Health Check tool

For comprehensive health assessment of adults with intellectual and developmental disabilities

Ian Casson MD MSc FCFP   Amy Hung MD CCFP   Elizabeth Grier MD CCFP   Sumaiya Karim

Case descriptions

Case 1. A 55-year-old woman visits your office with a staff member from the home for adults with intellectual and developmental disabilities (IDD) in which she lives. She has cerebral palsy. Her family and the staff have noted a functional decline in the past few years: she now requires a wheelchair, uses fewer words, and no longer does jigsaw puzzles, which she used to enjoy.

Case 2. A 25-year-old man, unfamiliar to you, comes for a checkup with his parent. He has autism and intellectual disability and was previously followed by a developmental pediatrician on occasional visits to a multidisciplinary clinic.

Case 3. A 35-year-old single mother requests that you complete a disability form. She has a recent psychologist's report indicating mild intellectual disability. In planning follow-up, you note that she has missed many appointments in the past for herself and for her children.

Adults with IDD have difficulty accessing health care services and present to family practices with complex health issues. A Health Check tool[1] is available to make encounters easier by providing structure and alerts for common issues (available at **CFPlus**).* This is useful in 2 situations: for solving existing clinical problems and for providing anticipatory, preventive care. The latter could be provided in an annual comprehensive health assessment, which is a recommendation, based on level I evidence, of the "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines."[2]

Development of the Health Check tool

A group of family physicians† with general practices who are associated with the Developmental Disabilities Primary Care Program[3] met and corresponded in 2018 to review resources[4,5] and revise previous versions of the tool.[6]

The tool will seem familiar to family physicians because it emphasizes multidisciplinary, comprehensive, continuing care focused on the patient-doctor relationship.

---

*A template for the Health Check tool, with annotations, is available at **www.cfp.ca**. Go to the full text of the article online and click on the **CFPlus** tab.

†The tool revision group consisted of **Drs Ian Casson, Meg Gemmill, Laurie Green, Elizabeth Grier, Amy Hung, Jessica Ladouceur, Amanda Lepp, Ullanda Niel,** and **Michelle Ross.**

The tool follows the usual steps of a family practice encounter: current concerns, past health, systems review (or risk assessment), physical examination, assessment, and planning, with emphasis on accommodations for patients with IDD. Annotations highlight issues and resources specific to this group. In particular, the routine content of the cumulative patient profile (CPP) is supplemented to increase the effectiveness of action plans. The systems review and physical examination promote a broad approach to offset key barriers to access: alternative communication needs, health literacy, and difficulty navigating the health care system.

Attempting a comprehensive health assessment for a patient with IDD is a familiar challenge for family doctors because it is similar to assessing patients with multimorbidity and complexity. Solutions include using follow-up appointments and electronic medical record (EMR) prompts. The annotations in the Health Check tool identify tools for data collection by patients and caregivers, as well as criteria to assess the need for referrals.

Where feasible, the work involved in Health Checks can be distributed in a systematic fashion. For instance, clerical staff could arrange appointments proactively, invite caregivers or individuals who can best support decision making to accompany the patient, or identify accommodations to increase accessibility in the office.[7] A practical guide to implementation of Health Checks points out facilitators and barriers,[8] which are also explored in pilot program evaluation reports.[9,10]

Discussion

Implementation of previous versions of this tool guided its design by identifying what is supportive to family physicians' practices and helpful to our patients.

Queen's Family Health Team in Kingston, Ont, a family medicine residency teaching practice of 18 000 patients, implemented a Health Check program in 2015. As of May 2018, 232 adults with IDD had been identified (2% of the adults in the practice), and more than 85% had had Health Checks. A quality-improvement program had been implemented, and a previous, similar version of the tool was made available in the EMR.

Updating the CPP is a key part of a Health Check. To study how the CPP was populated after the implementation of the Health Check program, a chart review was completed for patients with IDD within Queen's Family Health Team in October 2018. One hundred charts were selected using a random number generator, and S.K. and A.H. manually

reviewed CPP fields specific to IDD on the EMR; discrepancies were discussed and corrected to ensure consistency.

The review showed that 67% of charts had psychoeducational assessments noted, and 29% had an identified cause for the patient's IDD. Substitute decision makers or next of kin were identified in 81% of the charts; 54% identified lead caregivers and 48% identified developmental agencies. Accommodations, such as mobility or transfer needs, were recorded in 39% of charts, and 25% identified communication styles such as nonverbal expression. Fewer identified responses to pain, sensory needs, and safety concerns (7%, 6%, and 18%, respectively). Only 9% had crisis plans for acute mental or physical concerns documented. Risks and vulnerabilities such as trauma, drug use, or lack of social support were documented in various sections of the CPP, including in the risk factors, medical history, social history, or ongoing concerns fields.

The CPP section of the tool builds the groundwork for IDD-specific patient-centred care. Clinicians can use baseline information to tailor treatment plans and recognize early signs of illnesses. Areas of missing information in the CPP fields should be addressed and added into the action plan. Additional studies are needed to examine the barriers to completing the CPP and the Health Check.

Conclusion

Case resolutions. The cases above identify 3 common scenarios experienced by family doctors and their patients with IDD.

Diagnostic dilemmas in the setting of potential comorbidities: In the first case, after a Health Check and consultations from rehabilitation medicine and neurology, the diagnosis of exclusion was increasing frailty associated with aging.

Unrecognized health issues or missed opportunities for preventive care because of lack of continuity of care (eg, at the transition from pediatric to adult health care): In the second case, a Health Check was undertaken for this young man; with the help of his parent, records were obtained from the previous physician and multidisciplinary team members.

Undiagnosed IDD as a factor in our relationships with our patients, leading to missed opportunities for better communication: In the third case, recognition of this patient's disability led to improved financial resources, and the Health Check tool's annotations led the physician to suggest accessing local developmental disabilities services to arrange transportation and child care so the patient could attend follow-up appointments more easily.

With a comprehensive health assessment to guide the encounters, family doctors can feel better organized and equipped. The tool offers a framework to highlight and assess the unique needs of this population. ✿

Dr Casson is Associate Professor in the Department of Family Medicine at Queen's University in Kingston, Ont. Dr Hung is a resident in the third-year Family Medicine Developmental Disabilities Enhanced Skills Program in the Department of Family Medicine at Queen's University. Dr Grier is Assistant Professor in the Department of Family Medicine at Queen's University. Ms Karim is a master's student in the Faculty of Engineering at Queen's University.

References
1. Developmental Disabilities Primary Care Program. *Comprehensive health assessment (Health Check) tool*. Toronto, ON: Surrey Place; 2019. Available from: **http://ddprimarycare.surreyplace.ca/tools-2**. Accessed 2019 Mar 6.
2. Sullivan WF, Diepstra H, Heng J, Ally S, Bradley E, Casson I, et al. Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines. *Can Fam Physician* 2018;64:254-79 (Eng), e137-66 (Fr).
3. *Developmental Disabilities Primary Care Program* [website]. Toronto, ON: Surrey Place; 2019. Available from: **http://ddprimarycare.surreyplace.ca**. Accessed 2019 Mar 6.
4. Royal College of General Practitioners. *Annual health checks for people with learning disabilities—step by step toolkit*. London, UK: Royal College of General Practitioners; 2016. Available from: **www.rcgp.org.uk/clinical-and-research/a-to-z-clinical-resources/learning-disabilities.aspx**. Accessed 2018 Nov 19.
5. Casson I, Durbin J, Green L, Grier L, Lunsky Y, Perry A, et al. *Implementing Health Checks for adults with developmental disabilities: a toolkit for primary care providers*. Toronto, ON: Health Care Access Research and Developmental Disabilities; 2016. Available from: **www.porticonetwork.ca/web/hcardd/kte/primary-care-toolkit**. Accessed 2018 Nov 19.
6. Hennen B, O'Driscoll T, Berg JM, Block W, Forster-Gibson C, Joyce D, et al. Preventive care checklist for adults with a developmental disability (DD). In: Sullivan WF, Developmental Disabilities Primary Care Initiative Scientific and Editorial Staff, editors. *Tools for the primary care of people with developmental disabilities*. Toronto, ON: Surrey Place Centre, MUMS Guidelines Clearinghouse; 2011. p. 35-41. Available from: **http://ddprimarycare.surreyplace.ca/tools-2/general-health/preventive-care-checklist/**. Accessed 2018 Nov 19.
7. Zworth M, Selick A, Durbin J, Casson I, Lunsky Y. Improving care for adults with intellectual and developmental disabilities. Role of clerical staff. *Can Fam Physician* 2019;65(Suppl 1):S8-10.
8. Casson I, Broda T, Durbin J, Gonzalez A, Green L, Grier E, et al. Health checks for adults with intellectual and developmental disabilities in a family practice. *Can Fam Physician* 2018;64(Suppl 2):S44-50. Available from: **www.cfp.ca/content/cfp/64/Suppl_2/S44.full.pdf**. Accessed 2019 Jan 27.
9. Durbin J, Selick A, Casson I, Green L, Spassiani N, Perry A, et al. Evaluating the implementation of health checks for adults with intellectual and developmental disabilities in primary care: the importance of organizational context. *Intellect Dev Disabil* 2016;54(2):136-50.
10. Selick A, Durbin J, Casson I, Lee J, Lunsky Y. Barriers and facilitators to improving health care for adults with intellectual and developmental disabilities: what do staff tell us? *Health Promot Chronic Dis Prev Can* 2018;38:349-57.