Health checks for adults with intellectual and developmental disabilities in a family practice

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Abstract

Objective To provide tips and tools for primary care practitioners carrying out health checks for adult patients with intellectual and developmental disabilities (IDD) and for implementing a systematic program of health checks in a group or team practice.

Sources of information The "Primary Care of Adults with Intellectual and Developmental Disabilities. 2018 Canadian Consensus Guidelines" literature review and interdisciplinary input. Experience in implementing health checks in family practices was obtained through the primary care project of H-CARDD (Health Care Access Research and Developmental Disabilities).

Main message Annual comprehensive health assessments ("health checks") are a recommendation of the 2018 Canadian consensus guidelines for primary care of adults with IDD because of evidence of benefit in this population. Although health checks might require more time to complete for people with IDD than is usual for encounters in primary care, family physicians are in an ideal position to provide this service because of the attributes of family medicine, which include both an orientation to proactive care and the ability to provide continuity of care. Tips and tools are provided for carrying out health checks for adult patients with IDD and for implementing a systematic program of health checks in a group or team practice.

Conclusion Health checks can help enhance a family physician's approach to providing care for adults with IDD.

Editor's key points

- While annual physical examinations are not considered beneficial for asymptomatic adults with no risk factors in the general population, comprehensive health assessments, including a physical examination and preventive care actions, are recommended for adults with intellectual and developmental disabilities (IDD) in the 2018 Canadian consensus guidelines for primary care of adults with IDD.
- Although the time required for these assessments might be longer than typical encounters in family practice (and multiple appointments and collaborative care are likely required), the continuity and comprehensiveness of care in family practice in Canada make family physicians and family practice nurse practitioners ideal providers for this group.
- Links are provided to tips and tools from H-CARDD (Health Care Access Research and Developmental Disabilities) and Surrey Place Centre to assist family physicians and nurse practitioners with health checks for patients with IDD.

Points de repère du rédacteur

- Alors que les examens physiques annuels sont jugés futiles dans la population générale d'adultes asymptomatiques exempts de facteurs de risque, les Lignes directrices consensuelles canadiennes 2018 en matière de soins primaires aux adultes ayant une déficience développementale recommandent une évaluation de santé complète, y compris un examen physique et des mesures de prévention, chez les adultes ayant des déficiences intellectuelles et développementales (DID).
- Bien que ces évaluations demandent plus de temps que les rencontres typiques en pratique familiale (et qu'il faudra probablement plusieurs rendez-vous et des soins partagés), la continuité et l'intégralité des soins en pratique familiale au Canada placent les médecins de famille et les infirmières praticiennes en pratique familiale au premier plan pour dispenser ces services à ce groupe.
- Des liens sont fournis vers les conseils et les outils du projet H-CARDD (Health Care Access Research and Developmental Disabilities) et vers le Surrey Place Centre afin de prêter assistance aux médecins de famille et aux infirmières praticiennes en matière d'examens de santé des patients ayant des DID.

Examens médicaux en pratique familiale chez les adultes ayants des déficiences intellectuelles et développementales

Résumé

Objectif Fournir aux praticiens de première ligne qui effectuent un examen de santé chez les adultes ayant des déficiences intellectuelles et développementales (DID) des conseils et des outils en vue de la mise en œuvre d'un programme systématique d'examens de santé au sein d'un groupe ou d'une pratique d'équipe.

Sources d'information Revue de la littérature et contributions interdisciplinaires sur les « Lignes directrices consensuelles canadiennes 2018 en matière de soins primaires aux adultes ayant une déficience développementale ». L'expérience dans la mise en application des examens de santé en pratique familiale découle du projet de soins de première ligne H-CARDD (Health Care Access Research and Developmental Disabilities).

Message principal Les évaluations de santé annuelles complètes (« examens de santé ») sont une des recommandations des Lignes directrices consensuelles canadiennes 2018 en matière de soins primaires aux adultes ayant une déficience développementale qui s'appuient sur des données probantes selon lesquelles ces examens seraient bénéfiques dans cette population. Bien que les examens de santé auprès des patients ayant des DID demandent plus de temps que les rencontres habituelles en soins de première ligne, les médecins de famille occupent une place idéale pour dispenser ce service en raison des caractéristiques de la médecine familiale, dont l'orientation vers des soins proactifs et la capacité d'assurer la continuité des soins. Des conseils et des outils sont fournis pour effectuer les examens de santé chez les adultes ayant des DID et pour mettre en œuvre un programme systématique d'examens de santé au sein d'un groupe ou d'une pratique d'équipe.

Conclusion Les examens de santé contribuent à l'amélioration de l'approche de soins du médecin de famille chez les adultes ayant des DID.

The purpose of this article is to provide practical tips and tools for accomplishing a comprehensive health assessment for adults with intellectual and developmental disabilities (IDD), known in the IDD literature as a *health check*. Health checks are one of the recommendations of the "Primary Care of Adults with Intellectual and Developmental Disabilities. 2018 Canadian Consensus Guidelines."[1]

Case description

A 45-year-old woman with mild IDD noted since early childhood has come to your office. You do not see her often. You had asked your receptionist to arrange this appointment after you recently refilled the patient's antiepileptic medications in response to a request from her pharmacist. You recall that the patient lives with her elderly parents and has a boyfriend. Reviewing her chart, you note she has had emergency department visits in the past year for earache and knee pain. Your electronic medical record provides a prompt that she is overdue for cervical cancer screening. She comes on her own to the appointment and starts by saying that she is having abdominal pain. Obtaining her history is slow work. She answers most of your questions with a yes. An abdominal examination is difficult because of the patient's difficulty relaxing her muscles. You order an abdominal and pelvic ultrasound and some screening bloodwork. At the end of the time you have available at this appointment, you suggest a return visit to continue your workup. In the interim, no test results are reported and she does not return for the next appointment.

The scope of an encounter with any patient in a family practice might include current symptoms, chronic disease management, and preventive health issues. This case illustrates some of the additional issues experienced by adults with IDD: difficulty navigating the health care system, communication issues, barriers to physical examination, fear of investigations, and inadequate time in health care workers' schedules. A health check is a way to address these issues. It can provide a systematic approach and a lens to bring the extra issues into focus, as well as a reminder of resources to make care easier and more effective.

Sources of information

This article is informed by the 2018 Canadian consensus guidelines[1] literature review, as well as by interdisciplinary input. Experience in implementing health checks in family practices was obtained through the primary care project of H-CARDD (Health Care Access Research and Developmental Disabilities).

Main message

What is a health check and why is it necessary? A health check is a comprehensive health review for an adult with IDD, including a physical examination and prevention or screening, which results in a management plan.[2,3] It involves the following:

- collecting background information about intellectual and adaptive functioning and social supports to make the resulting action plan more achievable (eg, planning a blood test or cancer screening involves understanding the patient's capacity to consent and facilitating cooperation through appropriate accommodations and support);

- using knowledge of genetic syndromes and other associated conditions to guide care (eg, screening for hypothyroidism in a patient with Down syndrome); and
- undertaking a broader functional inquiry and physical examination, from head to toe, than would be done in a periodic health examination for patients of a similar age and sex in the general population to help compensate for communication challenges. People with IDD might not be able to ask for specific help or say what is wrong with their state of health. Documenting baseline health information can inform subsequent assessments (eg, knowledge of a patient's tendency to experience heartburn or constipation might help point to the cause in assessment of a nonspecific change in behaviour on another occasion).

Health checks require a proactive approach, including inviting adults with IDD for regular reviews and follow-up. This can reduce barriers to attending appointments caused, for example, by lack of health literacy or by poverty. Scheduling extra time and planning to spread the tasks of a comprehensive review among other caregivers and over multiple appointments helps avoid the risk that encounters will deal only with current symptoms.

A health check helps address inequities in access to health care services experienced by adults with IDD by increasing rates of preventive screening and health promotion and by identifying undiagnosed conditions.[4,5] The recommendation of health checks for adults with IDD might seem to contrast with recent recommendations against annual physical examinations for the general population.[6] However, those recommendations are for asymptomatic adults with no important risk factors, which is not the case for adults with IDD. The evidence for the benefit of health checks in adults with IDD highlights their special health issues and needs compared with members of the general population.

Why should family physicians perform health checks? Canada, as a signatory to the United Nations' Convention on the Rights of Persons with Disabilities,[7] is committed to providing resources for persons with disabilities that enable them to be included in the community. That would reasonably involve community-based primary health care services, which, in Canada, include access to a personal family physician and, in some places, a nurse practitioner.

Health checks are especially suited to action by family physicians because the fundamental principles of family medicine[8] and the basic skills of family physicians, such as continuity of care, comprehensiveness, communication skills, and collaboration with other health care providers, facilitate health checks.

Family physicians have a special responsibility to patients with IDD in their practices for multiple reasons. Persons with IDD are more likely to experience increased rates of mortality and morbidity compared with the general population.[9-12] They are vulnerable because of limitations in self-care, communication, and literacy, all of which can have considerable effects on their opportunities for good health and obtaining good health care compared with individuals without disabilities.[13] They are more likely to be living in poverty and, as such, have additional health risks such as higher rates of cardiovascular disease, diabetes, and compromised mental health.[14] Adults with IDD seek hospital emergency care more frequently than the general population does,[15,16] have higher rates of preventable admissions to hospital,[17,18] and have lower rates of cancer screening.[19-21]

Nevertheless, evidence from Ontario indicates that adults with IDD see a family physician as often as those in the general population and with similar continuity of care.[16] This level of access to a personal physician implies that family physicians have the opportunity to make a difference. There are barriers to care, however, that are difficult for family physicians to overcome, including lack of time in the clinical encounter and lack of systematic supports for gathering information, identifying referral resources, and ensuring other follow-up.[22-25] The following are tips and tools that might be helpful for addressing some of the barriers. The tips are based on the experience of 2 family health teams in Ontario[5,26,27] and they align with descriptions of successful health check programs delivered in Australia and the United Kingdom.[2,4,24] Tools that are helpful in implementing the tips can be found in *Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers*[28] and on the primary care webpages of the Surrey Place Centre website.[29]

Tips for conducting a health check. Consider using a medical record template for a cumulative patient profile[30] and a Preventive Care Checklist Form[31] based on the 2018 Canadian consensus guidelines[1] to help prompt various components of the health check (see summary of elements of a health check beyond the components applicable to the general population in **Table 1**).[1,28] If using electronic medical records, have the template embedded functionally in your record. The following are key components:

- "Systems Review in Primary Care for People with [Developmental Disabilities]," a 1-page document in *Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers,*[28] can serve as a reminder of the benefit of a broader functional inquiry among people with IDD, who might not be likely to volunteer symptoms, and can help family physicians focus on preventive care, including secondary prevention around comorbidities that are common among people with IDD.
- Think of the health check not as a single "annual physical," but as a process to accomplish over several appointments, so that both the needs of the patient and your practice routines can be accommodated.
- Extra time is often necessary to increase the capacity of patients to consent or assent and to decrease barriers to

Table 1. Steps for completing a health check: *The suggested tools are available from H-CARDD (www.porticonetwork.ca/web/hcardd/kte/primary-care toolkit) and the Surrey Place Centre DDPCI (surreyplace.ca/ddprimarycare).*

STEP	COMPONENTS
1. Update the cumulative patient profile with information relevant to making practical management plans	• IQ level and functional assessment (eg, by a psychologist or an occupational therapist or from a previous school psychoeducational report) to help inform capacity to consent to medical procedures and supports needed to enhance capacity • Cause of intellectual disability, associated condition (eg, autism, cerebral palsy) or genetic syndrome, including date of last genetic assessment; a reminder to make use of additional information available for management of specific syndromes (Health Watch Tables on the DDPCI website) • Names and contact information of substitute decision maker and caregivers (family members or paid caregivers) and income, housing, occupational, developmental service agency, and other social supports relevant to carrying out the management plan • Accommodations needed at office appointments (eg, communication, mobility, timing, and duration of appointments); tips from parents and caregivers • Dates of most recent vision, hearing, and dental assessments and specialists' appointments • Reasons for exclusions from preventive maneuvers, if any
2. Complete a history and physical examination; make an assessment and plan	• Ask about current symptoms (ie, the patient's "agenda" for the visit) • Assess chronic conditions, including syndrome-specific issues (refer to the DDPCI Health Watch Tables and the document, "Commonly Missed Diagnoses," in H-CARDD's tool kit for primary care providers[28]) • Do an IDD-relevant systems review to identify previously undiagnosed conditions (refer to "Systems Review in Primary Care for People with DD" in H-CARDD's tool kit[28]) • Offer screening maneuvers, as applicable to the general population • Do a physical examination relevant to the data elicited above and to IDD in general (refer to the physical health section of the 2018 Canadian consensus guidelines[1]) • Make an assessment and plan (refer to the H-CARDD tool kit's templates[28] to help identify medical specialists relevant for patients with IDD, financial supports, and patient and caregiver resources)

DD—developmental disabilities, DDPCI—Developmental Disabilities Primary Care Initiative, H-CARDD—Health Care Access Research and Developmental Disabilities, IDD—intellectual and developmental disabilities, IQ—intelligence quotient.

preventive care actions.[32] Gynecologic examinations for Papanicolaou tests, for example, are enabled by more preparation, communication, and planning for support from caregivers.[33] Use easy-to-understand patient information on breast, cervical, and colon cancer screening tests, and about going to the doctor for a checkup.[34,35]

- Ask your receptionist to inquire and request, when appropriate, that a caregiver who is familiar with the patient accompany him or her to the health check. Also, ask for the contact information of the patient's substitute decision maker, if different than the caregiver.
- Share the tasks resulting from your assessment or plan, identified through a health check, with other health care professionals.[36,37] The disciplines helpful for people with IDD might be more extensive than regular consultation sources. For example, if a psychologist's consultation is not available, an occupational therapist might be able to provide a functional assessment. A speech-language pathologist can help with communication issues. A physiatrist or a physiotherapist can address mobility issues. Nurses, including community care nurses and nurse practitioners, might be able to organize assessments at home, where history taking or tests like drawing blood or hearing assessments might be more successful for some patients. The patient's pharmacist could provide a medication review and reconciliation. Social workers and mental health workers can assess and support emotional needs as well as provide help for system navigation.
- Share the data-gathering tasks of a health check or the plans resulting from it with others who support the patient. Most patients benefit from family members, friends, volunteers, or paid health or social service caregivers, case managers, or other advocates to ensure they can access management and follow-up plans. If a caregiver is unavailable for the appointment, some information could be collected through monitoring tools (eg, for bowel movements, hours of sleep).[38] In some cases, however, if a patient is not accompanied to an appointment by a caregiver, it could be a red flag that services and supports are deficient.
- Make health checks more efficient and effective by implementing them as part of a practice-wide systematic effort. Share tasks to the extent possible given the administrative, clerical, and health care staff you have available.[26,27,39]

Tips and resources for implementing a program for health checks in your group or team practice. The following tips are based on, and expanded on with tools for implementation, *Implementing Health Checks for Adults with Developmental Disabilities: A Toolkit for Primary Care Providers*.[28] A discussion of the structural and systemic barriers and facilitators to implementation has been published separately.[5,26]

Provide leadership:

- Meet with members of your primary care team, including administrative, clerical, or reception and nursing or

nurse practitioner staff to build awareness and collaboration. Decide who will do the preparatory steps below.

- Consider identifying health checks as a quality improvement program goal for your practice. This could be a strategy for sustainability. Decide what data collection is available or necessary to measure outcomes.
- Prepare a list of local resources to which family physicians in your group and members of your team can refer. A local developmental service organization might already have a listing of helpful local providers and specialists.
- Use resources that are available to build awareness in the practice about IDD. Use resources to help identify, in advance, opportunities for collaboration among the members of the primary care team. For instance, nursing staff can provide education for the family members and other caregivers for various procedures such as blood glucose monitoring, seizure monitoring, and first aid; administration of tube feedings or laxatives (suppositories and enemas); and other procedures. Nurse practitioners could manage many chronic health conditions such as diabetes, in consultation with the physician for more complex cases.
- Ensure the patient-centredness of a health check. Mitigate difficulties faced by patients and caregivers, such as understanding the purpose and content of health checks, booking appointments and coming to offices, time spent in waiting rooms, physical accessibility of clinic rooms and examination tables, expressing and receiving information during the encounter, coordinating what is suggested in your office with other services the patient is receiving, and any financial constraints. In our experience, we have found that some patients might feel stigmatized when receiving an invitation for a health check, an intervention not recommended for the general population (eg, if they do not see themselves as having an IDD).

Preparatory steps:

- Identify the patients with IDD in your practice (eg, search your electronic medical record by key word or disease code, if available); if in a group practice, ask your colleagues or their practice nurses to review patient lists. If currently unidentified patients are thought to potentially have an IDD, use a screening questionnaire to help select those for whom the health check process and focus might be helpful, while seeking confirmation of the disability to facilitate access to social services.
- Promote a consistent way to denote patients as having IDD in your electronic medical record so that office staff and health care team members can subsequently be alerted, from visit to visit, to their special needs. This facilitates program evaluation, as well as annual reminders to receptionists to contact patients to offer appointments for annual health checks.
- Invite the patient, caregiver, and substitute decision maker for the health check. Provide a telephone script for your receptionist. It is helpful to place a reminder telephone call before the appointment to avoid no-shows.
- Consider a "meet and greet" appointment with the nurse or nurse practitioner as an initial step for some patients to get to know staff and help facilitate future assessments; desensitization to taking vital signs and performing other parts of the physical examination might be helpful. This appointment could also be an opportunity to gather background information; update the patient's cumulative patient profile (medical records summary) with past medical history; request copies of previous psychological, functional, and genetic assessments; and identify social history and supports.
- Make use of available resources developed for patients with IDD to help explain health checks to patients (eg, a narrated online "health booklet"[40]; a "social story" on the health check, available in a free online app[41]; and an online video about "going to the doctor."[42])

Case resolution

You decide that a health check might be a helpful basis for follow-up. Your receptionist calls the patient to ask if she would be willing to make another appointment and if she has someone she would like to bring with her. You download a template for a health check from the Internet (cumulative patient profile[30] and Preventive Care Checklist Form[31]) and note that it will take more than one appointment to accomplish the tasks involved. The patient comes with a support worker from the local Association for Community Living and her sister, who has recently taken over the role of substitute decision maker following her parents' request. During this appointment, you start to update the patient's cumulative patient profile. No specific cause of her IDD is known. She has recently begun a process to move from her parents' home to a community residence staffed by a social service agency's personal support workers. She had a therapeutic abortion in her 20s. She has never had a Pap test since then. There were no abnormalities in findings from her ultrasound and bloodwork. It seems that her abdominal pain might be due to constipation. You ask the patient if she could keep a record of her bowel movements on a chart you printed from an IDD primary care webpage[43] and start thinking about how you will adjust your communication if you decide to encourage lifestyle changes such as diet, fluid intake, and exercise. You introduce the idea of screening for cervical cancer. It seems that the patient does not understand enough about the test to have a discussion today about consent, although her sister is in favour. You show the patient an online booklet, "Checking All of Me. What I Need to Know About Pelvic Exams"[44] and invite the patient to return for another appointment.

Conclusion

Evidence is accumulating across jurisdictions regarding the benefits of health checks for people with IDD, including recent evidence of their effects in Ontario.[5] This paper adds to the literature by identifying practical ways to implement health checks. The updated Canadian consensus guidelines for primary care of adults with IDD[1] include recommendations that can be complicated to learn and follow without a structure to do so. We believe that regular health checks can be a vehicle to implement many of the recommendations in practice. Health checks can provide a focus for patient-centred care to make the accommodations that are necessary to reduce barriers to access to care. The health check ensures screening and preventive care actions are performed and enhances chronic disease management. In addition, health checks build and sustain the relationship between patient and provider that is at the core of family practice.

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Contributors

All authors contributed to the literature review and interpretation, and to preparing the manuscript for submission.

Competing interests

None declared

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