

Consensus guidelines for primary health care of adults with developmental disabilities

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ABSTRACT

OBJECTIVE To develop practical Canadian guidelines for primary health care providers based on the best available evidence for addressing health issues in adults with developmental disabilities (DD).

QUALITY OF EVIDENCE Authors of background papers synthesized information from their own clinical experience, from consultations with other experts, and from relevant professional publications. Based on discussions of these papers at a colloquium of knowledgeable health care providers, a consensus statement was developed. Standard criteria were used to select guidelines for consideration and to rank evidence supporting them. Most evidence was level III.

MAIN MESSAGE People with DD have complex health issues, some differing from those of the general population. Adequate primary health care is necessary to identify these issues and to prevent morbidity and premature death. Physical, behavioural, and mental health difficulties should be addressed, and primary health care providers should be particularly attentive to the interactions of biological, psychological, and social factors contributing to health, since these interactions can easily be overlooked in adults with DD. Attention must also be paid to such ethical issues as informed consent and avoidance of harm. Developmental disabilities are not grounds for care providers to withhold or to withdraw medically indicated interventions, and decisions concerning such interventions should be based on patients' best interests.

CONCLUSION Implementing the guidelines proposed here would improve the health of adults with DD and minimize disparities in health and health care.

RÉSUMÉ

OBJECTIF À partir des meilleures preuves disponibles, instaurer à l'intention des dispensateurs de soins primaires des directives canadiennes pratiques concernant les problèmes de santé des adultes présentant des affections congénitales invalidantes (ACI).

QUALITÉ DES PREUVES Les auteurs d'articles de fond ont fait une synthèse de leur propre expérience clinique, de consultations avec d'autres experts et de publications professionnelles pertinentes. La discussion de ces articles à un colloque réunissant des membres réputés du personnel soignant a permis de formuler une déclaration consensuelle. Des critères standards ont été utilisés pour choisir les directives à discuter et pour classer les preuves qui les soutiennent. La plupart des preuves étaient de niveau III.

PRINCIPAL MESSAGE Les personnes souffrant d'ACI ont des problèmes de santé complexes dont certains diffèrent de ceux de la population générale. Les soins de santé primaires doivent être adéquats si l'on veut identifier ces problèmes et prévenir toute morbidité ou une mort prématurée. Les difficultés physiques, comportementales et de santé mentale doivent être prises en charge et le personnel soignant devrait porter une attention particulière aux interactions entre les facteurs biologiques, psychologiques et sociaux contribuant à la santé, puisque ces interactions peuvent facilement être oubliées chez les adultes souffrant d'ACI. Il faut également tenir compte des questions d'éthique comme le consentement éclairé et l'obligation de ne pas nuire. La présence d'ACI ne doit pas servir de prétexte aux intervenants pour refuser ou retarder des interventions médicalement indiquées; les décisions concernant ces interventions devraient être prises dans le meilleur intérêt des patients.

CONCLUSION L'adoption des présentes directives améliorerait la santé des adultes présentant des ACI et diminuerait les problèmes de santé particuliers qui les affectent.

This article has been peer reviewed.

Cet article a fait l'objet d'une révision par des pairs.

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Developmental disabilities" (DD) is currently the term most commonly used in Canada to refer to lifelong limitations in intellectual and adaptive functioning initially identified in people younger than 18 years.¹ Severity of DD is often correlated with intelligence quotient scores as follows: mild (55-70), moderate (40-55), severe (25-40), and profound (below 25). Intellectual and adaptive functioning of people with DD varies widely and, hence, so does their capacity to function independently.² This heterogeneity must be considered when judging the relevance for individuals of general statements about people with DD. Various studies have estimated that such people constitute between 1% and 3% of the general population.^{3,4}

Because of high prevalence of comorbid physical and mental conditions, adults with DD require more attention from health care providers and have a greater need for health care resources than adults in the general population.⁵ Without adequate primary care, the health issues of people with DD often go unrecognized.^{6,7} Even when identified, these issues are often inadequately or inappropriately addressed.^{8,9} Such disparities between adults with DD and the general population substantially increase risk for preventable illnesses and premature death among the former.¹⁰ Considerable evidence shows that use of practice guidelines based on current research improves the quality of health care generally.¹¹ The

literature also suggests that annual, structured reviews that include known achievable health targets for people with DD improve continuity of care and patient and health care provider satisfaction.¹² Currently, however, there are no comprehensive Canadian guidelines for primary health care providers who treat adults with DD in Canada on which to base this annual review, a situation this article seeks to remedy.

Methods

Consensus development process. In November 2005, 50 health care providers, academics, and administrators, predominantly from Canada but also from the United States, the United Kingdom, and Australia, participated in a 4-day colloquium in Toronto, Ont, sponsored by the Surrey Place Centre Charitable Foundation, the Ontario Ministry of Community and Social Services, and the Ontario Ministry of Health and Long-Term Care. Many participants were associated with university-affiliated health science centres and had considerable expertise and experience in supporting people with DD. Some were internationally recognized leaders in DD in their respective disciplines.

Two commissioned background papers distributed to participants before the colloquium addressed epidemiologic and ethical issues, while 4 additional papers proposed guidelines on primary care of adults with DD based on the authors' personal clinical experience, consultations with other experts, and review of a prepared bibliography of relevant publications. During the colloquium, participants discussed guidelines proposed in these background papers. A draft of guidelines that were selected, revised, and prioritized by participants was further reviewed collectively at the time of the colloquium, and then circulated to participants 2 weeks after the colloquium for additional feedback. The authors of this article then prepared an updated version with additional references and ranking of evidence. All participants in the colloquium signified general agreement with the entire document and gave permission for their names to appear in it.

Colloquium participants adopted a "best available evidence" standard for these guidelines. The paucity of level I, and to some extent of level II, evidence for these guidelines is unsurprising, given the many variables among adults with DD that are difficult to control in studies and the barriers that exist in respectfully recruiting such people as research participants.¹³ The corroboration of comparison and descriptive studies or expert committee reports, when available, together with the consensus of colloquium participants, was considered sufficient to indicate the clinical direction to be generally followed.

Criteria for selecting guidelines and ranking quality of evidence. Authors of the background papers and colloquium participants were asked to apply the criteria for selecting guidelines as listed in **Table 1**¹⁴ and

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the levels of evidence outlined below. Colloquium participants also took into account ethical principles, such as respect for intrinsic dignity, interdependency, justice, beneficence, and nonmaleficence (ie, “do good, avoid harm”). Authors and colloquium participants were asked to focus on developing practical Canadian guidelines for primary health care providers that could be implemented in the current Canadian health care system.

Consensus recommendations about providing primary health care for people with DD in Canada and

CINAHL, Scopus, and PsycINFO were searched using the search terms mental retardation, mentally disabled persons, developmental disabilities, or intellectual disability. These terms were combined with 22 key words, such as primary health care, community health services, health status indicators, or health policy. Relevant retrieved citations were 693 English-language papers published between 1990 and 2005. In addition, searches by publication type were undertaken to identify all clinical trials from 1990 to 2005 related to physical, behavioural, and mental health in adults older than 18 years with mental retardation or DD. These searches yielded 197 papers. Further searches were undertaken for recent English-language publications that were relevant to the recommendations but published after the colloquium. Additional searches were performed using the “Related Articles” feature of PubMed and the “References Cited” feature of Scopus. Librarians with extensive familiarity with the published texts on DD and health care issues performed these searches. Most of the authors of this paper screened abstracts of pertinent articles and some read, in their entirety, the citations selected here.

Table 1. Guideline priority criteria

CRITERIA	EXPLANATION
Importance	Address the most prevalent health issues for people with developmental disabilities, especially the leading causes of ill health and death (eg, seizures, aspiration)
Disparity	Address issues that would not be identified by public health initiatives or illness-prevention measures that target the general population (eg, psychological and genetics assessments)
Usefulness	Suggest maneuvers that can be practically implemented and evaluated. These guidelines 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 (eg, thyroid function in Down syndrome, <i>Helicobacter pylori</i> , constipation, osteoporosis)
Information	Recommend activities that are supported by reliable clinical information and research evidence (eg, nutrition and physical activity, management of epilepsy)

Adapted from Linehan et al.¹⁴

Practice guidelines

The guiding principles for development of the guidelines are as follows.

The dignity of people with DD, based on their intrinsic value as human beings, requires respect and does not diminish with the absence or reduction of any ability.

Adults with DD need the same access to health care as anyone else without discrimination against them because of their disabilities. Decisions about health interventions should take into account not only medical benefits and risks, but also particular needs and circumstances. Adults with DD should have the opportunity and support needed to participate in making informed health care decisions.¹⁵

People with DD are nurtured throughout life by human relationships.

Their relationships with primary health care providers are essential foundations for optimal health care. Their relationships with their families and others in their support networks require respectful consideration when providing health care. These supporters can provide clinically relevant information and resources to primary health care providers.¹⁶

Primary health care providers need to take into account health issues particular to adults with DD, with or without specific known cause.

Primary health care providers should consult the specific guidelines presented here (Table 2^{1,18-75}) in addition to more general guidelines in periodic health examination checklists for average-risk adults in the general population.^{17,18}

Levels of evidence

Level I: At least one properly conducted randomized controlled trial, systematic review, or meta-analysis

Level II: Other comparison trials, non-randomized, cohort, case-control, or epidemiologic studies, and preferably more than one study

Level III: Expert opinion or consensus statements

about the education and support of primary health care providers were also developed. These recommended systemic changes of policies were proposed to the sponsoring government ministries to facilitate implementation of the practice guidelines and are not part of these consensus practice guidelines.

Literature review. A comprehensive bibliography was prepared and made available to all participants before the colloquium. General searches were conducted for the purpose of identifying key physical, behavioural, and mental health guidelines and policies. PubMed,

Table 2. Preventive care checklist for adults with developmental disabilities: Recommendations are in addition to those for periodic health examinations for average-risk adults¹⁸; syndrome-specific preventive care checklists are not included; level of evidence refers to the corresponding recommendation and is based on cited references.

CONSIDERATION	RECOMMENDATION	LEVEL OF EVIDENCE
GENERAL ISSUES IN PRIMARY CARE		
1. Known etiologies for patients' DD, with available information on associated health issues, should be considered by primary care providers. ¹⁹	<input type="checkbox"/> If no cause is known, refer patient to a genetics centre for comprehensive etiologic assessment, including genetic testing, if indicated. Periodic reassessment might be necessary at intervals (eg, 5 years). ²¹	III
DD of known genetic or environmental origin might have specific health challenges that require monitoring. ²⁰	<input type="checkbox"/> Consult guidelines available for many of these conditions. ²⁰	III
2. Current levels of adaptive functioning (eg, mild, moderate, severe, or profound DD), in addition to underlying etiologic bases for patients' DD, are often crucial to know in order to provide effective health care. ¹	<input type="checkbox"/> Psychological assessment in adulthood is needed to determine current levels of intellectual and adaptive functioning, especially when concerns about changes in behaviour or appropriateness of supports exist. ¹	III
3. Multiple medications prescribed because of comorbid conditions can result in risk of harm that can be alleviated through vigilance. ²²	<input type="checkbox"/> The same health care provider should review all medications, ideally every 3 months. This review should include indications, dosage, efficacy, compliance, and side effects. ²⁶	III
Adults with DD are often prescribed several medications for behavioural or mental health problems and might be unable to communicate side effects. ²³	<input type="checkbox"/> Record all prescriptions, including dates and changes. ²⁶	III
	<input type="checkbox"/> Test serum drug levels regularly. ²⁶	III
	<input type="checkbox"/> Review medications for mental health problems regularly. ²³	III
They might respond differently to psychotropic medications than the general population does ²⁴ ; older adults in general might respond differently to such medications, and some drugs are often not indicated for older patients. ²⁵	<input type="checkbox"/> Review, at least annually, psychiatric diagnostic or specific behavioural pharmacological justification for long-term use of psychotropic drugs. ²⁷	II
4. Abuse and neglect of people with DD are prevalent. Nonspecific signs of abuse or neglect, such as aggression, might be present. ²⁸	<input type="checkbox"/> Screen regularly (at least annually) for signs of neglect or of physical, sexual, emotional, or financial abuse and report them to the appropriate authorities. ^{29,30}	III
5. Proactive and anticipatory primary health care is needed in addressing the health needs of people with DD. ³¹	<input type="checkbox"/> Encourage advance planning for such circumstances as loss of capacity to give consent, important life events, or health-related crises. ³²	III
	<input type="checkbox"/> Discuss decisions about life-sustaining measures. ³²	III
	<input type="checkbox"/> Develop such plans with adults with DD to the extent possible, as well as with their families or others in their support networks who have power of attorney. ³²	III
6. Informed consent necessitates understanding and appreciating a decision's implications, including adequately weighing possible personal benefits and burdens of intervening or of not intervening. ³³	<input type="checkbox"/> When health care decisions are required, assess capacity to consent. Adapt communication to patients' levels of functioning. ³⁴	III
	<input type="checkbox"/> Involve family or social support network members to facilitate informed decisions. ³⁴	III
	<input type="checkbox"/> When this is impossible, legal substitute decision makers should be assigned to make decisions based on patients' best interests and taking into account patients' wishes. ³⁴	III
7. Interdisciplinary coordination of care is often necessary; a team of health practitioners should include a family physician and nurse along with others as needed, with someone designated as the coordinator. ³⁵	<input type="checkbox"/> Care coordinators need to bear in mind patients' requirements and those of their families and support networks. ³⁶	III
Complex problem behaviour or mental health concerns affecting some patients with DD might give rise to needs that cannot reasonably be addressed by primary health care providers alone.	<input type="checkbox"/> If necessary, seek consultation from or refer patients to specialized, interdisciplinary mental health teams. ³⁷	III

CONSIDERATION	RECOMMENDATION	LEVEL OF EVIDENCE
PHYSICAL HEALTH GUIDELINES		
<p>8. Obesity and lack of health-promoting physical activity are reduced by nutritional and physical-activity interventions.^{38,39}</p> <p>A health-promotion program, including exercise and health education, can improve attitudes toward physical activity and life satisfaction.⁴⁰</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Counsel patients annually about nutrition and physical activity.³⁰ <input type="checkbox"/> Promote optimal nutrition and physical fitness according to the Canadian guidelines regarding healthy active living⁴¹ and eating.⁴² <input type="checkbox"/> Help patients incorporate regular physical activity into daily routines.⁴⁰ 	<p>III</p> <p>III</p> <p>I</p>
<p>9. Vision and hearing impairment in people with DD are underdiagnosed,⁴³ leading to substantial difficulties in behaviour, learning, and activities of daily living.⁴⁴</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Perform office-based screening of vision and hearing annually, as recommended for average-risk adults.¹⁸ <input type="checkbox"/> Refer patients for vision and glaucoma assessments at least once before age 40 (age 30 for patients with Down syndrome) then every 2 y after age 40.³⁰ <input type="checkbox"/> Refer patients for hearing assessment every 5 y after age 45 (every 3 y throughout life for patients with Down syndrome).⁴⁵ <input type="checkbox"/> Reevaluate vision and hearing if problems are reported or changes in behaviour are noted.³⁰ 	<p>III</p> <p>III</p> <p>III</p> <p>III</p>
<p>10. Dental disease, if undetected, can account for problem behaviour.⁴⁶</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Promote dental health through regular oral hygiene practices, assessment by a dentist at least every 6 months, and timely management of dental disease.⁴⁷ 	<p>III</p>
<p>11. Thyroid disease can account for changing clinical presentations in patients with DD; it is common among those with Down syndrome.²⁶</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Regularly screen for thyroid disease (every 1 to 3 y, but more often in high-risk subgroups, such as patients with Down syndrome).³⁰ 	<p>III</p>
<p>12. Cardiovascular diseases and malformations are frequently found in patients with specific DD syndromes (eg, tuberous sclerosis and Williams syndrome).^{48,49} Some neuroleptic medications have substantial cardiac side effects and elevate risk factors for cardiac disease.⁵⁰</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Screen for cardiovascular disease earlier and more regularly than in the general population.³⁰ 	<p>II</p>
<p>13. Respiratory problems, often caused by aspiration, are the second most common cause of death in patients with DD.⁵¹</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Ensure vaccinations for <i>Haemophilus influenzae</i> and <i>Streptococcus pneumoniae</i> are current.¹⁸ 	<p>III</p>
<p>14. Detection of gastrointestinal diseases is important. Chronic dysphagia, leading to aspiration, can occur in patients with DD without typical signs, such as coughing.⁵²</p> <p>Gastroesophageal reflux disease⁵³ and chronic constipation, especially in non-communicative people, can cause physical and behavioural problems.⁵⁴</p> <p>The risk of <i>Helicobacter pylori</i> infection is higher for people with DD who have been in close contact with others or who have severe DD.⁵⁵</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Screen for dysphagia and aspiration in patients with DD and neuromuscular dysfunction.⁵³ <input type="checkbox"/> Screen regularly for gastroesophageal reflux disease and constipation if presentation changes.⁵⁶ <input type="checkbox"/> Check for <i>H pylori</i> infection if persistent signs of dyspepsia or unexplained behavioural changes are noted, particularly in those who are at risk.⁵⁵ <input type="checkbox"/> Retest in 3 to 5 years after eradication of <i>H pylori</i>.⁵⁵ 	<p>III</p> <p>III</p> <p>II</p> <p>III</p>
<p>15. Sexually transmitted diseases and sexual abuse of adolescents and adults with DD are important issues to consider.⁵⁷</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Screen sexual practices regularly. Where there might be at-risk behaviour, offer sexual health care services, including appropriate education regarding sexual rights, protection from sexually transmitted diseases, and prevention of unwanted pregnancy.⁵⁸ 	<p>III</p>
<p>16. Osteoporosis and osteoporotic fractures tend to occur earlier among people with DD than among the general population. Higher risk derives from long-term use of anticonvulsive or antipsychotic medications, diminished mobility, or presence of specific genetic syndromes (eg, Down and Prader-Willi).⁵⁹</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Patients at high risk warrant regular screening starting at age 19.³⁰ 	<p>III</p>

CONSIDERATION	RECOMMENDATION	LEVEL OF EVIDENCE
17. Epilepsy among patients with severe DD is common and profoundly affects function and mortality rates. Epilepsy can be difficult to recognize, evaluate, and control. ⁶⁰	<input type="checkbox"/> Regularly reassess the management of epilepsy, including reviewing medications. ⁶¹	II
	<input type="checkbox"/> Provide lifelong education to patients with epilepsy and their caregivers regarding acute management of seizures and safety practices. ²⁶	III
BEHAVIOURAL AND MENTAL HEALTH GUIDELINES		
18. Problem behaviour , such as aggression and self-injury, common reasons for referral for psychiatric assessment, might have causes other than psychiatric illness. ⁶²	<input type="checkbox"/> Assess possible physical, environmental, and emotional factors (eg, pain, stress, grief) when evaluating problem behaviour or considering a psychiatric diagnosis. ⁶³	III
19. Psychiatric disorders , often underdiagnosed, are more common in patients with DD than in the general population. ^{64,65}	<input type="checkbox"/> A comprehensive psychiatric formulation should take into consideration the axes in Table 3. ⁶⁶	III
20. Input from patients with DD and from their support networks is vital for understanding and treating problem behaviour and psychiatric illness. ⁶³	<input type="checkbox"/> In collaboration with affected patients and families or other caregivers, identify problem behaviour (eg, sleep disturbance) to be targeted in treatment. ⁶⁷	III
	<input type="checkbox"/> Changes in such targeted behaviour (eg, as tracked in a sleep chart) can be used as markers for monitoring treatment effectiveness. ⁶⁷	III
21. Problem behaviour and psychiatric illness can be reduced by such interventions as education and skill development, environment modification, psychological and behavioural therapy, and caregiver support. ⁶⁸	<input type="checkbox"/> In addition to psychotropic medications, support and monitor appropriate interdisciplinary interventions. For instance, cognitive-behavioural therapy is effective in decreasing anger and addressing depression. ⁶⁹	I
22. Psychotic disorders are extremely difficult to diagnose when delusions and hallucinations cannot be expressed verbally. ²³ Self-talk and other unusual uses of language might be mistaken for thought disorders. ⁷⁰	<input type="checkbox"/> Input from specialists in psychiatry, psychology, and speech-language pathology, in the context of an interdisciplinary mental health team, is often necessary to diagnose psychotic disorders definitively in patients with limited verbal ability or unusual use of language. ⁷¹	III
23. Risk for dementia is increased for many people with DD, especially those with Down syndrome. ⁷² Signs might be subtle and can manifest as changes in emotion, social behaviour, or motivation so diagnosis is often missed or delayed. Dementia has many causes. ²³	<input type="checkbox"/> Educate family and others in the support network of adults with DD about early signs of dementia. <input type="checkbox"/> For patients at risk of dementia, neuropsychologic testing to establish a baseline of cognitive functioning is recommended at about age 40. ⁷³	III III
24. Crisis responses need to be developed as an important element of caring for people with DD who have problem behaviour or psychiatric illness. ⁷⁴ Acute crisis management plans and continuing comprehensive long-term treatment plans are distinct strategies for addressing problem behaviour and psychiatric illness. ⁷⁴	<input type="checkbox"/> Develop crisis plans in consultation with patients at risk of crisis and their caregivers. Review this plan annually and after any crisis. ⁷⁵ <input type="checkbox"/> Acute crisis management needs to be followed by reassessment and planning for long-term treatment. ⁷⁵	III III

DD—developmental disabilities.

Discussion

As a group, people with DD have poorer health and greater difficulty accessing primary health care services than those in the general population. These problems have been recognized internationally,^{6-10,76} and health targets and indicators are being developed for people with DD.^{26,77} The transition of such people from institutions to communities has meant that, increasingly, professionals without specialized

knowledge of the health needs of adults with DD are asked to care for them.

To inform clinical decision making and be useful for busy primary health care providers, practice guidelines should be concise and indicate the rigour of the evidence cited.⁷⁸ There are no such comprehensive Canadian guidelines for those providing primary care to adults with DD. Existing resources include 3 recent texts^{20,22,77} and some syndrome-specific preventive health care guidelines and checklists.

Table 3. Multiaxial system for mental retardation

AXIS	FEATURES
I	Severity of retardation and problem behaviour
II	Associated medical conditions
III	Associated psychiatric disorders
IV	Global assessment of psychosocial disability
V	Associated abnormal psychosocial situations

Data from Division of Mental Health and Prevention of Substance Abuse, World Health Organization.⁶⁶

The recommendations presented in this article are based on an effort to assemble and to review the current state of knowledge on health issues of adults with DD, with the aim of making considered and concise recommendations for primary health care of adults with DD within the parameters of the existing Canadian health and social service systems. The guidelines also urge attention to such ethical issues as informed consent and avoidance of harm. Although relevant for everyone, these issues warrant particular emphasis because some people with DD are habituated to always be compliant, others cannot communicate their wishes, and still others lack the capacity to give informed consent or can do so only with support. Developmental disabilities are not grounds for care providers to withhold or to withdraw medically indicated interventions; decisions concerning such interventions should be based on patients' best interests.

Some remarks are necessary about the scope and applicability of these guidelines. First, the guidelines mainly address health issues that particularly affect people with DD, especially those issues not screened for by routine health assessments of average-risk adults. Some of the recommendations, however, also address health issues that were judged important even though they are part of routine preventive care and standard treatment of average-risk adult patients, because variables that are often present among adults with DD or in their living situations might complicate assessment and treatment. Most recommendations specific to syndromes associated with DD were excluded, other than those particularly applicable to Down syndrome, because that condition is relatively common.

Second, there are many causes of DD, and there is great variability in functioning among affected patients. Primary health care providers need to seek current information about health issues specific to particular etiologies, if known, of adults' DD and to take into account levels of intellectual and adaptive functioning when applying these guidelines.

Third, the order of the recommendations that colloquium participants adopted reflects participants' agreement that physical, behavioural, and mental health difficulties should be addressed. Although the guidelines are organized, for the sake of clarity, into separate sections on physical health and on behavioural and mental

health, primary health care providers should be particularly attentive to the interactions of biological, psychological, and social factors contributing to illness, since these interactions can easily be overlooked in adults with DD. To take into account such interactions, the guidelines highlight the importance of interdisciplinary health care for adults with DD and of working with patients' families and support networks. Within the physical health section, recommendations are ordered to correspond with the order of the periodic health examination for average-risk adults. The behavioural and mental health guidelines prioritize behavioural problems and psychiatric disorders and then sequentially address issues related to diagnosis, intervention, and future planning.

Limitations and implications for future research

Randomized controlled trials (level I evidence) were found to support only 2 of these guidelines. Non-randomized comparison studies (level II evidence) supported another 4 guidelines. The fact that there are few such studies suggests that the health care disparities experienced by people with DD extend to the lack of relevant research.¹³ The reasons for this and possible solutions need exploration.

Ontario's Ministries of Health and Long-Term Care and of Community and Social Services are sponsoring a training initiative to teach these guidelines to primary care providers in 4 regions of Ontario, beginning in the fall of 2006. This will provide an opportunity to pilot-test the guidelines, to identify barriers to their application, and to develop tools and resources (such as syndrome-specific health-watch tables) to facilitate their implementation. It is hoped that such training can thereafter be extended to other Canadian provinces. Because evidence for various guidelines will improve, we anticipate an update to the guidelines will be necessary in 2 to 3 years.

Conclusion

These proposed Canadian practice guidelines for the primary health care needs of adults with DD are based on the expertise of colloquium participants and their awareness of the best available evidence in this area. The guiding principles of respect for human dignity, support of human relationships, and equitable attention to the general and specific primary health care needs of adults with DD are specified concretely by these guidelines, which address current barriers accounting for disparities in Canada between the primary health care of adults with DD and of the general population. By overcoming some of these existing barriers owing to the lack of an annual structured review that includes achievable health targets, these proposed guidelines, if implemented, could improve the health of people with DD and reduce their experience of disparities in health and health care.



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Competing interests

None declared

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EDITOR'S KEY POINTS

- As a group, people with developmental disabilities have poorer health and greater difficulty accessing primary care than those in the general population do.
- These guidelines focus on physical and mental health issues that particularly affect those with developmental disabilities, especially those issues not screened for by routine health assessments of the general population.
- Ethical issues, such as informed consent and avoidance of harm, are specifically addressed.

POINTS DE REPÈRE DU RÉDACTEUR

- Comme groupe, les gens qui ont des affections congénitales invalidantes (ACI) sont en moins bonne santé que ceux de la population générale et accèdent plus difficilement aux soins de santé primaires.
- Les présentes directives portent sur les problèmes de santé physique et mentale qui touchent particulièrement ceux qui ont des ACI, notamment les problèmes qui ne sont pas dépistés par l'évaluation de santé généralement utilisée dans la population générale.
- Les questions d'éthique comme le consentement éclairé et l'obligation de ne pas nuire sont traitées de façon spécifique.

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