

# What adults with intellectual and developmental disabilities say they need to access annual health examinations

## System navigation support and person-centred care

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### Abstract

**Objective** To gain an understanding of the support needs of adults with intellectual and developmental disabilities (IDD) when scheduling, traveling to, and attending annual health examinations (AHEs).

**Design** Qualitative study that is part of a large population-level intervention aiming to increase uptake of AHEs among adults with IDD.

**Setting** Ontario.

**Participants** A total of 8 men and 5 women with IDD took part in semistructured interviews about their personal experiences related to AHEs.

**Methods** Thematic analysis was used to examine experiences relating to scheduling, traveling to, and attending AHEs.

**Main findings** Support emerged as the overarching theme. Support included assistance navigating the health care system (assistance scheduling AHEs, reminders to book AHEs, financial assistance, transportation) and person-centred care (respect of privacy and autonomy, communication style, kindness, compassion, rapport with physician, health advocacy, and collaboration). Barriers to this support were also identified (lack of rapport, perception of unfriendliness, perception that the physician is too busy to tend to needs, and perception that the physician did not want to perform AHEs).

**Conclusion** For adults with IDD, system navigation support and person-centred care were central to accessing AHEs. In collaboration with informal caregivers, physicians have an important role in reducing barriers to patients accessing this valuable preventive care opportunity. Physicians can fulfil some of the needs disclosed by adults with IDD related to attending AHEs by offering support for scheduling appointments, by linking patients with IDD to resources that facilitate appointment attendance, and by increasing consultation duration.

### Editor's key points

- ▶ Based on evidence of high morbidity and the complex health issues of adults with intellectual and developmental disabilities (IDD), a comprehensive health examination for this population is recommended. Such assessments have traditionally been performed at annual health examinations (AHEs); however, few adults with IDD receive AHEs.
- ▶ From the perspective of adults with IDD, system navigation support and person-centred care are valued qualities of effective provision of preventive primary care. Physicians can fulfil some of these needs by ensuring that adults with IDD have sufficient support to schedule appointments, have resources to attend appointments, have sufficient time during appointments to communicate health concerns, and have a good understanding of what is happening during the examination and of any recommendations.
- ▶ Collaborating with informal caregivers in instances in which additional support is needed is also beneficial. In the absence of person-centred care and support, some adults with IDD will not attend AHEs and will miss out on this valuable preventive health care opportunity.

### Points de repère du rédacteur

► Compte tenu des preuves attestant que les adultes présentant des déficiences intellectuelles et développementales (DID) ont une morbidité élevée et des problèmes de santé complexes, il est recommandé qu'ils subissent un examen de santé complet à chaque année. Traditionnellement, ce type d'évaluation fait partie de l'examen de santé annuel (ESA); toutefois, peu d'adultes ayant des DID subissent ces examens.

► Selon les adultes ayant des DID, il importe particulièrement de bénéficier d'une aide pour s'y retrouver dans le système et de soins centrés sur la personne afin de pouvoir d'avoir accès à des soins prophylactiques efficaces. Les médecins sont en mesure de répondre à ce type de demande en s'assurant que ces patients ont suffisamment de soutien pour prendre un rendez-vous, possèdent les ressources pour s'y rendre, ont suffisamment de temps durant la consultation pour faire part de leurs inquiétudes de santé, et comprennent bien ce qui se passe durant l'examen et chacune des recommandations qu'ils reçoivent.

► Pour les cas qui nécessitent davantage de soutien, il est également avantageux d'obtenir la collaboration de certains soignants. En l'absence d'un soutien et de soins centrés sur la personne, certains de ces patients n'iront pas à leur ESA et rateront ainsi une excellente occasion d'obtenir d'importants soins prophylactiques.

# Les besoins que disent avoir les adultes ayant des déficiences intellectuelles et développementales pour avoir accès à des examens de santé annuels

## De l'aide pour s'y retrouver dans le système et des soins centrés sur la personne

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### Résumé

**Objectif** Mieux comprendre ce dont ont besoin les adultes qui ont des déficiences intellectuelles et comportementales (DID) pour prendre rendez-vous pour un examen de santé annuel (ESA), s'y rendre et subir l'examen.

**Type d'étude** Une étude qualitative qui fait partie d'une intervention visant à augmenter l'accès à des ESA pour un grand nombre d'adultes ayant des DID.

**Contexte** L'Ontario.

**Participants** Un total de 8 hommes et de 5 femmes ayant des DID, qui ont participé à des entrevues semi-structurées sur leurs propres expériences relatives à l'ESA.

**Méthodes** On s'est servi d'une analyse thématique pour étudier les expériences des participants quant à la prise de rendez-vous, aux déplacements nécessaires et à la consultation comme telle.

**Principales observations** Le besoin de soutien était le thème primordial. Cela comprenait de l'aide pour s'y retrouver dans le système des soins de santé (pour prendre rendez-vous, se souvenir de réserver cette date, trouver l'argent et le transport nécessaires) et la qualité des soins centrés sur la personne (le respect de l'intimité et de l'autonomie, le mode de communication, la gentillesse, la compassion, le rapport avec le médecin et sa collaboration avec le patient pour lui permettre d'obtenir ce dont il a besoin). On a également identifié des facteurs faisant obstacle au soutien au patient (l'absence de rapport, la perception d'une certaine froideur, et l'impression que le médecin est trop occupé pour s'occuper des besoins du patient et qu'il n'est pas intéressé à faire l'ESA).

**Conclusion** Pour les adultes ayant des DID et voulant subir un ESA, il était primordial d'être aidés pour s'y retrouver dans le système et d'avoir des soins centrés sur la personne. Les médecins, en collaboration avec d'autres soignants, ont un rôle important pour réduire les obstacles qui empêchent ces patients de profiter de cette excellente occasion d'obtenir des soins prophylactiques. Les médecins peuvent répondre à certaines demandes des patients qui souhaitent subir un ESA en leur offrant de l'aide pour prendre rendez-vous, en les mettant en contact avec des ressources qui favoriseront leur présence au rendez-vous et en augmentant la durée de la consultation.

Chronic health problems, morbidity, and complex health issues are more prevalent among adults with intellectual and developmental disabilities (IDD).<sup>1</sup> An annual comprehensive preventive care assessment is therefore recommended for this population,<sup>2,3</sup> although it is no longer emphasized for low-risk adults in the general population.<sup>4</sup> Despite this recommendation,<sup>2,3</sup> only 22% of adults with IDD in Ontario were shown to have had an annual health examination (AHE) in a 2-year period.<sup>5</sup>

Common barriers to optimal health care for adults with IDD include time-limited appointments that give little opportunity for adults with IDD to adequately express themselves,<sup>6-8</sup> physicians addressing caregivers rather than patients, and overreferral or underreferral to non-family physician specialists.<sup>7</sup> Moreover, poor physician-patient rapport might lead to dissatisfaction with primary care and reduced primary health care uptake.<sup>9</sup>

In response to the sparsity of information pertaining to the low uptake of AHEs by adults with IDD in Ontario, this study sought to gain an understanding of the support needs of adults with IDD when scheduling, traveling to, and attending AHEs.

## — Methods —

This qualitative study<sup>10-12</sup> is part of a larger population-level intervention aiming to increase AHE uptake among adults with IDD across Ontario. Ethics approval was obtained from the University of Ottawa's research ethics board and the Health Sciences and Affiliated Teaching Hospitals Research Ethics Board of Queen's University in Kingston. Permission for this study was also granted by the Ministry of Community and Social Services of Ontario.

### Participants

Participants were recruited in partnership with the Ministry of Community and Social Services. An information package containing details about our study and information encouraging AHE attendance was mailed to Ontario Disability Support Program (ODSP) recipients with IDD (N=39 868). Interested recipients, their caregivers, or both were invited to participate in a telephone interview to briefly discuss experiences related to the AHE and to screen for eligibility to participate in a more detailed in-person interview; respondents included 85 persons with IDD. In this article, we report on follow-up, in-person interviews with adults with IDD (n=13) who subsequently attended an AHE following receipt of the information package. (Caregivers were not invited to participate in in-person interviews because the purpose of those interviews was to obtain the perspectives of adults with IDD.) From the 85 respondents with IDD, 31 respondents scheduled an AHE following receipt of the information package. Reasons for not scheduling an AHE included not having a family physician, already having

attended an AHE, or frequent visits to a primary care provider for reasons other than AHEs. Reasons for not participating in the in-person interview, despite attending an AHE, included lack of interest, inaccessibility owing to distance (some respondents resided in remote areas that were not accessible to the researchers), and difficulties maintaining contact with participants.

Participants provided informed consent by answering a series of questions to verify their comprehension of the study and their understanding of their rights as research participants (ability to withdraw consent at any time without consequence, right to not answer all questions, etc).

### Data collection

Data were collected through audiorecorded, in-person, semistructured interviews. Semistructured interviews are commonly used in qualitative research to allow for individual opinions, perspectives, and experiences to emerge<sup>13</sup>; moreover, they have been used successfully with individuals with IDD.<sup>14</sup> Key components of the interview guide included questions related to scheduling, getting to, and attending the AHE, such as the following:

- How did you book the appointment for the yearly checkup?
- What did the staff at the doctor's office say or do?
- How did you get to the appointment?
- Did you go alone or with someone?
- What happened when you got to the appointment?
- Was this appointment different than when you usually see your doctor?
- Was there anything you wanted your doctor to do differently?

Prompts and additional questions were used according to participants' responses to elicit more detailed information. To minimize the possibility of bias, the researchers adhered to established guidelines for interviewing persons with IDD<sup>15-17</sup> and maintained awareness of possible personal biases.

Four individuals conducted the interviews. They were undergraduate or graduate students in psychology and life sciences (all female students). All had previous experience doing research with adults with IDD. Two senior researchers (H.O.K., V.C.) provided training to the 4 individuals based on their experiences interviewing persons with IDD and published guidelines for research with persons with IDD.<sup>15-19</sup>

Participants chose the location of the interview; some chose to be interviewed at the agency where they received services, and others chose to be interviewed in their homes. All interviews were audiorecorded with the participants' consent. Four participants chose to have a caregiver present during the interview. All caregivers signed confidentiality agreements. Interviews ranged from 20 minutes to 1 hour. All participants were assigned pseudonyms.

## Data analysis

Throughout the analyses, the researchers reflected on personal and research biases and adhered to qualitative research guidelines.<sup>10-12</sup>

Interviews were analyzed following data collection using thematic analysis. Adhering to descriptive analysis guidelines,<sup>10-12,20</sup> the first (L.A.P.) and second (C.F.) authors first familiarized themselves with the data by validating the accuracy of the transcribed interviews. During that time, the researchers also engaged in a process of reflection in which they recorded preliminary ideas (ie, memo writing). Using the broad categories of the interview guide (scheduling, traveling to, and attending the AHE) and theories of support (eg, support structure and functions of support),<sup>21,22</sup> a preliminary coding structure was developed that was flexible and that was expected to evolve throughout the analyses.<sup>11</sup> Initially, text segments from 5 of the 13 interviews were coded line by line, by the first author (L.A.P.). This preliminary coding structure was verified by the second author (C.F.). Then, the remaining 8 interviews were coded independently by the first and second authors. The 2 coders consulted regularly with the senior researchers (H.O.K., V.C.) throughout the analyses to ensure agreement on the evolving coding structure, the emerging themes, and the relationships among the emerging themes. Analyses were carried out using NVivo 10.

## — Findings —

### Participant and interview characteristics

In total, 8 men and 5 women were interviewed (N=13). Participants' ages ranged from 24 to 61 years (mean [SD] of 36.77 [12.48] years). Six participants lived independently and 7 resided with caregivers. One participant was blind and 2 were illiterate. Twelve participants were interviewed in English and 1 was interviewed in French. Nine participants independently participated in the interview and 4 were accompanied by caregivers.

### Support needs

*Support* emerged as the overarching theme regarding participant experiences during the AHE. This theme included assistance navigating the health care system (assistance scheduling the AHE, reminders to book the AHE, financial assistance, transportation) and person-centred care (respecting privacy during the AHE, acknowledging the patient's level of autonomy, communication style, kindness and compassion, familiarity and rapport with physician, advocacy for health-related needs, and collaboration). As described by participants, support served *practical* (eg, transportation, financial assistance), *informational* (eg, facts and advice), and *emotional* functions (eg, kindness and comfort),<sup>23</sup> and was provided by physicians and family.<sup>22</sup> Barriers to this support were also identified (lack of rapport, perception of unfriendliness, perception that the

physician is too busy to tend to needs, and perception that the physician did not want to perform an AHE).

Results are organized to illustrate different support needs and barriers as individuals schedule, travel to, and attend the AHE.

**Scheduling the AHE.** Eight participants scheduled the AHE themselves; 2 were scheduled by physicians; 3 were scheduled by family members. During this time, assistance navigating the health care system emerged as an important theme. Some physicians facilitated scheduling the AHE by providing reminders to schedule the appointment or scheduling the appointment for participants: "She [physician] books it when I'm in there .... My doctor knows that I can't read and write." (Marcelle)

However, one participant discussed how she expected yearly reminders to attend the AHE: "See, normally your family doctor's supposed to phone you once a year to make that appointment, but they don't always do it." (Juliette)

For some, the perception that medical staff members were unfriendly or too busy created ambivalence about scheduling an appointment: "The secretary at my doctor's office is very busy ... they're not too friendly there .... I don't wanna phone, but I phone." (Juliette)

Other times, family members scheduled the AHE. One participant explained that he struggled with verbal expression and thus had difficulties communicating with receptionists when they spoke too quickly and asked complicated questions. Consequently, his mother scheduled his appointments.

Je fais comme un peu gêné ... à cause de ma difficulté ... à exprimer ... des fois moi je [suis] un petit peu énervé ... c'est pas facile de faire des rendez-vous, parce que des fois il y en a qu'y veut me demander des questions compliquées et tout ça. Pour moi ... je ne veux pas qui explique comme very vite .... D'habitude c'est elle [mère] qui appelle ... mon rendez-vous ... pour examen annuel. (Jacob)

Other times, parents provided information that helped the individuals schedule the appointment themselves: "My mom was with me as well and made sure that 'do you remember this number?'" (Colin)

**Getting to the AHE.** Eight participants traveled independently to the AHE; 5 were accompanied by a caregiver or caregivers. Financial assistance was indispensable to getting to the AHE for many adults with IDD; for example, provincial social assistance programs enabled reimbursement for taxi fares to medical appointments and the purchase of bus passes at a reduced fee: "Because I'm on ODSP, I pay \$46.75 [for my bus pass] which is a lot more attainable for me because I'm on a fixed income and it's very strenuous." (Arthur)

One participant had a service dog that facilitated walking to the appointment: "I walked down the road; I take my guide dog, and she know[s] where everything is." (Léo)

Other participants received transportation to AHEs or were accompanied on public transit by a family member: "We're working on taking the [public transit] because I think it's important that Colin be able to go to the doctor independently." (Colin's mother)

**Attending the AHE.** As noted, 8 participants attended the AHE alone; 5 were accompanied by a caregiver or caregivers. During the AHE, person-centred care emerged as the main support theme. The importance of respecting individual needs and tailoring support to these needs was emphasized (eg, privacy).

André is a very private person so he found that [physical examination] very difficult .... just to have to remove his clothing and put the gown on, like that threw him .... I explained to André and I explained to the doctor, that we can let him have as much privacy as he wanted. I left the room when he was changing. (André's mother)

Physician communication style also contributed to comfort during AHE procedures: "But my doctor, she explains everything to me ahead of time. Like when I'm going for a physical ... she'll say, OK, this is what we're going to do .... I have a really good doctor." (Marcelle)

Moreover, kindness and compassion demonstrated emotional support and were valuable components of person-centred care:

My doctor, she's very gentle, she talks to you in a way that you don't feel uncomfortable .... When she does the test [Papanicolaou test] with me, she says it might feel uncomfortable ... if it does feel pain, let her know, right? (Audrey)

One participant discussed the importance of familiarity and rapport; he explained that he liked seeing his doctor and had been his patient for a long time: "Moi je vois mon médecin je suis très de bonne humeur .... Parce que j'aime ça aller là .... J'ai un bon médecin de famille .... Je le connais longtemps." (Jacob)

For some participants, however, lack of rapport was an issue:

But I know he's so busy, and so, like, I don't even think he pays attention to me when I go there, you know? He's always doing other stuff, so I already know that maybe I should go to someone that can pay more attention to me .... My family doctor he's very busy so I could talk to him, it'll go right over his head. But others have very ... they listen .... It matters the personality of your doctor, right? .... So they need to work on this stuff. You know, be more caring, and

act like you're the only person in the room .... So, it deters you from even seeing a doctor, especially if they act like they don't care. (Juliette)

Furthermore, some participants reported that their physicians hesitated to perform an AHE when they thought their patients were healthy: "He didn't want to do it because he thinks I'm healthy." (Daniel)

Informal caregivers sometimes advocated for needs and helped the individuals explain things or ask questions of their physicians:

It's important that it's his checkup and the doctor is respectful of his privacy, and so he always goes in by himself and then if I need to clarify anything about the medication or we have something particular to talk about, then the doctor will come out and get me. (Colin's mother)

## — Discussion —

When speaking of their experiences with scheduling, traveling to, and attending the AHE, study participants emphasized the importance of support navigating the health care system and of person-centred care. Person-centred care demonstrated through a respectful communication style and advocacy for health-related needs was identified as important to adults with IDD in this study. Physicians can foster rapport and demonstrate respect for autonomy by providing accessible health-related information and engaging patients in decision making.<sup>24</sup> Advocacy can reduce health inequalities<sup>25</sup>; therefore, physicians can play an important role in diminishing current health disparities. Moreover, collaboration with physicians was important to individuals in this study.

Navigating the health care system was linked to informational and practical support; in the current study, this included reminders to schedule the AHE, support for scheduling appointments, and referral to financial support for access to transportation. This finding is consistent with a recent study that reported the experiences of adults with developmental disabilities accessing primary care in British Columbia.<sup>26</sup> Moreover, an initiative in the United Kingdom in which general practitioners sent reminders to their patients with IDD to schedule an AHE has demonstrated an increased uptake of the examination.<sup>27</sup>

Barriers to attending the AHE were discussed. For example, some participants reported feeling hurried during their appointments, which left them feeling uncared for. Physician surveys have consistently identified time constraints as a barrier to adequate primary care for persons with IDD.<sup>28-30</sup> Increasing consultation length and physician remuneration have been offered as strategies in the United Kingdom and Australia.<sup>28,31</sup> However, the success of these strategies depended on physician training and governmental policies for providing comprehensive health examinations.

## Limitations

The described experiences are those of ODSP recipients with IDD who attended AHEs with their family physicians and who could verbally engage in an interview. Findings might not reflect the experiences of all adults with IDD (eg, those without a family physician, those who are nonverbal, those who have more complex needs, and those who reside in remote areas) with regard to obtaining a comprehensive health examination. Difficulties establishing and maintaining contact with adults with IDD led to the small sample size, which raises questions regarding our ability to reach theoretical saturation. Further research is needed to understand the complex individual and system-level factors that might affect the primary care of adults with IDD.

## Conclusion

This study demonstrates that from the perspective of adults with IDD, system navigation support and person-centred care from their physicians are valued qualities of effective provision of preventive primary care. Physicians can fulfil some of these needs by ensuring that adults with IDD have sufficient support to schedule appointments, have resources to attend appointments, have sufficient time during appointments to communicate health concerns, and have a good understanding of what is happening during the examination and of any recommendations. Collaborating with informal caregivers in instances when additional support is needed is also beneficial. In the absence of person-centred care and support, some adults with IDD will not attend AHEs and will miss this valuable preventive health care opportunity.

Core family physician competencies reported as desirable by patients with IDD, such as communication, collaboration, and health advocacy, are part of the family physician competency framework adopted by the College of Family Physicians of Canada.<sup>24</sup> This competency framework guides family medicine training in Canada and elsewhere. This paper contributes to understanding how these foundational competencies lead to better person-centred care.

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### Contributors

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

### Competing interests

None declared

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Cet article a fait l'objet d'une révision par des pairs.

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