Improving care for adults with intellectual and developmental disabilities

Role of clerical staff

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As a group, people with intellectual and developmental disabilities (IDD) are at higher risk of a number of adverse health conditions and have poorer overall health than those without IDD.[1-4] One strategy that is increasingly being regarded as effective for improving the identification of health needs in people with IDD is the Comprehensive Health Assessment (Health Check).[5-7] In 2009 to 2010, only 22% of 66 848 adults with IDD in Ontario had an annual Health Check or physical examination (ie, a general assessment of an individual who has no apparent physical or mental illness) billed to the health insurance plan.[8] The "Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines" (hereafter referred to as *the guidelines*) provide recommendations on how to most effectively address key physical and mental health issues for adults with IDD and emphasize periodic preventive health assessments.[9]

Identifying barriers to care

The literature identifies several barriers that might prevent people with IDD from accessing primary care and receiving Health Checks. Clinical staff have pointed to the physical inaccessibility of health clinics, communication difficulties between patients and staff, and time constraints due to the additional time needed for scheduling and providing Health Checks.[10-13] Patients with IDD have reported struggling to make appointments, arriving at health clinics uninformed about the details of a health examination, experiencing anxiety around attending an appointment,[14,15] and becoming frustrated with inattentive receptionists in the waiting room.[16] Some of these barriers can be addressed by front-line clerical staff in family practices and health clinics, although this group is seldom addressed in medical research around improving patient care. Considering the role of clerical staff in facilitating the delivery of care might therefore be helpful to improving the primary care experience and rate of Health Checks for people with IDD.

As part of our ongoing effort to implement Health Checks for people with IDD throughout Ontario, we worked with 3 family health teams to implement Health Checks and evaluated the results, including the factors that contributed to the realization of successful Health Check practices. We identified 4 core components of the implementation process[1]: identification of patients with IDD[2]; proactive telephone invitations for the Health Check visit[3]; staff education and training; and delivery of the Health Check in alignment with guidelines.[4] (See Durbin et al for more detail on the intervention.[6]) Feedback from this work showed us the key role of clerical staff in this process.

Through surveys with 33 clerical staff from 2 family health teams before Health Check implementation, data on Health Check delivery rates, and focus group feedback from clinical and clerical staff about the implementation process, we gained some important insights about the contributions clerical staff can make and where more support and process improvements would be helpful.

Important role of clerical staff

Clerical staff played an active role in Health Check implementation in all stages of the process: before, during, and following the Health Check. Before the Health Check, clerical staff were responsible for inviting patients to the clinic for an appointment, and our data showed that these telephone invitations improved rates of attendance for patients with IDD. Clerks were also responsible for reminding clinical staff that the patient had an IDD through a direct message or alert on the file, and for referring them to resources like the guidelines when the appointment was imminent. As one family physician remarked, "The other part [of Health Checks] is the pre-encounter part—just getting people in the door and that for sure has happened because of clerical and program manager type people."

During Health Check appointments, clerical staff played a role in accommodating patients in the waiting room. This included assisting patients with mobility needs and providing a separate space where patients could wait (eg, if sensory sensitivities were an issue). Some clerks also described adapting their communication (eg, coming out from behind the desk to talk directly to the patient). Some also reported developing a rapport with patients with IDD, which might help increase patients' comfort coming to the office and future willingness to attend appointments, as some clerks illustrated:

> It's nice that I can kind of build a rapport with those patients as well and they get to know me.

> It is a social experience, it's a friendly face … it's a whole event. They tell you about their day; it's enjoyable.

Following the Health Check, clerical staff helped with facilitating referrals and clarifying instructions for patient follow-up.

Knowledge, attitudes, and room for improvement

Beyond examining clerical staff roles in implementing the Health Check, we surveyed clerks before implementing the Health Check about their general experiences working with practice patients with IDD. Almost all clerks reported seeing at least 1 patient with IDD in the past 2 years (82%), and most (70%) expressed some comfort in this role. That said, about a third of clerks reported sometimes feeling frustrated when interacting with patients with IDD, and many clerks expressed concern about the time it takes to assist a patient with IDD.

> Providing care for patients with IDD often requires more time than I have. I always try to find the time regardless. I spend extra time when informing them of instructions for referrals, but do find it frustrating if there are no supports to help the patient when understanding may be difficult. (Clerk)

Although clerks were willing to find ways to accommodate the needs of patients with IDD, many reported that they needed better information and resources to do so. A number of clerks expressed frustration with the current lack of supports for identifying patients with IDD and keeping track of each patient's unique needs. Half of respondents said they were only sometimes able to locate caregiver information in the patient chart, even though they recognized the importance of having such information to help with planning communication. Several clerks pointed out that they can only schedule extra time for an appointment or organize a separate room where a patient can wait if they have sufficient advanced knowledge about a patient's situation. Clerical staff, therefore, need mechanisms to identify patients so they can better meet their needs and support improved care delivery.

> Patients in wheelchairs are difficult to maneuver for tests, to keep one room open for these patients to keep them out of the waiting room for various reasons, perhaps it's stressful for them. You can organize this kind of stuff in advance when you know the patient is coming in. (Clerk)

Another challenge identified was orienting and supporting multiple staff members in clerical roles. Related to the Health Check, an effective solution was to identify a single clerical staff member who could provide the key function of telephoning patients and caregivers to explain the Health Check, offer an appointment, and seek to reduce barriers to attendance. Limiting the responsibility to a single individual allowed that person to become more comfortable with the process and increased the likelihood of task completion.

Just under half of the clerks surveyed expressed that they were willing and ready to make changes in their practices and work toward improving care for people with IDD, and the overall attitude toward people with IDD among clerical staff was quite positive. However, some clerks were concerned that they lacked the time and resources to make changes, and some were not yet ready to do so. This suggests that we need to consider resources for serving patients with IDD that can be adopted easily in a time-pressed environment and think about ways to support staff members who are not ready to make changes to their current practice.

> Clerical [staff] should have the knowledge and understanding when dealing with people that have [IDD]. The hospital offers a course; everyone should take it. Because people with [IDD] need special care. (Clerk)

> I think that most patients with [IDD] require special attention. Because some of them don't bring caregivers and also they have some difficulty in expressing themselves and they are confused. (Clerk)

Conclusion and recommendations

Clerical staff can play an important role in facilitating Health Checks for people with IDD and making this patient group feel more comfortable during office visits. In our project, these staff members helped identify hurdles to providing appropriate care, including limited time to explain the appointment and next steps, and insufficient advanced knowledge of the patients' needs in order to arrange modifications. Incorporating questions at the time of booking appointments to identify accommodations and recording a "flag" or other alert in the medical record and appointment schedule can help overcome some of these barriers. The tool kit *Implementing Health Checks for Adults with Developmental Disabilities*[17] has resources for making systemic changes to facilitate the work of clerical staff, as well as clinic managers, nurses, and doctors. Our experience demonstrates the importance of including clerical staff as we work to promote new practices in primary care settings. We believe that with the proper resources and support, clerical staff members can be important allies in improving rates of preventive care for people with IDD.

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None declared

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