

Circles of care for people with intellectual and developmental disabilities

Communication, collaboration, and coordination

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Abstract

Objective To review health information exchange (HIE) processes that affect the health of people with intellectual and developmental disabilities (IDD) and to suggest practical tips and strategies for communicating, collaborating, and coordinating in the primary care setting.

Sources of information The “Primary care of adults with intellectual and developmental disabilities. 2018 Canadian consensus guidelines” literature review and interdisciplinary input.

Main message Disparities exist between the provision of health care for the general population and that for people with IDD. These disparities are due in part to gaps in HIE. Health information exchange involves documenting, collecting, and disseminating a patient’s health information. In exploring ways to improve HIE for people with IDD, the communication skills of the family physician are considered in the context of the triad that includes the patient, his or her caregivers, and the family physician. The framework of the Patient’s Medical Home is used in exploring these processes, and various strategies are offered for communicating, collaborating, and coordinating health care that can be implemented by family physicians in order to narrow the gaps in care that exist for people with IDD.

Conclusion Improvements in HIE by communicating, collaborating, and coordinating health care better will improve health outcomes for people with IDD.

Editor’s key points

- ▶ Family physicians are skilled communicators; however, communicating with people with intellectual and developmental disabilities (IDD) requires extra time and adaptations to the individual’s specific communication skills and preferences.
- ▶ Improving triadic communication facilitates health information exchange within a model that is patient- and family-centred.
- ▶ The Patient’s Medical Home is a helpful framework for understanding the need to collaborate and coordinate effectively with other primary care team members when caring for people with IDD.
- ▶ Coordinating care for people with IDD requires good communication and collaboration that should occur at many levels, including coordinating health information, procedures, and members of the health care team.

Points de repère du rédacteur

- ▶ Les médecins de famille sont de bons communicateurs; toutefois la communication avec des personnes ayant des déficiences intellectuelles et développementales (DID) exige plus de temps et doit être adaptée aux aptitudes en communication et aux préférences spécifiques à la personne.
- ▶ Une bonne communication triadique facilite le partage de renseignements dans le contexte d’un modèle centré sur le patient et la famille.
- ▶ Le Centre de médecine de famille représente un cadre conceptuel utile pour comprendre la nécessité de collaborer et d’agir en coordination de façon efficace avec les autres membres de l’équipe de soins primaires dans la prise en charge des personnes ayant des DID.
- ▶ La coordination des soins aux personnes ayant des DID nécessite de bien communiquer et de collaborer, et ce, à de nombreux niveaux, notamment en coordonnant les renseignements sur la santé, les interventions et le travail des membres de l’équipe de soins de santé.

Des cercles de soins pour les personnes ayant des déficiences intellectuelles et développementales

Communication, collaboration et coordination

Résumé

Objectif Passer en revue les processus du partage de renseignements sur la santé qui concernent la santé des personnes ayant des déficiences intellectuelles et développementales (DID), et proposer des conseils pratiques et des stratégies de communication, de collaboration et de coordination en milieux de soins primaires.

Sources de l'information La recherche documentaire et les contributions interdisciplinaires sur lesquelles reposent les « Lignes directrices consensuelles canadiennes sur les soins primaires aux adultes ayant des déficiences intellectuelles et développementales (DID) de 2018 ».

Message principal Il existe des disparités entre les soins de santé prodigués à la population en général et ceux que reçoivent les personnes ayant des DID. Ces disparités s'expliquent en partie par des lacunes dans le partage de renseignements sur la santé. Ce partage exige qu'on documente, recueille et dissémine les renseignements du patient en matière de santé. Dans l'examen de moyens d'améliorer ce partage lorsqu'il s'agit de personnes ayant des DID, les habiletés en communication du médecin de famille sont envisagées dans le cadre d'une triade comprenant le patient, son ou ses aidants et le médecin de famille. En explorant ces processus, nous nous appuyons sur le cadre conceptuel du Centre de médecine de famille, et nous suggérons diverses stratégies de communication, de collaboration et de coordination des soins de santé, que les médecins de famille peuvent mettre en pratique dans le but de combler les lacunes dans les soins qui existent pour les personnes ayant des DID.

Conclusion Des améliorations dans le partage de renseignements sur la santé grâce à de meilleures communications, à une collaboration plus étroite et à une plus grande coordination des soins de santé se traduiront par de meilleurs résultats pour la santé des personnes ayant des DID.

Case description 1: communication

Thelma is a 65-year-old woman who has spastic quadriplegia and a moderate intellectual and developmental disability (IDD) of unknown cause. She is deaf and communicates her needs with facial expressions and gestures. When Thelma's caregivers thought that she was in pain, they brought her to her family physician

to assess her for medical causes. The family physician ruled out an acute health issue and attributed the pain to contractures and deteriorating posture. He suggested a non-communicating adult pain checklist¹ to help determine when Thelma was in pain.

Thelma's caregivers personalized the checklist by including her cues (eg, moaning, gesturing). They considered possible triggers for her pain such as thirst, hunger, positioning, clothing texture, and access to her toys. Caregivers give Thelma as-needed analgesics when nonpharmaceutical interventions fail. In the past 3 months, Thelma seems more content. Her family physician and caregivers are better able to interpret her pain cues, and the use of as-needed analgesics has declined.

Sources of information

This article is informed by the 2018 Canadian consensus guidelines on primary care of adults with IDD² literature review, as well as by interdisciplinary input.

Main message

People with IDD can have complex and diverse health and communication needs. In the updated 2018 Canadian consensus guidelines, guidelines 1 and 2 recommend attention to communicating with adults with IDD, collaborating with caregivers and others, and coordinating health care interventions.² This call for reasonable adjustments in the primary care of people with IDD is consistent with the Convention on the Rights of Persons with Disabilities, which Canada has ratified.³

In a confidential inquiry into premature deaths of people with learning disability in the United Kingdom, 42% of deaths among people with IDD were premature and avoidable. Factors contributing to premature death included the following: family and caregivers feeling "not listened to," problems recognizing the needs of people with IDD and not adjusting care appropriately, and problems with coordinating health care, sharing information, and keeping and being able to access records readily.⁴ In other words, premature deaths among people with IDD were owing to problems with health information exchange (HIE).

Health information exchange is the process of sharing or transferring verbal or written personalized health information.⁵ It is an essential element of the relationships between the patient and his or her family physician and the patient's caregivers and family physician. Health information exchange is also an important component of the Patient's Medical Home (PMH), which is a framework for understanding and practising coordinated and comprehensive primary care.⁶

Communication

The family physician as communicator: Communication is a fundamental skill for Canadian family physicians.⁷ Studies show that family physicians feel that they are competent in communicating with

patients with mild and moderate IDD.⁸ When studies compared family physicians' skills with the skills that people with IDD value in their physicians, there was agreement on most of these skills. What did not match, however, was the difference in expectations of family physicians and patients with IDD regarding the time needed for the clinical encounter, the need for an explanation of the physical examination, and communication among the physician, patient, and caregiver (triadic communication).⁹ Patients believed the key strengths of their family physicians were their ability to listen, their willingness to support various communication strategies, and their assistance in navigating the health care system.¹⁰ Other patients with IDD, however, thought that they were rushed and not listened to, stating, "Doctors are over worked and over stretched."¹¹

Communicating with people with IDD and practical tips for the family physician: People with IDD communicate in many ways: verbal, symbolic (signs, pictures, picture exchange communication systems), and pre-symbolic (gestures, facial expression, body language). Those who have verbal skills might have better expressive than receptive language, displaying extensive vocabulary and using words in the right context. However, these phrases might have been memorized from past experiences and might not be fully understood. It is vital, as with all patients, to verify comprehension by asking them what they understand and providing written instruction to avoid dangerous misunderstandings.

In order to optimize communication, family physicians should look directly at their patients, speak slowly and clearly, avoid jargon, and consider using pictures and drawings. The level of IDD, certain medications, motor skills, and anxiety can all affect communication skills. With this in mind, it is important for family physicians to provide information in the form that the patient is most likely to understand, and to provide it at the time when they are most likely to understand it.¹²

When family physicians attempt to communicate with people with IDD who communicate pre-symbolically, like Thelma, they need to go beyond typical patient-centred competencies of rapport building. They should align themselves emotionally and behaviourally with such patients in order to understand the subtleties of their communication, which involves a process called *attuning*. How well people attune to one another is manifested in the degree to which they empathize and cooperate with each other.¹³ Various techniques can be used to develop one's attuning skills. One example is to "recognize the individual," which means being able to see the person as likable and self-determined, and to connect with them through building trust and respect while sharing moments of humour and fun.¹⁴ It is important for family physicians to remember that attempts at communication are expressions of our patients'

autonomy, and their behaviour is purposeful communication. When interpreted correctly, such behaviour can be an opportunity to understand and acknowledge the self-determination of the other.¹⁵ In Thelma's case, her caregivers' modification of the pain scale offered an opportunity for her gestures and vocalizations to be understood, not medicated.

Tips for triadic communication: Much of physicians' communication with patients with IDD is triadic. When participating in a 3-way conversation, it is important for the family physician to have an approach that can be tailored to the patient's needs. **Table 1** outlines an adapted summary of the approaches of several authors.^{11,16,17}

Collaboration and triadic communication: In triadic communications, the patient is the focus and the triad forms the base of the collaborative network (the PMH). Good triadic exchange is strongly linked to matters of autonomy and the self-determination of the person with IDD.¹⁸ This approach can be time-consuming, especially for the solo family physician, as it requires conscious attention to how the patient and the practitioner themselves are communicating. The benefit to this time investment is improved health care for the person with IDD⁵—a downstream improvement in collaboration and coordination (**Figure 1**).

Triadic communication is essential to gathering health care data, informing decision making, and constructing and executing a patient's care plan; it is the foundation of HIE and depends on the availability of caregivers, who act as sources, interpreters, and record keepers of the patient's health information.¹⁸ When triadic communication breaks down, patient-centred care is affected, advocacy is hindered, and gaps occur in the care plan, all of which put the patient's health at risk. Physicians feel that optimal health care delivery for people with IDD requires consistent caregivers who have the capacity, interest, and motivation to be part of the health assessment process¹⁹; caregivers think improvements could be seen if family physicians were willing to provide support outside of the office consultation, for example by being available by telephone to speak to group home supervisors or family members for collateral history.¹⁸ Family physicians and caregivers alike could benefit from more training in the area of triadic communication.^{8,17,18} Also, assigning tasks to both the family physician and caregiver before, during, and after the consultation might improve the collaborative process.^{5,20}

Collaboration within the PMH: The concept of the PMH, endorsed by the College of Family Physicians of Canada,²¹ provides a useful model for augmenting collaboration in primary care for people with IDD.⁶ The College's recommendation for the PMH is that it is patient-centred and individualized, in keeping with community-based resources.⁶ Based on the individual's needs, team members might include physicians, nurses, clergy, physiotherapists, occupational therapists, social

Table 1. The 5 As of triadic communication

5 As	TIPS AND SUGGESTIONS
Ask the person ...	<ul style="list-style-type: none"> • for consent before using her or his first name • if she or he is comfortable with eye contact • how she or he communicates and says yes and no • if she or he would like the support worker to stay in the room for all or part of the examination
Advise the caregivers ...	<ul style="list-style-type: none"> • that you will speak directly to the patient throughout the interview • that it is important that you connect with the patient and build trust and rapport • that you will tell the patient when you understand and when you do not understand • to please listen to the conversation as if you were speaking to them • to please fill in gaps if they can when you glance at them
Assess by ...	<ul style="list-style-type: none"> • being curious • asking testing questions throughout the interview and looking for a response • using humour as a test—a smile can mean the patient is listening! • persisting in your curiosity over time; anxiety plays a big role, and it might take several visits before the patient relaxes
Augment by ...	<ul style="list-style-type: none"> • using the patient’s communication tools, as well as pictures and gestures • pointing out body parts or miming (eg, checking ears) • spending time explaining the physical examination • encouraging the use of the patient’s communication tools across environments • considering the high rates of hearing (50%) and vision (40%) impairments—screen for them and adjust your communication accordingly
Allow time ...	<ul style="list-style-type: none"> • to build rapport and attune to the person • to address emotions in the communication triad and gaps in information • for the patient to respond (10 s for those with receptive or expressive delay) • to check in on what the patient and caregiver understood • to provide written communication of the management plan, with visual cues in keeping with the level of health literacy

Adapted from Perry et al,¹¹ Kelly,¹⁶ and Therapeutic Guidelines Limited.¹⁷

workers, friends, speech-language pathologists, administrative assistants, behavioural therapists, teachers, medical specialists, and neighbours.

Another aspect of the PMH is that it allows for unique approaches to accommodating a specific patient’s needs. These adaptations could include modifying the clinic so that patients with IDD are able to bypass busy waiting rooms, having wheelchair-accessible clinics and examination tables, and, in some cases, offering home visits.

In the United States, using a PMH model for people with IDD led to reduced emergency department use, reduced length of hospitalizations, improved preventive care and chronic disease management, improved case coordination, and increased patient and caregiver satisfaction.⁶

Case description 2: collaboration

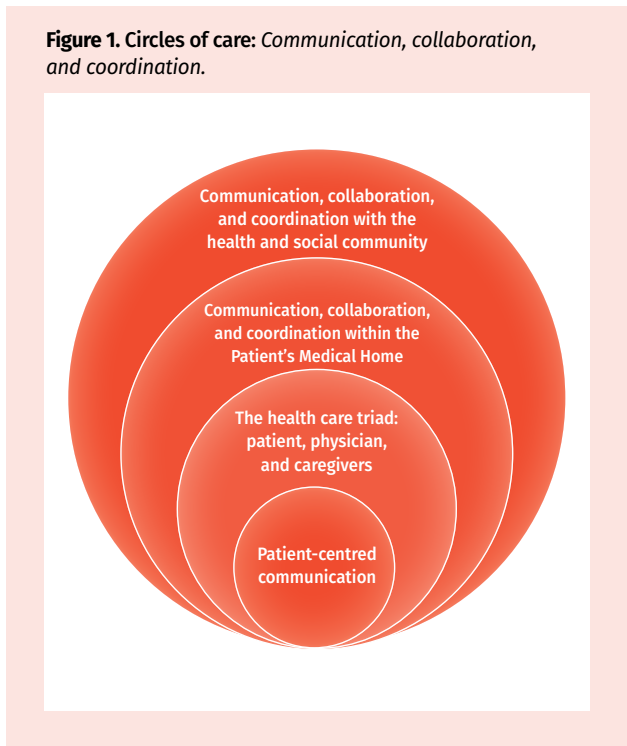
Hilary, a healthy adult with IDD of unknown origin, has lived in a group home since she was 18 years old. She had been healthy with the exception of multiple dental caries and extractions. At the age of 58 she had a dental extraction followed by a course of antibiotics. She had no history of cardiac murmurs. Six weeks after the extraction she became unwell, and was crying and agitated, and had poor appetite; this was uncharacteristic for her. She was diagnosed with and treated for pneumonia; despite this, she

became septic and was noted to have a new murmur. Findings of a transesophageal echocardiogram done while in the intensive care unit (ICU) identified subacute bacterial endocarditis. In hospital, Hilary was wailing and very agitated, especially when investigations were undertaken. The small ICU was very accommodating, incorporating special adaptations in order to make her more comfortable. Her family brought in her favourite things and stayed by her side. Unfortunately, when Hilary transitioned from the ICU to the ward, the consistency and continuity of her care was lost, and her family physician was no longer involved in her hospital care. The staff on the ward had difficulty interpreting her behaviour and labeled her as a “cry baby,” “unmotivated,” and “lazy.” The staff did not understand her nor did they recognize that she remained unwell. Tragically, Hilary deteriorated; an echocardiogram at the bedside diagnosed a ruptured valve; she did not recover.

Coordination strategies for the family physician.

Coordination unifies communication and collaboration, and the family physician plays an integral role in this capacity. There are several ways in which a family physician might take on the role of coordinator in providing care for a patient with IDD: coordinating information, medical procedures, and the care team.

Figure 1. Circles of care: Communication, collaboration, and coordination.



Coordinating information: Effective HIE is beneficial for the care of patients with IDD.⁵ One specific example is the use of hand-held health records—medical summaries that patients carry with them. These tools lead to more discussion about health problems, increase health-related knowledge, and increase awareness of personal health issues for people with IDD.²² Further, when health actions were recorded in a hand-held health record, there was improved health care of people with IDD in the short term.²³

It is not enough, however, for people with IDD to have health assessments and hand-held records of medical history; there must also be an action plan that travels with the patient.⁴ Several recommendations have been made regarding coordination of health care for people with IDD, including assigning a health care coordinator for people with complex health needs, and providing hand-held health records to these patients.⁴


In Hilary's case, a hand-held record might have helped the ward staff to understand her baseline function, speech, and typical behaviour, and to recognize her continued discomfort. There are several examples of hand-held health records being used in Canada, including the Comprehensive Health Assessment Program, About Me: My Health Information, the Health Information Passport, and Coordinated Care Plans.²⁴⁻²⁷ The option of a patient carrying an electronic data storage device (USB key) containing his or her medical record allows for a document that can be edited; however, most of the examples of hand-held health records currently used are in paper format.⁴ For effective HIE, these records should be available online to allow multiple providers to input and access them readily.

Coordinating medical procedures: As health advocates, family physicians coordinate medical investigations and procedures for their patients. As in Hilary's case, procedures such as imaging tests and phlebotomy can be difficult for people with IDD owing to fear, lack of understanding, and communication barriers. A specific example of a family physician advocating for their patients who are unable to tolerate having their blood drawn would be to coordinate phlebotomy to occur while the patient is under general anesthetic for another medical procedure. In Hilary's case, her ICU team coordinated her medical procedures to occur when family and favourite, comforting items were close by. These simple acts of coordination facilitated the successful completion of Hilary's medical procedures with reduced distress.

Coordinating the health care team: The PMH will vary in its composition depending on the needs of the patient, resources available, and geographic location. The PMH is a virtual hub from which a family physician, health care provider, or family takes responsibility for coordinating medical services that might or might not be taking place in a traditional collaborative setting. Often, it is assumed that the family physician will take on the responsibility of being the gatekeeper and coordinator of the medical information; however, the members of the PMH might agree to designate another team member to lead, such as a social worker, the parent, or the group home supervisor. Health care teams should discuss and decide who should take on this responsibility. This can be helpful for a family physician working in a solo practice. It allows him or her to delegate collaboration and coordination to other team members while remaining a key collaborator and modeling strong communication skills to members of the PMH to ensure safe, high-quality patient care.

The 2018 Canadian consensus guidelines for primary care of adults with IDD highlight the importance of interprofessional primary care teams in coordinating medical care and services for patients with IDD.² These teams are especially vital for addressing complex medical, mental health, and behavioural concerns.^{28,29} Having the family physician participate in periodic team meetings can facilitate collaboration and communication with patients and their families when implementing care plans. In one example, having access to a behavioural therapist to negotiate a care plan with the patient and the team resulted in reduced use of psychotropic medications.²⁹ We acknowledge interprofessional teams are not available to all Canadian family physicians, and there is a dire need for access to skilled mental health services and behavioural therapy for patients with IDD. More research is needed in this area to find innovative, efficient, and fiscally responsible ways to use scarce mental health and behavioural resources that will serve all Canadians with IDD who need such resources.

Conclusion

Patient- and family-centred care of people with IDD involves many individuals and requires a concerted effort to communicate, collaborate, and coordinate health care information. Family physicians are strategically positioned to assume these tasks or initiate a discussion within the health care team regarding who on the team is best suited to take on this responsibility in view of the person with IDD's specific needs. Individualized adaptations for people with IDD can ensure a smooth flow of information and promote optimal outcomes for this vulnerable population. 

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Contributors

All authors contributed to the literature review and interpretation, and to preparing the manuscript for submission.

Competing interests

None declared

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This article has been peer reviewed.

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

Can Fam Physician 2018;64(Suppl 2):S51-6