

# Teaching family medicine residents about care of adults with intellectual and developmental disabilities

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## Abstract

**Problem addressed** Adults with intellectual and developmental disabilities (IDD), a group with complex health problems and inequities in access to health care, look to family physicians for primary care.

**Objective of program** To enable residents to learn and demonstrate competencies that are unique to the care of adults with IDD with minimal extra time and resources required of the residency program.

**Program description** In their regular family medicine teaching practices, residents undertake planned encounters with adults with IDD involving comprehensive health assessments with physical examinations. Tools to implement the Canadian guidelines for primary care of adults with IDD are available to support the residents in their encounters. Background information in the form of self-learning and small group learning resources, field notes with rubrics to assess residents' development of competencies, and faculty development resources are also available.

**Conclusion** It is important to include such planned clinical experiences in family medicine residency curricula because people with IDD have special needs that are difficult to learn about in other settings. It is a benefit to residents to have patients and families actively contributing to teaching.

## Editor's key points

- ▶ The described program was designed to increase the confidence and competence of family medicine residents in their care of adults with intellectual and developmental disabilities (IDD) by ensuring clinical encounters with such patients during residency.
- ▶ With leadership from at least 1 preceptor in a group, and support from administrative and clerical staff, family medicine residents were assigned to 1 or more patients with IDD from their teaching practices who accepted an invitation for a Health Check.
- ▶ Among the competencies unique to the primary care of adults with IDD, family medicine residents identified respect and communication as key themes in reflecting on their clinical experiences with these patients.

### Points de repère du rédacteur

- ▶ Le programme décrit vise à donner confiance aux résidents en médecine familiale et à rehausser leurs compétences lorsqu'ils dispensent des soins aux adultes ayant des déficiences intellectuelles et développementales (DID), en veillant à ce que des rencontres cliniques aient lieu avec ces patients durant la résidence.
- ▶ Sous le leadership d'au moins 1 précepteur dans un groupe, et avec le soutien du personnel administratif et de bureau, les résidents en médecine familiale comptaient au moins 1 patient ayant des DID, dans leur pratique de résidence, qui avait accepté une invitation à recevoir un bilan de santé.
- ▶ Lorsqu'ils ont réfléchi à leurs expériences cliniques avec les adultes ayant des DID, les résidents en médecine familiale ont mentionné notamment le respect et la communication parmi les compétences particulières aux soins de première ligne chez ces patients.

# Enseigner les soins pour adultes ayant des déficiences intellectuelles et développementales aux résidents en médecine familiale

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## Résumé

**Problème abordé** Les adultes ayant des déficiences intellectuelles et développementales (DID), un groupe qui présente des problèmes de santé complexes et qui subit des iniquités en matière d'accès aux soins de santé, se tournent vers les médecins de famille pour recevoir des soins de première ligne.

**Objectif du programme** Permettre aux résidents d'acquérir et de démontrer les compétences propres aux soins des adultes ayant des DID en exigeant du programme de résidence le minimum de ressources et d'heures supplémentaires.

**Description du programme** Durant leur pratique régulière de résidence en médecine familiale, les résidents ont des rencontres planifiées avec des adultes ayant des DID, qui incluent un examen médical complet et un examen physique. Durant les rencontres, les résidents ont accès aux outils de mise en application des lignes directrices consensuelles canadiennes en matière de soins primaires aux adultes ayant une déficience développementale. Ils ont aussi accès à de l'information générale sous forme de ressources d'autoapprentissage et d'apprentissage en petits groupes à des notes d'observation avec rubriques visant à évaluer les compétences acquises et à des ressources de formation professorale.

**Conclusion** Il importe d'inclure de telles expériences cliniques planifiées dans le cursus de résidence en médecine familiale puisque les personnes ayant des DID ont des besoins spéciaux qu'il est difficile d'apprendre à connaître dans d'autres contextes. Les résidents ont la chance de profiter de la participation active des patients et des familles à leur apprentissage.

The primary recommendation of a United Kingdom inquiry into the health of people with intellectual and developmental disabilities (IDD) was that there be mandatory competency-based health care training that involves people with IDD and their caregivers.<sup>1</sup>

In Canada, deinstitutionalization, “community living,” and discharge from the care of pediatric developmental specialists and multidisciplinary clinics have led adults with IDD and their families to seek care from family physicians. Recent data from Ontario show that there is good access to primary care: adults with IDD are as likely to see family physicians as members of the general population are and they have similar rates of continuity of care with their own family physicians.<sup>2</sup> Despite this, rates of cancer screening are lower among adults with IDD compared with the general population and rates of preventable hospital admissions are higher.<sup>3</sup> This suggests that there are challenges to providing primary care to adults with IDD. In a survey in an academic teaching practice, faculty and residents felt more comfortable with their communication skills and knowledge with respect to care issues and less comfortable with the community and other resources needed to help make accommodations.<sup>4</sup>

This article describes the outline of a teaching program at Queen’s University in Kingston, Ont, intended to increase the confidence and competence of family medicine residents in their care of adults with IDD. The program is based on the “Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines” (hereafter, *the guidelines*) and makes use of clinical tools that are available to assist implementing the guidelines’ recommendations.<sup>5</sup> A curriculum resource for family medicine residency programs on care of adults with IDD is also available.<sup>6</sup> It contains sections on competencies specific to the care of adults with IDD, a primer of basic knowledge, case modules for self-learning or small group learning, and rubrics for assessing residents’ development of the competencies.

The Medical Council of Canada has added knowledge and skill objectives regarding care of adults with IDD as criteria for qualifying new physicians.<sup>7</sup> Some medical schools in Canada, such as McMaster University in Hamilton, Ont, have integrated IDD competencies into their curricula to promote a progression of experiential learning.<sup>8</sup>

At the family medicine residency level, there is an opportunity to develop clinical expertise with this population. A group of interested Canadian family physicians who practise comprehensive family medicine proposed 4 competencies specific to the care of adults with IDD as a national standard for family medicine residency curricula.<sup>6</sup> Competent family medicine residents should be able to do the following:

- demonstrate awareness of ethical considerations (eg, with respect to obtaining consent);
- promote access to care, including practising effective communication;

- seek the cause or origin of the IDD (eg, a genetic syndrome) and assess the level of functioning to help facilitate effective management plans for persons with IDD; and
- apply knowledge of both common conditions and atypical presentations in this population.<sup>6</sup>

The main resources for the program are the clinical encounters with adults with IDD that family medicine residents have in their teaching practices. A general practice of 1500 patients could be expected to have about 10 adults with IDD.<sup>9</sup> In our experience, the competencies can best be achieved and demonstrated through a planned clinical encounter such as an annual comprehensive health assessment (including physical examination and preventive maneuvers). This kind of encounter is known in the IDD literature as a *Health Check*, and its benefits, in contrast with the current advice against “annual physicals” in the low-risk general population, have been demonstrated in adults with IDD.<sup>10</sup> Health Checks are a main recommendation of the guidelines.<sup>5</sup> Residents learn by engaging with persons with IDD, family members, and other caregivers. It is a benefit to residents to have patients and families actively contributing to teaching about the diversity of people with IDD, the patient-doctor relationship, the need for more time in clinical encounters, and the potential difficulties in accessing investigations and treatments.

### Objective of program

The program enables residents to develop the identified competencies, supports them in implementing the guideline recommendations, and increases their confidence in caring for adults with IDD.

Using a clinical encounter as the main learning resource minimizes the need for adding time in already busy family medicine residency curricula and can provide deeper learning than simply offering didactic education on the health issues of people with IDD. Such experiences can be implemented in both community teaching practices and academic units. In our experience, the involvement of a local champion can be an asset in implementing such educational innovations.

### Program description

**Learning resources.** The main learning resources are clinical encounters with patients, specifically, a planned Health Check.<sup>11</sup> Appointments are arranged by engaging the teaching practice’s clerical staff.<sup>12</sup> Suggestions are available to accomplish specific steps.<sup>13</sup>

- Identify 1 or more adults with IDD for each resident in a teaching practice. If the practice nurse or preceptor is unable to identify such patients, conduct a search of the electronic medical records.
- Invite the patient for a Health Check.
- Notify the resident and preceptor in advance of the appointment by e-mail or electronic medical record message. Also provide them with web links to

resource material for use before, during, and after the encounter.<sup>6,13</sup>

- To orient residents and support their learning during the clinical encounters, modules are available to facilitate small group problem-based learning (eg, in a core seminar series).<sup>6,14</sup> If possible, schedule an introductory seminar early in the first academic year before the planned clinical encounters.

Residents are particularly interested in seeing how to interact with adult patients with IDD, learning how to do physical examinations, and understanding how to minimize discomfort and distress. Preceptors are in a good position to model this with patients from their practices with whom they are familiar. Videos are also available.<sup>15-18</sup>

The views of people with IDD and their caregivers can be integrated into the clinical experience by explicitly inviting them to take part in teaching and assessments, exemplifying the disability rights movement's goal, "Nothing about us, without us" and the idea of "Being with, rather than doing to."<sup>19,20</sup> Videos and articles on patient and caregiver perspectives on interactions with family physicians are available.<sup>21-27</sup> Family physicians can enhance the capacity of patients with IDD and their caregivers to participate in the clinical encounter by sending them web links for tools such as an available e-book series about doctor's appointments or a template to fill out to help prepare for the visit beforehand.<sup>28,29</sup>

Given the needs of this population for interdisciplinary health care, other health care professionals will be especially valuable collaborators. Residents' presentations of cases at team meetings are an opportunity for interdisciplinary input into management plans.

### **Assessment of resident competencies**

**Field notes:** Field notes are templates for teachers to provide formative feedback to residents based on the 4 competencies demonstrated in an encounter with a patient with IDD.<sup>6</sup>

An unpublished review of 100 field notes on Queen's University family medicine residents' encounters with patients with IDD showed that the most common of the 4 competencies assessed by the teachers was the residents' communication skills. Teachers most often identified communication as a strength (eg, choosing words to suit a patient's level of understanding, allowing time for a patient to process questions and formulate an answer, involving the patient in discussion about his or her health, and not speaking only to the care provider). Teachers also noted improvements in communication as an issue for residents to consider (eg, engaging appropriately with family members and other caregivers of the patient as sources of collateral information about the patient). Another competency teachers assessed was a resident's ability to use knowledge of the cause of the patient's IDD to make appropriate plans (eg, assessing for dementia in an adult with Down syndrome).

**Case reflections:** Case reflections can promote self-assessment. This exercise requires residents to write a short reflection about the cognitive and emotional effects of their encounters with patients with IDD on themselves. A preceptor can review the reflection to promote discussion around challenging situations and reinforce positive aspects of the encounter, thereby facilitating deeper learning. Qualitative analysis of such case reflections by family medicine residents at Queen's University identified 4 themes. The first concerned empathy and respect, as the following quotations taken from residents' reflections demonstrate:

I recognized how vulnerable this population is.

I also gained some insight on how I view people with disabilities and I recognize that I am inwardly patronizing.

The second theme pertained to communication, facilitation, and support:

Interviewing a patient with IDD is not just about interviewing the patient; it is about interviewing his or her caregiver and relying on the caregiver's knowledge of the patient.

I was sensitive to the fact that the patient was in the room throughout the duration of our meeting with the home manager and made sure to look at him intermittently to communicate that we were talking about him and that we would be examining him shortly.

The third theme was about competence and confidence. As one resident illustrated, "The case challenged my critical thinking as I had to justify my actions more than usual, working with less information in a patient who was medically complex and had a unique social element as well."

The fourth theme related to the resident's own perceived learning needs: "Communication tools and adaptability to different communication methods are key to interacting with this population."

**Faculty development.** A challenge in implementing residency education is that teachers might not feel "expert" enough to effectively teach residents to care for people with IDD. Yet faculty development in this area could be as simple as a reminder that key characteristics of family medicine (eg, effective communication, continuity of care, comprehensive care) are also key elements of what makes for effective primary care for patients with IDD.

Just-in-time faculty development can be accomplished when the message from clerical staff to teachers regarding an upcoming clinical encounter with a patient with IDD (noted earlier as part of the preparation for a Health Check) is coupled with a reminder regarding the

**Table 1. Curriculum resources: Three websites provided resources referred to in this paper.**

RESOURCE	DESCRIPTION	WEBSITE
<i>Family Medicine Curriculum Resource. Adults with Developmental Disabilities</i> <sup>6</sup>	An 81-page booklet with a curriculum outline in 4 parts: competencies, primer, case modules, and rubrics for assessment	<a href="http://www.cfpc.ca/uploadedFiles/Directories/_PDFs/Family_Medicine_Curriculum_Resource_web_version_July_2014.pdf">www.cfpc.ca/uploadedFiles/Directories/_PDFs/Family_Medicine_Curriculum_Resource_web_version_July_2014.pdf</a>
<i>Curriculum of Caring</i> <sup>30</sup>	Series of videos, including “Keys to success when examining people with developmental disabilities” <sup>18</sup>	<a href="https://machealth.ca/programs/curriculum_of_caring">https://machealth.ca/programs/curriculum_of_caring</a>
<i>Implementing Health Checks for Adults with Developmental Disabilities: a Toolkit for Primary Care Providers</i> <sup>13</sup>	A 61-page booklet to help in the initial steps of implementing a program of Health Checks (“EMR key word search strategies,” “Searching and assigning ICD9 codes for IDD,” “Invitation script”) and then performing a Health Check (“Systems review in primary care for people with IDD,” “Commonly missed diagnoses: head-to-toe assessment”)	<a href="http://www.porticonetwork.ca/documents/38160/99698/Primary+Care+Toolkit_FINAL_ym2.pdf/dfa654d6-8463-41da-9b79-3478315503eb">www.porticonetwork.ca/documents/38160/99698/Primary+Care+Toolkit_FINAL_ym2.pdf/dfa654d6-8463-41da-9b79-3478315503eb</a>

EMR—electronic medical record, IDD—intellectual and developmental disabilities.

IDD guidelines and implementation tools or resident field notes. A small group discussion of a case module at a teachers’ meeting, along with a discussion of the competencies and formative feedback around competency development using field notes, can be a useful faculty development group session.<sup>6</sup>

Table 1 identifies 3 websites that provided resources referred to in this paper that might be helpful.<sup>6,13,18,30</sup>

## Discussion

Experiential learning in the primary care of adults with IDD is important for future family physicians and their patients. A blend of resources, mentored clinical encounters, and reflective exercises can foster a special interest in family medicine residents in the primary care of adults with IDD. The Health Check encounter is one way to implement a competency-based IDD curriculum systematically in a residency program.

We have learned that the following considerations are important for such a curriculum. Clinical encounters enable learning and allow demonstration of the competencies that are specific to the primary care of adults with IDD. Patients, families, and caregivers should be involved in teaching. Preceptors should model encounters with patients with IDD. Faculty development should be undertaken to improve faculty comfort with teaching about IDD.

## Conclusion

It is important to include IDD-specific education in the family medicine residency curriculum because of the unique health needs of people with IDD. Such a teaching program for family medicine residents provides education not only about people with IDD but also about responsive, person-centred practices. We hope the methods and resources discussed in this paper can act as a guide for Canadian family medicine programs to integrate such training into their curricula. 🌱

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### Contributors

All authors contributed to the concept and design of the program and evaluation; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

### Competing interests

None declared

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### References

1. Michael J. *Healthcare for all: report of the independent inquiry into access to health-care for people with learning disabilities*. London, UK: National Health Service; 2008. Available from: [webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099255](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255). Accessed 2017 Feb 25.
2. Isaacs BJ, Jaakkimainen RL, Barnsley J, Klein-Geltink JE, Balogh RS, Cobigo V, et al. Health services utilization. In: Lunskey Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults with developmental disabilities in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013. p. 41-62. Available from: [www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e](http://www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e). Accessed 2017 Feb 13.
3. Ouellette-Kuntz HMJ, Cobigo V, Balogh RS, Wilton AS, Lunskey Y. Secondary prevention. In: Lunskey Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults with developmental disabilities in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013. p. 65-86. Available from: [www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e](http://www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e). Accessed 2017 Feb 13.
4. Casson I, Durbin J, Grier E, Griffiths J, Khodaverdian A, Lake J, et al. Exploring barriers to care: knowledge, comfort level, and attitudes of primary care providers towards patients with developmental disability. *J Dev Disabil* 2014;20(3):111.
5. 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).
6. Developmental Disabilities Primary Care Initiative Curriculum Working Group. *Family medicine curriculum resource. Adults with developmental disabilities*. Toronto, ON: Surrey Place Centre; 2014. Available from: [www.cfpc.ca/uploadedFiles/Directories/\\_PDFs/Family\\_Medicine\\_Curriculum\\_Resource\\_web\\_version\\_July\\_2014.pdf](http://www.cfpc.ca/uploadedFiles/Directories/_PDFs/Family_Medicine_Curriculum_Resource_web_version_July_2014.pdf). Accessed 2019 Mar 13.
7. Medical Council of Canada. *Objectives for the qualifying examination—adults with developmental disabilities*. Ottawa, ON: Medical Council of Canada; 2012. Available from: [http://apps.mcc.ca/Objectives\\_Online/objectives.pl?lang=english&role=expert&id=21-1](http://apps.mcc.ca/Objectives_Online/objectives.pl?lang=english&role=expert&id=21-1). Accessed 2017 Feb 26.
8. Boyd K. The curriculum of caring: fostering compassionate, person-centered health care. *AMA J Ethics* 2016;18(4):384-92.

9. Lin E, Selick A, Balogh RS, Isaacs BJ, Ouellette-Kuntz HM, Klein-Geltink JE, et al. Prevalence, demographic and disease profiles. In: Lunsky Y, Klein-Geltink JE, Yates EA, editors. *Atlas on the primary care of adults with developmental disabilities in Ontario*. Toronto, ON: Centre for Addiction and Mental Health, Institute for Clinical Evaluative Sciences; 2013. p. 20-40. Available from: [www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e](http://www.porticonetwork.ca/documents/38160/99698/Atlas+revised+2014/c2d68a41-ed3d-44dc-8a14-7f30e044c17e). Accessed 2017 Sep 15.
10. Robertson J, Hatton C, Emerson E, Baines S. The impact of health checks for people with intellectual disabilities: an updated systematic review of evidence. *Res Dev Disabil* 2014;35(10):2450-62. Epub 2014 Jun 28.
11. 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.
12. 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.
13. Durbin J, Lunsky Y, Green L, Perry A, Casson I, Grier L, 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/documents/38160/99698/Primary+Care+Toolkit\\_FINAL\\_ym2.pdf/dfa654d6-8463-41da-9b79-3478315503eb](http://www.porticonetwork.ca/documents/38160/99698/Primary+Care+Toolkit_FINAL_ym2.pdf/dfa654d6-8463-41da-9b79-3478315503eb). Accessed 2018 May 1.
14. *Developmental disabilities in adults*. Hamilton, ON: Foundation for Medical Practice Education; 2011.
15. Lunsky Y; H-CARDD Team. *Best practice series: adapting medical procedures (teaching points)* [video]. Toronto, ON: Centre for Addiction and Mental Health, Health Care Access Research and Developmental Disabilities; 2016. Available from: [www.youtube.com/watch?v=aJPrud3EsfI&list=PLNuPQneaGMwAsD5xIHQFiLD-I9Ds1\\_h2Z](http://www.youtube.com/watch?v=aJPrud3EsfI&list=PLNuPQneaGMwAsD5xIHQFiLD-I9Ds1_h2Z). Accessed 2017 Aug 22.
16. Lunsky Y; H-CARDD Team. *Best practice series: improving primary care (teaching points)* [video]. Toronto, ON: Centre for Addiction and Mental Health, Health Care Access Research and Developmental Disabilities; 2016. Available from: [www.youtube.com/watch?v=YG\\_y7ztnvSI&list=PLNuPQneaGMwAsD5xIHQFiLD-I9Ds1\\_h2Z&index=2](http://www.youtube.com/watch?v=YG_y7ztnvSI&list=PLNuPQneaGMwAsD5xIHQFiLD-I9Ds1_h2Z&index=2). Accessed 2017 Aug 22.
17. Lunsky Y; H-CARDD Team. *Best practice series: agitated patient (teaching points)* [video]. Toronto, ON: Centre for Addiction and Mental Health, Health Care Access Research and Developmental Disabilities; 2016. Available from: [www.youtube.com/watch?v=PldhnNUgUH0&list=PLNuPQneaGMwAsD5xIHQFiLD-I9Ds1\\_h2Z&index=10](http://www.youtube.com/watch?v=PldhnNUgUH0&list=PLNuPQneaGMwAsD5xIHQFiLD-I9Ds1_h2Z&index=10). Accessed 2017 Aug 22.
18. Grier L. Phase 2: keys to success when examining people with developmental disabilities [video]. In: *Curriculum of caring: a curriculum of caring for people with developmental disabilities*. Hamilton, ON: McMaster University; 2015. Available from: [https://machealth.ca/programs/curriculum\\_of\\_caring/m/mediagallery/2204](https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2204). Accessed 2017 Feb 11.
19. Moores G, Lidster N, Boyd K, Archer T, Kates N, Stobbe K. Presence with purpose: attitudes of people with developmental disability towards health care students. *Med Educ* 2015;49(7):731-9.
20. Bradley E, Caldwell P, Korosy M. "Nothing about us without us": understanding mental health and mental distress in individuals with intellectual and developmental disabilities and autism through their inclusion, participation and unique ways of communicating. *J Relig Soc* 2015;(Suppl 12):94-109. Available from: <https://dspace2.creighton.edu/xmlui/bitstream/handle/10504/65683/2015-32.pdf?sequence=3>. Accessed 2017 Jan 30.
21. Phase 1: voices of experience. How do you want to be treated? [video]. In: *Curriculum of caring: a curriculum of caring for people with developmental disabilities*. Hamilton, ON: McMaster University; 2015. Available from: [http://machealth.ca/programs/curriculum\\_of\\_caring/m/mediagallery/1870](http://machealth.ca/programs/curriculum_of_caring/m/mediagallery/1870). Accessed 2017 Feb 11.
22. Skotko BG, Levine SP, Goldstein R. Having a brother or sister with Down syndrome: perspectives from siblings. *Am J Med Genet A* 2011;155A(10):2348-59. Epub 2011 Sep 9.
23. Skotko BG, Levine SP, Goldstein R. Having a son or daughter with Down syndrome: perspectives from mothers and fathers. *Am J Med Genet A* 2011;155A(10):2335-47. Epub 2011 Sep 13.
24. Skotko BG, Levine SP, Goldstein R. Self-perceptions from people with Down syndrome. *Am J Med Genet A* 2011;155A(10):2360-9. Epub 2011 Sep 9.
25. Mastebroek M, Naaldenberg J, van den Driessen Mareeuw FA, Lagro-Janssen AL, van Schroyen Lantman-de Valk HM. Experiences of patients with intellectual disabilities and carers in GP health information exchanges: a qualitative study. *Fam Pract* 2016;33(5):543-50. Epub 2016 Jul 12.
26. Perry J, Felce D, Kerr M, Bartley S, Tomlinson J, Felce J. Contact with primary care: the experience of people with intellectual disabilities. *J Appl Res Intellect Disabil* 2014;27(3):200-11.
27. Wilkinson J, Dreyfus D, Bowen D, Bokhour B. Patient and provider views on the use of medical services by women with intellectual disabilities. *J Intellect Disabil Res* 2013;57(11):1058-67. Epub 2012 Sep 14.
28. Liu J. *My health booklet* [e-book series]. Toronto, ON: Surrey Place Centre. Available from: [www.surreyplace.ca/resources-publications/my-health-booklet-series-2/](http://www.surreyplace.ca/resources-publications/my-health-booklet-series-2/). Accessed 2019 Mar 12.
29. Sullivan WF, Cheatham T, Forster-Gibson C, Kelly M, Grier E, McDonell S, et al. Today's visit. 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 Guideline Clearing House; 2011. p. 24-5. Available from: <http://ddprimarycare.surreyplace.ca/tools-2/general-health/todays-visit/>. Accessed 2017 Aug 22.
30. Boyd K. *Curriculum of caring: a curriculum of caring for people with developmental disabilities*. Hamilton, ON: McMaster University; 2015. Available from: [machealth.ca/programs/curriculum\\_of\\_caring](http://machealth.ca/programs/curriculum_of_caring). Accessed 2017 Feb 11.

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