

Improving the quality of primary care for adults with intellectual and developmental disabilities

Value of the periodic health examination

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Abstract

Objective To implement a Health Check protocol for patients with intellectual and developmental disabilities (IDD) and assess outcomes.

Design Retrospective chart review and staff survey.

Setting Two Ontario family health teams.

Participants Of 276 patients with IDD identified, 139 received the Health Check (Health Check group). A convenience sample (N = 147) of clinical staff participated in the survey.

Main outcome measures The protocol included patient identification, invitation, and modified health examination. Chart review assessed completion of 8 preventive maneuvers, and clinical staff were surveyed on their comfort, knowledge, and skills in care of patients with IDD. Logistic regression analyses were used to compare outcomes for the Health Check and non-Health Check groups, adjusted for practice site.

Results Documentation of blood pressure, weight, body mass index, and influenza vaccination was significantly higher ($P < .001$) in the Health Check group, exceeding 70% of patients. Screening rates were higher for mammograms (63% vs 54%), fecal occult blood testing (39% vs 23%), and diabetes testing (80% vs 61%), but not significantly so, and they were similar to general population rates. Papanicolaou test rates were low for both groups (34% vs 32%). Staff comfort and skills were rated significantly higher ($P < .05$) for those who performed the Health Check. Still, fewer than half thought they had the necessary skills and resources to care for patients with IDD.

Conclusion Performing the Health Check was associated with improved preventive care and staff experience. Wider implementation and evaluation is needed, along with protocol adjustments to provide more support to staff for this work.

Editor's key points

- ▶ Canadian guidelines for the primary care of patients with intellectual and developmental disabilities (IDD) recommend a comprehensive health review (Health Check), but implementation is challenging. This study assessed the effectiveness of a Health Check protocol in 2 family health teams.
- ▶ Periodic health examinations can improve preventive screening rates and increase staff comfort and skill caring for patients with IDD, as was the case in this study. Inviting patients with IDD in for periodic health examinations can help to shift from reactive to proactive care.
- ▶ Processes can be implemented to make examinations more feasible to conduct and more beneficial for patients with IDD.

Points de repère du rédacteur

► Les lignes directrices consensuelles canadiennes en matière de soins primaires aux adultes ayant une déficience intellectuelle et développementale (DID) recommandent l'évaluation médicale périodique complète (examen médical), mais il peut être difficile de mettre cette recommandation en pratique.

Cette étude a évalué l'efficacité du protocole d'examen médical auprès de deux équipes de santé familiale.

► L'examen médical périodique peut améliorer le taux de dépistage préventif et accroître l'aisance et les compétences du personnel durant les soins aux patients ayant une DID, comme cela était le cas dans cette étude. Le fait d'inviter les patients ayant une DID à subir un examen médical périodique fait passer les soins de réactifs à proactifs.

► Il est possible de mettre des protocoles en place pour faciliter la faisabilité des examens et les rendre plus bénéfiques aux patients ayant une DID.

Améliorer la qualité des soins de première ligne pour les adultes ayant des déficiences intellectuelles et développementales

Valeur de l'examen de santé périodique

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Résumé

Objectif Mettre en place un protocole relatif aux examens médicaux des patients ayant une déficience intellectuelle et développementale (DID) et évaluer les résultats.

Type d'étude Revue rétrospective des dossiers et enquête auprès du personnel.

Contexte Deux équipes de santé familiale de l'Ontario.

Participants Sur les 276 patients ayant une DID identifiés, 139 ont reçu un examen médical (groupe examen médical). Un échantillon *ad hoc* (n = 147) de membres du personnel clinique a répondu à l'enquête.

Principaux paramètres à l'étude Le protocole incluait l'identification des patients, une invitation et un examen médical modifié. La revue des dossiers a évalué l'exécution de 8 manœuvres de prévention, et les membres du personnel clinique ont répondu à des questions sur leur aisance, leurs connaissances et leurs compétences pour dispenser des soins aux patients ayant une DID. Des analyses de régression logistique ont comparé les résultats entre les groupes examen médical et absence d'examen médical, ajustés en fonction de la pratique.

Résultats La documentation de la tension artérielle, du poids, de l'indice de masse corporelle et de la vaccination antigrippale était significativement supérieure ($p < 0,001$) dans le groupe examen médical, dépassant 70 % des patients. Le taux de dépistage était plus élevé, sans l'être de façon significative, dans le cas des mammographies (63 c. 54 %), des recherches de sang occulte dans les selles (39 c. 23 %) et des tests de dépistage du diabète (80 c. 61 %), et il était similaire au taux observé dans la population générale. Le taux de tests de Papanicolaou était faible dans les deux groupes (34 c. 32 %). Le taux d'aisance et d'aptitudes du personnel était significativement plus élevé ($p < 0,05$) chez les membres du personnel qui avaient réalisé un examen médical. Cependant, moins de la moitié étaient d'avis qu'ils possédaient les compétences et les ressources nécessaires pour dispenser des soins aux patients ayant une DID.

Conclusion La réalisation d'un examen médical était associée à l'amélioration des soins préventifs et de l'expérience du personnel. Il est nécessaire d'élargir la mise en pratique et l'évaluation, de même que l'ajustement du protocole, afin d'offrir plus de soutien au personnel pour ce type de travail.

Adults with intellectual and developmental disabilities (IDD) have a unique pattern of health challenges, including increased rates of physical disabilities, sensory impairments, obesity, psychiatric disorders, seizure disorders, and disorders of the respiratory, gastrointestinal, and endocrine systems.¹⁻³ They also have high rates of emergency department visits and inpatient admissions, some of which are for ambulatory care-sensitive conditions.⁴⁻⁶ Owing to difficulties accessing care that meets their health needs,^{7,8} patients with IDD generally receive care that is reactive rather than proactive, with preventive care rates being particularly low.^{2,9}

Although no longer recommended for the general population,¹⁰ comprehensive health reviews (or Health Checks) are an evidence-based strategy for improving preventive care in adults with IDD.¹¹ They are associated with increased preventive care testing, detection of new health conditions, and better follow-up management,^{2,9} and they can enhance practitioner comfort and knowledge of IDD health needs.^{11,12} The Health Check is recommended in the "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines."¹¹

Policy initiatives to promote Health Checks for people with IDD have been introduced in a number of jurisdictions internationally.¹¹ While the rate of delivery has increased, the effects on preventive screening and disease recognition vary.^{2,13} For the patients, factors such as poor health literacy and communication skills and dependence on carers might complicate examination participation and preventive screening uptake. Clinical staff might lack adequate time to conduct examinations, knowledge of the specific disease risks associated with IDD, and comfort interacting with the patients.^{12,14,15} In Ontario, a recent study using administrative health data found that, while most adults with IDD have primary care physicians, only 22% received a comprehensive examination over a 2-year period, and rates of preventive screening were lower than for the general population.¹⁶

Our team worked with 2 Ontario family health teams (FHTs)¹⁷ to implement a protocol for conducting the Health Check and evaluated the results. The implementation is described elsewhere.¹⁸ Here we report on outcomes. Specifically, we assessed the effects on preventive screening rates and on staff comfort and knowledge related to care of adult patients with IDD.

— Methods —

Health Check implementation

Each FHT site identified patients with IDD through an electronic medical record (EMR) key word and diagnostic code search (IDD cohort). These patients were proactively invited for a Health Check, and staff were supported to conduct the examination with point-of-care tools and education about IDD in primary care.¹⁹ The implementation period was 22 months at FHT 1 (July 2013 to April 2015) and 15 months at FHT 2 (June 2014 to August 2015).

Outcome measures and sample

We employed a cross-sectional design using a chart audit and a staff survey to assess outcomes at the end of the implementation period for those who did and did not receive or deliver Health Checks.

Chart audit. The audit assessed delivery of 8 preventive maneuvers recommended in the Canadian guidelines and for which data were available (**Table 1**).²⁰⁻²³ We calculated the portion of eligible patients who received each maneuver during a 2-year period. The IDD cohort constituted the audit sample.

Staff survey. A questionnaire on staff views about care of patients with IDD was developed based on existing attitude measures^{24,25} and refined through 2 rounds of pilot-testing. The final survey asked about overall confidence in the quality of care provided to patients with IDD (1 item); skills, knowledge, and comfort in care of patients with IDD (5 items); and practice supports (2 items). Three additional items on the intervention fit, benefit, and feasibility were only completed by staff who had performed a Health Check. For each item, staff rated their agreement on a 5-point Likert scale from strongly disagree to strongly agree. Surveys were anonymous and voluntarily completed by physicians and nurses at rounds and staff meetings following implementation (convenience sample).

Analysis

Logistic regression analyses were used to assess the effects of Health Check delivery. For preventive care outcomes, performance of each maneuver was the dependent variable and whether or not the patient received a Health Check was the predictor. For staff experience outcomes, the portion of respondents positively rating each survey item was the dependent variable and whether or not they had performed a Health Check was the predictor. To assess whether the relationship between Health Check delivery or receipt and outcomes persisted independent of site, we adjusted the models for practice site. Percentages, odds ratios, 95% CIs, and *P* values were reported to summarize and compare results between groups. With only 2 practice sites and relatively small sample sizes for some tests with limited eligibility, such as mammograms, we could not evaluate the influence of additional practice or provider factors on outcomes.

Ethics approval was obtained from the home institutions of the research team and the 2 primary care sites.

— Results —

Preventive testing

Of the 276 patients with IDD identified at the 2 FHT sites, 139 (50%) attended a Health Check (**Table 2**). Most had blood pressure, weight, and body mass index (BMI) recorded; many had received a hemoglobin A_{1c} test,

influenza vaccine, and mammogram; and few had had Papanicolaou tests or fecal occult blood tests (FOBTs). Provision of general health tests (blood pressure, weight, BMI) and influenza vaccination was higher in the Health Check than the non-Health Check group, and these differences held in the adjusted models. For cancer and diabetes screening, rates did not differ between the 2 groups in either the unadjusted or adjusted models.

Staff feedback

Surveys were completed by 147 staff, of whom 98 (67%) had performed a Health Check (Table 3). Of those who performed the Health Check, most were familiar with the Canadian consensus guidelines for primary care of adults with IDD. Many felt able to adapt their approach and were comfortable caring for the patients. Fewer reported being aware of specific health comorbidities and community

resources or having the necessary skills, training, and resources to make needed accommodations. Overall, half believed they could provide high-quality care to patients with IDD. Across all 8 items, ratings were significantly higher for staff who completed the Health Check compared with those who did not, and most differences remained significant in the adjusted analyses.

Those who completed Health Checks indicated that the intervention fit with the FHT mandate (94%) and benefited patients (87%), and two-thirds thought they were feasible to perform.

— Discussion —

The Health Check has been shown to increase the quality of care for patients with IDD in other countries, and it is recommended in the Canadian consensus guidelines

Table 1. Preventive maneuvers evaluated in the chart audit

MANEUVER	ELIGIBLE PATIENTS AND RECOMMENDED FREQUENCY
General health status	
• BP measurement recorded	Adult patients, at each HC visit
• Weight measurement recorded	Adult patients, at each HC visit ²⁰
• BMI measurement recorded	Adult patients, at each HC visit ²⁰
Screening tests	
• Papanicolaou test result (cervical cancer screening) recorded	Female patients, aged 21-69 y; every 2-3 y ²¹
• Mammogram test result recorded	Female patients, aged 50-74 y; every 2 y ²¹
• FOBT (colorectal cancer screening) result recorded	Adult patients, aged 50-74 y; every 2 y ²²
• FPG or HbA _{1c} result recorded	Adult patients, BMI > 29 kg/m ² or aged > 39 y, every 2 y ²³
Administration of influenza vaccine recorded	Adult patients, annually

BMI—body mass index, BP—blood pressure, FOBT—fecal occult blood test, FPG—fasting plasma glucose, HbA_{1c}—hemoglobin A_{1c}, HC—Health Check.

Table 2. Association between attending Health Checks and preventive health maneuvers completed, adjusted by practice site

PREVENTIVE MANEUVER (NO. ELIGIBLE IN FHT 1, FHT 2)	MANEUVER COMPLETED,* %		UNADJUSTED MODEL, OR (95% CI), P VALUE	ADJUSTED MODEL, [†] OR (95% CI), P VALUE
	HEALTH CHECK GROUP (N = 139)	NON-HEALTH CHECK GROUP (N = 137)		
BP recorded (139, 137)	91	64	5.4 (2.7-10.5), P < .001	5.5 (3.1-9.8), P < .001
Weight recorded (139, 137)	89	62	4.7 (2.5-8.8), P < .001	5.5 (2.8-0.5), P < .001
BMI recorded (139, 137)	84	50	5.0 (2.8-8.7), P < .001	5.5 (3.1-9.8), P < .001
Influenza vaccine received (139, 137)	70	47	2.6 (1.6-4.2), P < .001	2.7 (1.7-4.6), P < .001
Papanicolaou test* (68, 50)	34	32	1.1 (0.5-2.4), P = .835	1.0 (0.5-2.2), P = .980
Mammogram [§] (27, 13)	63	54	1.5 (0.6-1.5), P = .582	1.3 (0.3-5.1), P = .723
FOBT (49, 31)	39	23	2.2 (0.8-6.0), P = .136	2.4 (0.8-7.0), P = .107
HbA _{1c} test (46, 36)	80	61	2.6 (1.0-7.0), P = .057	2.5 (0.9-6.8), P = .070

BMI—body mass index, BP—blood pressure, FHT—family health team, FOBT—fecal occult blood test, HbA_{1c}—hemoglobin A_{1c}, OR—odds ratio.

*At least 1 result recorded during past 2 y.

[†]Adjusted for practice site.

[‡]Eligible population is female patients aged 21-69 y (site 2 excluded those who were not sexually active).

[§]Eligible population is female patients aged 50-74 y.

^{||}Eligible population is patients aged 50-74 y.

[¶]Eligible population is those with BMI > 29 kg/m² or age > 39 y.

Table 3. Staff feedback on Health Check delivery, adjusted by practice site

STAFF RATINGS	PERFORMED HEALTH CHECK, %, N = 98	DID NOT PERFORM HEALTH CHECK, %, N = 49	UNADJUSTED MODEL, OR (95% CI), P VALUE	ADJUSTED MODEL, OR (95% CI), P VALUE
Overall				
• I feel confident that I can provide high-quality care to the individual*	54	33	2.4 (1.2-4.9), P = .018	2.4 (1.1-5.2), P = .023
Knowledge, skills, and comfort				
• I am familiar with guidelines on primary care of adults with IDD†	84	42	6.6 (3.0-14.5), P < .001	8.5 (3.5-20.7), P < .001
• I feel skilled in adapting my communication and approach†	64	43	2.4 (1.2-4.8), P = .014	2.2 (1.0-4.5), P = .040
• I feel comfortable caring for patients with IDD†	59	35	2.7 (1.3-5.6), P = .006	3.3 (1.5-7.2), P = .003
• I feel knowledgeable about common comorbidities and care issues†	33	12	3.5 (1.3-9.0), P = .010	4.6 (1.6-12.7), P = .003
• I feel familiar with community resources†	27	10	3.2 (1.1-8.9), P = .027	3.3 (1.1-9.6), P = .031
Preparation and support				
• I feel I have the necessary skills and training to care for a patient with IDD†	40	22	2.3 (1.0-5.0), P = .039	2.1 (0.9-4.7), P = .086
• I feel equipped with resources for desired accommodations†	30	14	2.5 (1.0-6.2), P = .046	2.1 (0.8-5.5), P = .117

IDD—intellectual and developmental disabilities, OR—odds ratio.

*Proportion who agree or strongly agree.

†Proportion responding yes.

for primary care of adults with IDD.^{1,11} Implementation in the Canadian context is important to understand and is the contribution of this study. We worked with 2 Ontario primary care practices to implement a Health Check protocol, and assessed the effects on patient care and staff experience. Our findings showed some positive results but also some areas of challenge.

Regarding preventive care, documentation of blood pressure, weight, and BMI was significantly higher in the Health Check group, exceeding 80% of patients. The rate of diabetes screening, at 80%, was also high, although this was not significantly different from the non-Health Check group (61%). These screening tests are important given that both the risks and complications associated with diabetes and obesity are greater for individuals with IDD than comparable populations with no such disability.^{26,27}

The completion rates for FOBTs (39%) and mammograms (63%) were higher for the Health Check group (although not significantly so), and they are comparable to Ontario general population rates of 29%²⁸ and 65%,²⁹ respectively. Both of these tests are completed outside of the office, and the FOBT is a difficult screening test to perform. Thus, while our sample was small, our results are encouraging. Learning more about how these tests were explained to patients, and their caregivers when present, would be valuable as would continued monitoring to see if these results are sustained.

Pap test completion rates were not significantly different between the groups (34% and 32% for Health Check and non-Health Check groups, respectively) and are much lower than for the Ontario general population (63% in 2012 to 2014).²⁹ The Pap test is an invasive procedure that can create anxiety and discomfort in patients. It is mostly relevant for sexually active women. For patients with IDD, obtaining an accurate history to determine relevance might be challenging. Additionally, if a Pap test is appropriate, a discussion is needed to obtain consent or to arrange the conditions to facilitate assent.^{16,30} While the Health Check creates an opportunity to administer a Pap test, extra time might be needed to inquire about patient sexual activity and risk behaviour to determine need, explain the test using language adapted to the patient's cognitive level, and obtain approval to proceed.^{8,16,30} Few staff in our study reported feeling equipped with necessary time and resources to make needed accommodations for the Health Check, and a Pap test might be one example of a preventive care maneuver that clinical staff believed they could not easily accommodate.

While point-of-care tools and education about Health Check delivery were available to all clinical staff, those who performed Health Checks reported more comfort and knowledge in the care of patients with IDD across most assessed areas. Although the staff who

were willing to perform the Health Check might have already felt more knowledgeable and skilled, the value of direct contact to prepare staff to care for patients with IDD has been noted elsewhere.^{12,14,31} In our survey, most of those who performed the Health Check also thought that it benefited patients, so having direct contact might increase commitment to the intervention as well as enhance comfort and skills, and might be a key factor in the sustainable implementation of Health Checks.

Despite some positive results, staff indicated a need for more support, and there are a number of refinements to the Health Check protocol that might enhance practice capacity. If a standard approach to documenting the presence of IDD in patient charts is established, an EMR-based process can alert staff before Health Checks, and accommodations such as extra time and physically accessible clinic rooms can be planned. Nursing staff can help prepare both the patients and their caregivers for the examination, particularly the more invasive procedures, and can assist with some parts of the Health Check (eg, obtain health history).¹² Clerical staff can help to make patients more comfortable and less anxious while in the waiting room.³² Physicians can use health assessment instruments that have been modified specifically for care of patients with IDD.^{19,33} The Ontario H-CARDD (Health Care Access Research and Developmental Disabilities) initiative has developed a tool kit of resources that are freely available online, and both study sites have embedded some tools in their EMRs. Follow-up could further assess the use and value of these tools.³⁴

At the system level, incentive payments to account for the extra time that might be required to perform Health Checks have led to increased delivery in some jurisdictions. Registries of patients with IDD, also maintained in some jurisdictions, can be used to identify patients with IDD to invite to the Health Check and for other targeted prevention work.^{2,11}

Limitations

The study has a number of limitations. Staff feedback was based on a convenience sample and might not be generally representative of staff views about the care of patients with IDD. Also, staff perceptions might not align with actual practice. Related to patient outcomes, the eligible sample for some tests was small, limiting what we could learn about rates of delivery and group differences. However, our results align with the work of others suggesting that Health Checks have benefit. Also, some health issues common among patients with IDD (eg, related to vision, hearing, thyroid disease, gastrointestinal function) were not consistently recorded in practice EMRs and could not be examined. We only assessed 2 practices, and wider evaluation of this effort in more varied practice settings is needed. Finally, the study focused on preventive screening outcomes but other effects should be explored, including earlier or

more accurate recognition of disease, follow-up management, and team contributions to care.

Conclusion

A Health Check is a proactive strategy to comprehensively address the health needs of adults with IDD in primary care. In this study, in the context of Canadian family practice, the Health Check was associated with more preventive tests in some areas and higher levels of staff comfort with this patient group. Further studies can assess other effects and supports for practice staff to manage the patient visits so that the full value of the Health Check can be realized.

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Contributors

Dr Lunskey conceived the project. **Drs Durbin** and **Lunskey** designed the study and oversaw implementation and analyses. **Dr Durbin** led the writing of the manuscript. **Ms Selick** managed the implementation, performed the analyses, and contributed to the writing. **Ms Abou Chacra** assisted with preparing the survey and chart audit data. All authors discussed the results critically and assisted with and commented on the manuscript.

Competing interests

None declared

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