Canadian Task Force on Preventive Health Care. Prevention of influenza in the general population: recommendation statement from the Canadian Task Force on Preventive Health Care. *CMAJ* 2004;171(10):1169-70.
115. National Advisory Committee on Immunization. *Canadian immunization guide*. 7th ed. Ottawa, ON: Public Health Agency of Canada; 2006. Available from: [www.phac-aspc.gc.ca/naci-cnci/index-eng.php](http://www.phac-aspc.gc.ca/naci-cnci/index-eng.php). Accessed 2009 Jul 16.
116. World Health Organization. 23-valent pneumococcal polysaccharide vaccine. WHO position paper. *Wkly Epidemiol Rec* 2008;83(42):373-84.
117. National Advisory Committee on Immunization. Statement on human papillomavirus vaccine. An Advisory Committee Statement (ACS). *Can Commun Dis Rep* 2007;33(ACS-2):1-32.
118. Mast EE, Weinbaum CM, Fiore AE, Alter MJ, Bell BP, Finelli L, et al. A comprehensive immunization strategy to eliminate transmission of hepatitis B virus infection in the United States: recommendations of the Advisory Committee on Immunization Practices (ACIP) part II: immunization of adults. *MMWR Recomm Rep* 2006;55(RR-16):1-33.
119. Advisory Committee on Immunization Practices (ACIP), Fiore AE, Watsley A, Bell BP. Prevention of hepatitis A through active or passive immunization: recommendations of the Advisory Committee on Immunization Practices (ACIP). *MMWR Recomm Rep* 2006;55(RR-7):1-23.
120. Sullivan SG, Hussain R, Threlfall T, Bittles AH. The incidence of cancer in people with intellectual disabilities. *Cancer Causes Control* 2004;15(10):1021-5.
121. Quint EH, Elkens TE. Cervical cytology in women with mental retardation. *Obstet Gynecol* 1997;89(1):123-6.
122. Morrison BJ. Screening for breast cancer. In: Canadian Task Force on the Periodic Health Examination, editor. *Canadian guide to clinical preventive health care*. Ottawa, ON: Health Canada; 1994. p. 788-95. Available from: [www.phac-aspc.gc.ca/publicat/clinique/pdf/s10c65e.pdf](http://www.phac-aspc.gc.ca/publicat/clinique/pdf/s10c65e.pdf). Accessed 2009 Aug 25.
123. Elford RW. Screening for testicular cancer. In: Canadian Task Force on the Periodic Health Examination, editor. *Canadian guide to clinical preventive health care*. Ottawa, ON: Health Canada; 1994. p. 892-8. Available from: [www.phac-aspc.gc.ca/publicat/clinique/pdf/s10c74e.pdf](http://www.phac-aspc.gc.ca/publicat/clinique/pdf/s10c74e.pdf). Accessed 2009 Dec 11.
124. Feightner JW. Screening for prostate cancer. In: Canadian Task Force on the Periodic Health Examination, editor. *Canadian guide to clinical preventive health care*. Ottawa, ON: Health Canada; 1994. p. 892-8. Available from: [www.phac-aspc.gc.ca/publicat/clinique/pdf/s10c67e.pdf](http://www.phac-aspc.gc.ca/publicat/clinique/pdf/s10c67e.pdf). Accessed 2009 Aug 25.
125. Leddin D, Hunt R, Champion M, Cockeram A, Flook N, Gould M, et al. Canadian Association of Gastroenterology and the Canadian Digestive Health Foundation: guidelines on colon cancer screening. *Can J Gastroenterol* 2004;18(2):93-9.
126. Hemmings CP, Gravestock S, Pickard M, Bouras N. Psychiatric symptoms and problem behaviours in people with intellectual disabilities. *J Intellect Disabil Res* 2006;50(Pt 4):269-76.
127. Bradley EA, Hollins S. Assessment of patients with intellectual disabilities. In: Goldbloom DS, editor. *Psychiatric clinical skills*. Revised 1st ed. Toronto, ON: Centre for Addiction and Mental Health; 2010. p. 257-76.
128. Banks R, Bush A, Baker P, Bradshaw J, Carpenter P, Deb S, et al. *Challenging behaviour: a unified approach*. London, UK: Royal College of Psychiatrists, British Psychological Society, Royal College of Speech and Language Therapists; 2007. Available from: [www.rcpsych.ac.uk/files/pdfversion/cr144.pdf](http://www.rcpsych.ac.uk/files/pdfversion/cr144.pdf). Accessed 2008 Aug 19.
129. Matson JL, Neal D. Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: an overview. *Res Dev Disabil* 2009;30(3):572-86. Epub 2008 Oct 8.
130. Tsiouris JA. Pharmacotherapy for aggressive behaviours in persons with intellectual disabilities: treatment or mistreatment? *J Intellect Disabil Res* 2010;54(1):1-16. Epub 2009 Dec 8.
131. Tyrer P, Oliver-African 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.
132. Deb S, Clarke D, Unwin G. *Using medication to manage behaviour problems among adults with a learning disability: quick reference guide (QRG)*. Birmingham, UK: University of Birmingham; 2006. Available from: [www.ld-medication.bham.ac.uk/downloads.shtml](http://www.ld-medication.bham.ac.uk/downloads.shtml). Accessed 2008 Jul 8.
133. Deb S, Kwok H, Bertelli M, Salvador-Carull 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. Available from: [www.ncbi.nlm.nih.gov/pmc/articles/PMC2758582/pdf/wpa030181.pdf](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2758582/pdf/wpa030181.pdf). Accessed 2011 Apr 7.
134. Deb S, Matthews T, Holt G, Bouras N. *Practice guidelines for the assessment and diagnosis of mental health problems in adults with intellectual disability*. Brighton, UK: Pavilion; 2001.
135. Royal College of Psychiatrists. *DC-LD: diagnostic criteria for psychiatric disorders for use with adults with learning disabilities/mental retardation*. London, UK: Gaskell; 2001.
136. Aman MG, Burrow WH, Wolford PL. The Aberrant Behavior Checklist-Community: factor validity and effect of subject variables for adults in group homes. *Am J Ment Retard* 1995;100(3):283-92.

137. Moss S, Prosser H, Costello H, Simpson N, Patel P, Rowe S, et al. Reliability and validity of the PAS-ADD checklist for detecting psychiatric disorders in adults with intellectual disability. *J Intellect Disabil Res* 1998;42(Pt 2):173-83.
138. Mohr C, Costello H. Mental health assessment and monitoring tools for people with intellectual disabilities. In: Bouras N, Holt G, editors. *Psychiatric and behavioural disorders in intellectual and developmental disabilities*. 2nd ed. Cambridge, UK: Cambridge University Press; 2007. p. 24-41.
139. Perez-Achiaga N, Nelson S, Hassiotis A. Instruments for the detection of depressive symptoms in people with intellectual disabilities: a systematic review. *J Intellect Disabil* 2009;13(1):55-76.
140. Hodapp RM, Dykens EM. Behavioral effects of genetic mental retardation disorders. In: Jacobson JW, Mulick JA, Rojahn J, editors. *Handbook of intellectual and developmental disabilities*. New York, NY: Springer; 2007. p. 115-31.
141. O'Brien G. *Behavioural phenotypes in adulthood*. London, UK: St George's, University of London; 2003. Available from: [www.intellectualdisability.info/mental-health/behavioural-phenotypes-in-adulthood](http://www.intellectualdisability.info/mental-health/behavioural-phenotypes-in-adulthood). Accessed 2009 Dec 15.
142. O'Brien G. *Behavioural phenotypes in clinical practice*. London, UK: Mac Keith; 2002.
143. Society for the Study of Behavioural Phenotypes. *SSBP syndrome information sheets*. Cambridge, UK: SSBP Online. Available from: [www.ssbp.co.uk/ssbp/pages/syndrome-sheets.php](http://www.ssbp.co.uk/ssbp/pages/syndrome-sheets.php). Accessed 2009 Jun 18.
144. 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, Engl: Wiley-Blackwell; 2009. p. 51-66.
145. Myers B. Psychotic disorders in people with mental retardation: diagnostic and treatment issues. *Ment Health Aspects Dev Disabil* 1999;2(1):1-11.
146. Lunskey 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.
147. Deb S, Thomas M, Bright C. Mental disorder in adults with intellectual disability. 1: prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *J Intellect Disabil Res* 2001;45(Pt 6):495-505.
148. Hurley AD. Psychotic features in persons with mental retardation. In: Fletcher R, Griffiths D, Nagy-McNelia D, editors. *On the dawn of a new era: reflecting on the past, moving toward the future: 16th annual conference—Niagara Falls Ontario, Canada (November 1999)*. New York, NY: NADD; 1999. p. 30-2.
149. Craft MJ, Bicknell DJ, Hollins S. *Mental handicap: a multi-disciplinary approach*. London, UK: Baillière Tindall; 1985.
150. 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. Available from: [www.naddontario.org/pdf/EnglishPublication/Chapter10.pdf](http://www.naddontario.org/pdf/EnglishPublication/Chapter10.pdf). Accessed 2011 Mar 23.
151. Crossley R, Withers P. Antipsychotic medication and people with intellectual disabilities: their knowledge and experiences. *J Appl Res Intellect Disabil* 2009;22(1):77-86.
152. Parish SL, Moss K, Richman EL. Perspectives on health care of adults with developmental disabilities. *Intellect Dev Disabil* 2008;46(6):411-26.
153. Summers J, Stavrakaki C, Griffiths D, Cheetham T. Comprehensive screening and assessment. 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. 151-92. Available from: [www.naddontario.org/pdf/EnglishPublication/Chapter5.pdf](http://www.naddontario.org/pdf/EnglishPublication/Chapter5.pdf). Accessed 2011 Mar 23.
154. Hurley AD. Using the ABC sheet to analyze behavior: a training guide. *Habilit Ment Healthc News* 1997;16(5):81-9.
155. Gardner WI, Graeber-Whalen JL, Ford DR. Behavioral therapies: individualizing interventions through treatment formulations. In: Dosen A, Day K, editors. *Treating mental illness and behavior disorders in children and adults with mental retardation*. Washington, DC: American Psychiatric Press; 2001. p. 69-100.
156. McCabe MP, McGillivray JA, Newton DC. Effectiveness of treatment programmes for depression among adults with mild/moderate intellectual disability. *J Intellect Disabil Res* 2006;50(Pt 4):239-47.
157. Taylor JL, Lindsay WR, Willner P. CBT for people with intellectual disabilities: emerging evidence, cognitive ability and IQ effects. *Behav Cogn Psychother* 2008;36(6):723-33.
158. Hollins S, Sinason V. Psychotherapy, learning disabilities and trauma: new perspectives. *Br J Psychiatry* 2000;176:32-6.
159. 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.
160. McGinnity M, Banks R, Barnes G, Frankish P, Hollins S, Hutchinson D, et al. *Psychotherapy and learning disability*. London, UK: Royal College of Psychiatrists; 2004. Available from: [www.rcpsych.ac.uk/files/pdfversion/cr116.pdf](http://www.rcpsych.ac.uk/files/pdfversion/cr116.pdf). Accessed 2010 Jul 4.
161. Sequeira H, Howlin P, Hollins S. Psychological disturbance associated with sexual abuse in people with learning disabilities. Case-control study. *Br J Psychiatry* 2003;183:451-6.
162. Cottis T. *Intellectual disability, trauma, and psychotherapy*. New York, NY: Routledge; 2008.
163. Bhaumik S, Branford D. *The Frith prescribing guidelines for adults with learning disability*. 2nd ed. London UK: HealthComm UK Ltd; 2008.
164. Virani AS, Bezchlibnyk-Butler KZ, Jeffries JJ. *Clinical handbook of psychotropic drugs*. 18th revised ed. Ashland, OH: Göttingen: Hogrefe and Huber; 2009.
165. Kalachnik JE, Leventhal BL, James DH, Sovner R, Kastner TA, Walsh K, et al. Guidelines for the use of psychotropic medication. In: Reiss S, Aman MG, editors. *Psychotropic medications and developmental disabilities: the international consensus handbook*. Columbus, OH: Ohio State University, Nisonger Center; 1998. p. 45-72.
166. McKee JR, Bodfish JW, Mahorney SL, Heeth WL, Ball MP. Metabolic effects associated with atypical antipsychotic treatment in the developmentally disabled. *J Clin Psychiatry* 2005;66(9):1161-8.
167. Rush AJ, Frances A. Guideline 4: medication treatment: general principles. Expert Consensus Guideline Series: treatment of psychiatric and behavioral problems in mental retardation. *Am J Ment Retard* 2000;105(3):178-9.
168. De Kuijper G, Hoekstra P, Visser F, Scholte FA, Penning C, Evenhuis H. Use of antipsychotic drugs in individuals with intellectual disability (ID) in the Netherlands: prevalence and reasons for prescription. *J Intellect Disabil Res* 2010;54(7):659-67. Epub 2010 Apr 20.
169. Lunskey Y, Gracey C, Gelfand S. Emergency psychiatric services for individuals with intellectual disabilities: perspectives of hospital staff. *Intellect Dev Disabil* 2008;46(6):446-55.
170. Lunskey Y. Frequent use of the emergency department by a man with learning disability: an analysis of clinical and systemic contributors. *Adv Ment Health Learn Disabil* 2008;2(4):51-4.
171. Pasic J, Russo J, Roy-Byrne P. High utilizers of psychiatric emergency services. *Psychiatr Serv* 2005;56(6):678-84.
172. Grossman SA, Richards CF, Anglin D, Hutson HR. Caring for the patient with mental retardation in the emergency department. *Ann Emerg Med* 2000;35(1):69-76.
173. Sullivan W, Berg JM, Bradley EA, Brooks-Hill RW, Goldfarb CE, Lovering JS, et al. Enhancing the emergency department outcomes of patients with mental retardation. *Ann Emerg Med* 2000;36(4):399-400.
174. Bradley E, Lofchy J. Learning disability in the accident and emergency department. *Adv Psychiatr Treat* 2005;11:45-57.
175. 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.
176. Lunskey Y, Bradley E, Durbin J, Koegl C, Canrinus M, Goering P. The clinical profile and service needs of hospitalized adults with mental retardation and a psychiatric diagnosis. *Psychiatr Serv* 2006;57(1):77-83.
177. Lunskey Y, Balogh R. Dual diagnosis: a national study of psychiatric hospitalizations patterns of persons with developmental disability. *Can J Psychiatry* 2010;56(11):721-8.
178. Ball SL, Holland AJ, Treppner P, Watson PC, Huppert FA. Executive dysfunction and its association with personality and behaviour changes in the development of Alzheimer's disease in adults with Down syndrome and mild to moderate learning disabilities. *Br J Clin Psychol* 2008;47(Pt 1):1-29.
179. Royal College of Psychiatrists, British Psychological Society. *Dementia and people with learning disabilities: guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia*. London, UK: Royal College of Psychiatrists, British Psychological Society; 2009. Available from: [www.rcpsych.ac.uk/files/pdfversion/cr155.pdf](http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf). Accessed 2010 Jan 28.
180. Bhaumik S, Branford D. Dementia and ageing. In: *The Frith prescribing guidelines for adults with learning disability*. 2nd ed. London, UK: HealthComm UK Ltd; 2008. p. 69-80.
181. Van Schroyensteyn Lantman-de Valk H, Linehan C, Kerr M, Noonan-Walsh P. Developing health indicators for people with intellectual disabilities. The method of the POMONA project. *J Intellect Disabil Res* 2007;51(Pt 6):427-34.
182. Walsh PN; POMONA Group. Applying an indicator set to survey the health of people with intellectual disabilities in Europe. *J Policy Pract Intell Disabil* 2008;5(3):211-3.
183. Tomlinson M, Swartz L, Officer A, Chan KY, Rudan I, Saxena S. Research priorities for health of people with disabilities: an expert opinion exercise. *Lancet* 2009;374(9704):1857-62.
184. Oliver-Africano P, Dickens S, Ahmed Z, Bouras N, Cooray S, Deb S, et al. Overcoming the barriers experienced in conducting a medication trial in adults with aggressive challenging behaviour and intellectual disabilities. *J Intellect Disabil Res* 2010;54(1):17-25. Epub 2009 Jul 21.
185. Veenstra MY, Walsh PN, van Schroyensteyn Lantman-de Valk HM, Haveman MJ, Linehan C, Kerr MP, et al. Sampling and ethical issues in a multicenter study on health of people with intellectual disabilities. *J Clin Epidemiol* 2010;63(10):1091-100. Epub 2010 Mar 20.

\*\*\*