Comprehensive preventive care assessments for adults with intellectual and developmental disabilities
Part 2: 2003 to 2014

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Abstract
Objective  To determine if there has been an increase in preventive care among adults with intellectual and developmental disabilities (IDD) as a result of the publication of the Canadian consensus guidelines on the care of adults with IDD in 2006 and 2011.

Design  Ecological study.

Setting  Ontario.

Participants  The study group consisted of community-dwelling adults with IDD between the ages of 40 and 64 living in Ontario identified in 2009-2010 through administrative health and social services data. The comparison group consisted of a propensity-score-matched sample of the remaining Ontario population.

Main outcome measures  A combined measure of a health examination or a Primary Care Quality Composite Score (PCQS) of 0.6 or greater, or both. Both measures were identified using administrative health data.

Results  Adults with IDD were 2.04% more likely to have had a health examination or a PCQS of 0.6 or greater before 2011-2012 and 1.70% less likely after 2011-2012. Adults without IDD were 1.03% more likely before 2011-2012 and 13.74% less likely after 2011-2012 to have had a health examination or a PCQS of 0.6 or greater. Male patients with IDD were 15.60% more likely and male patients without IDD were 7.39% less likely to have had a health examination or PCQS of 0.6 or greater compared with female patients.

Conclusion  Despite the publication of the guidelines there has not been a corresponding increase in the uptake of the annual health examination or in the quality of preventive care among adults with IDD. More is required to reduce this documented inequity in care.

Editor’s key points
- While there is consensus that comprehensive preventive care should be a priority for adults with intellectual and developmental disabilities (IDD), many patients do not receive such care. This study aimed to assess if the Canadian consensus guidelines on the care of adults with IDD published in 2006 and 2011 had affected uptake of the annual health examination or the quality of preventive care (measured by the Primary Care Quality Composite Score [PCQS]) among adults with IDD.
- Only 57.37% of adults with IDD received an annual health examination or had a high PCQS in 2011-2012; this is lower than for adults without IDD (63.07%). Both adults with IDD and those without were more likely to have received an annual health examination or to have a higher PCQS before 2011-2012 than after.
- Mixed messages regarding annual health examinations in Ontario most likely contributed to the decrease observed after 2011-2012, as Ontario implemented a new fee code in January 2013 replacing the annual health examination, emphasizing that apparently healthy adults do not need an annual examination. However, the Canadian consensus guidelines recommend that adults with IDD receive an annual health examination including age- and sex-specific screening.
Évaluation des soins prophylactiques que reçoivent les adultes qui ont des déficiences intellectuelles et développementales

Partie 2 : de 2003 à 2014

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Résumé

Objectif Vérifier s'il y a eu une augmentation des soins prophylactiques chez les adultes qui ont des déficiences intellectuelles et développementales (DID) après la publication des lignes directrices consensuelles canadiennes de 2006 et 2011 sur les soins de ces patients.

Type d'étude Une étude écologique.

Contexte L'Ontario.

Participants Un groupe de patients âgés de 40 à 64 ans qui avaient des DID, qui vivaient dans leur milieu naturel en Ontario et qui avaient été identifiés en 2009-2010 à partir de données administratives des services sanitaires et sociaux. Le groupe témoin consistait en un échantillon de membres de la population générale ontarienne appariés en fonction de leur score de propension.

Principaux paramètres à l'étude La présence d'un examen de santé ou d'un score d'au moins 0,6 au PCQS, ou une combinaison des deux. Ces deux paramètres ont été obtenus à partir des données administratives sur la santé.

Résultats Les patients avec DID étaient 2,04 % plus susceptibles d'avoir subi un examen de santé ou eu un PCQS de 0,6 ou plus avant 2011-2012 et 1,70 % moins susceptibles d'en avoir eu après 2011-2012. Les adultes sans DID étaient 1,03 % plus susceptibles d'avoir subi un examen de santé avant 2011-2012 et 13,74 % moins susceptibles d'avoir eu un ou un PCQS d'au moins 0,6 après 2011-2012. Les sujets mâles avec DID étaient 15,60 % plus susceptibles et les patients mâles sans DID 7,39 % étaient moins susceptibles d'avoir subi un examen de santé ou eu un PCQS égal ou supérieur à 0,6. Les patients mâles avec DID étaient 15,60 % plus susceptibles et ceux sans DID 7,39 % étaient moins susceptibles d'avoir subi un examen de santé ou eu un PCQS de 0,6 ou plus par rapport aux patientes.

Conclusion Malgré la publication de lignes directrices sur l'importance des EAS pour les adultes ayant des DID, on n'a pas observé d'augmentation des examens de ce type chez ces patients ni de la qualité des soins prophylactiques qui leur ont été prodigués. D'autres interventions seront nécessaires pour corriger une telle iniquité.
While there is consensus that comprehensive preventive care should be a priority for adults with intellectual and developmental disabilities (IDD), less than 60% of those 40 to 64 years of age in 2013-2014 appeared to be receiving such care in Ontario.\(^1\) Does this represent a positive trend in keeping with the publication of consensus guidelines for this population,\(^2,3\) a downward trend reflecting a general move away from provision of annual health examinations for asymptomatic adults,\(^4\) or stability over time? This brief report examines the trend in the provision of comprehensive preventive care to adults with and without IDD in Ontario since 2003.

There are numerous physician practice guidelines developed and updated as new evidence becomes available. Some apply to broad patient groups, while others like the Canadian consensus guidelines on the primary care of adults with IDD target a small segment of a physician’s practice.\(^5,6\) This can result in competing messages being promoted; what might be recommended for a specific group might be discouraged for the broader patient population. The preventive care recommendations concerning annual health examinations or “physicals” is a case in point.

Up until very recently, the annual health examination was a primary component of comprehensive preventive care assessments. The health examination is an appointment made expressly for asymptomatic adults to receive screening.\(^5\) In Canada, there is a movement away from using the health examination as a tool to deliver preventive care. In Ontario, the annual health examination for apparently healthy adults was replaced in 2013 by the personal health visit:

> The personal health visit is for healthy patients who have no apparent medical problems, the physician and patient can use the appointment to discuss prevention like screening for cancer and other health issues relevant to the individual patient’s medical history and lifestyle. In addition, any examination required can be focused on the individual needs of the patient relevant to their risk profile depending on their age, sex and health history.\(^6\)

As defined, the personal health visit is consistent with the 2011 consensus guideline recommendation for comprehensive preventive care assessment for adults with IDD, which calls for attention to the risk profile of this subpopulation.\(^5\)

With the movement away from the traditional annual health examination in Ontario, it is important to assess the effect this is having on the quality of preventive care received by adults with and without IDD and the ability of physicians to meet the guideline recommendations of an annual health examination for adults with IDD. The objective of this study was to determine if there has been an increase in preventive care among adults with IDD as a result of the publication of the Canadian consensus guidelines in 2006 and 2011.\(^2,5\)

### Methods

#### Study population

The study group consisted of community-dwelling adults with IDD, between the ages of 18 and 64 living in Ontario identified in 2009-2010 through administrative health and social services data.\(^7\) This group was followed from 2003-2004 to 2013-2014, with members only entering the cohort if they aged in (ie, became 18 years old) and exiting if they aged out (ie, turned 65 years of age), were admitted to long-term care, or died. A comparison group of the remaining Ontario population was also used to control for any secular trend. Initially, the comparison group was matched on sex in order to decrease the potential number of matches, and then they were matched on propensity score. The propensity score was calculated using age, morbidity (number of Aggregated Diagnostic Groups [Johns Hopkins ACG System, version 10]), neighbourhood income quintile, and rurality (2008 Rurality Index for Ontario).\(^8\) A new propensity-score-matched comparison group was created for each fiscal year to ensure the continued similarity of the groups over time. A 1-to-1 matching ratio with a 0.2 caliper was used. For more information on the study population see Smith.\(^9\)

For the analyses presented in this paper, the study population was restricted to those 40 years of age and older because the screening maneuvers examined focus on this group.

#### Outcome

As discussed in part 1,\(^1\) measuring the provision of comprehensive preventive care using health administrative data is challenging. To address some of these challenges, an indicator combining health assessment or health visit codes with Dahrouge and colleagues’ Primary Care Quality Composite Score (PCQS)\(^10\) was used in this analysis. The PCQS combines 7 screening maneuvers that are identified as either up-to-date or not. A score is created based on the proportion of eligible maneuvers that are up-to-date. Each year, an individual was deemed to have received comprehensive preventive care if he or she had had a general health assessment (A003 with diagnostic code 917 or 319) or a periodic health visit (K131) or a PCQS of 0.6 or higher.

#### Statistical analyses

Data sets were linked using unique encoded identifiers and analyzed at ICES in Kingston, Ont. All analyses were conducted using SAS, version 9.4. A negative binomial segmented regression was used to quantify the trend seen, to determine if the trend changed, and if so, to
determine at what time point. Segmented regression is a type of nonlinear regression that allows for the relationship between the outcome and exposure to change after a certain point. The simplest form is one where 2 straight lines join sharply at the join point (the point where the trend changes). The model assessed included year (treated as a continuous variable), group, age (treated as continuous), and sex, and group by year, group by age, and group by sex interaction terms, as well as an offset term equal to group size. Age was included because of the way the study was designed, with the age of the population shifting upward each year. The effect of age was allowed to vary across groups; previous work demonstrated that adults with IDD were less likely to have a health examination than adults without IDD were, and this difference increased as age increased. A group-by-year interaction term was included because this previous literature reported that adults with IDD were less likely to have a health examination, and it was hypothesized that the publication of the guidelines might alter the magnitude of this difference over time.

--- Results ---

Study population
After propensity score matching, group sizes ranged from 21024 in 2003-2004 to 28825 in 2013-2014. Table 1 provides the characteristics for each group in 2009-2010.

Segmented regression
Figure 1 shows the proportion of adults who received a health examination or who had a PCQS of 0.6 or greater from 2003-2004 to 2013-2014 by IDD status and sex. Only 57.37% of adults with IDD received an annual health examination or had a high PCQS in 2011-2012, compared with 63.07% of adults without IDD. The segmented regression revealed that adults with IDD were 2.04% more likely to have had a health examination or a PCQS of 0.6 or greater before 2011-2012 and 1.70% less likely after 2011-2012. Adults without IDD were 1.03% more likely before 2011-2012 and 13.74% less likely after 2011-2012 to have had a health examination or a PCQS of 0.6 or greater. Male patients with IDD were 15.60% more likely and male patients without IDD were 7.39% less likely to have had a health examination or a PCQS of 0.6 or greater compared with female patients. These results need to be interpreted with caution, as SAS was unable to estimate the standard error for the effect of year before and after 2011-2012, most likely owing to the small number of data points available after 2011-2012.

--- Discussion ---

The Canadian consensus guidelines for the primary care of adults with developmental disabilities recommend that adults with IDD receive an annual health examination and age- and sex-specific screening. Despite these recommendations, only 57.37% of adults with IDD received an annual health examination or had a high PCQS in 2011-2012; this is lower than for adults without IDD (63.07%). The proportions decreased after 2011-2012 for both groups, indicating the publication of the guidelines did not increase the uptake of the health examination or improve PCQS. This finding could in part be owing to the short follow-up period. Balas and Boren estimated that it takes approximately 10 years for clinical recommendations from guidelines, reviews, or textbooks to be adopted by at least 50% of physicians. Mixed messages regarding annual health examinations in Ontario most likely contributed to the decrease observed after 2011-2012. Debate about these examinations was highlighted in Canadian Family Physician beginning in 2011. In January of 2013, Ontario implemented a new fee code with a corresponding decrease in payment and renamed the annual health examination the personal health visit, emphasizing that apparently healthy adults do not need an annual health examination.

It is recognized that physicians might require administrative and clinical supports to identify their patients with IDD, to communicate effectively with them and their caregivers about the need for comprehensive preventive care, and to adapt their practice to ensure delivery of all age- and sex-specific screening maneuvers.

Limitations
As mentioned, measuring the provision of comprehensive preventive care using health administrative data is challenging, and additionally, SAS was unable to estimate the standard error for the effect of year before

<table>
<thead>
<tr>
<th>Table 1. Group characteristics in 2009-2010</th>
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<tr>
<td>CHARACTERISTICS</td>
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<tr>
<td>No. of patients</td>
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<tr>
<td>Mean (SD) age, y</td>
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<tr>
<td>Female sex, %</td>
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<tr>
<td>Mean (SD) morbidity*</td>
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<td>Neighborhood income,* %</td>
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<td>• 1 (Low)</td>
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<td>• 5 (High)</td>
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<td>Mean (SD) rurality*</td>
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*ADGs—Aggregate Diagnostic Groups, IDD—intellectual and developmental disabilities. Morbidity is the number of ADGs (Johns Hopkins ACG System, version 10), neighbourhood income is neighborhood income quintile, and rurality is the 2008 Rurality index for Ontario score.
and after 2011-2012. The follow-up period, particularly following publication of the 2011 guidelines, was also relatively short. Further, this study relied on administrative data collected in Ontario, and might not be generalizable to other parts of Canada.

**Conclusion**

Despite the publication of the guidelines2,3 there has not been a corresponding increase in the uptake of the annual health examination or in the quality of preventive care among adults with IDD. More is required to reduce this documented inequity in care. Some countries have had success with incentivizing the health examination for adults with IDD4,5,6 or providing support through tools.7-21 Ongoing efforts in Ontario require continued tracking of adherence to practice guidelines for this vulnerable population.

**Ms Smith** was a master’s student in the Department of Public Health Sciences at Queen’s University in Kingston, Ont, at the time of the study and is a methodologist with ICES at the University of Ottawa in Ontario and the Ottawa Hospital Research Institute. **Dr Ouellette-Kuntz** is an epidemiologist and Professor in the Department of Public Health Sciences and with ICES at Queen’s University. **Dr Green** is Professor in the Department of Public Health Sciences and the Department of Family Medicine, Head of the Department of Family Medicine, Senior Adjunct Scientist with ICES, past Director of the Centre for Health Services and Policy Research, and Associate Director of the Centre for Studies in Primary Care, all at Queen’s University.

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**Contributors**

**Ms Smith** completed the analyses and wrote the article. **Drs Ouellette-Kuntz and Green** assisted with analyses and with writing the article, and were the lead author’s supervisors for this project.

**Competing interests**

None declared

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