

# Consumer inclusion

## Experience of patients with intellectual and developmental disabilities informs primary care

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*Those we most often exclude from the normal life of society, people with disabilities, have profound lessons to teach us.*

Jean Vanier, founder of L'Arche internationale

**H**igh-quality health care includes integrating patient perspectives on how they experience and receive care. Applying this principle, the voices of consumers and the people who support them (eg, family members, other caregivers) have been included as sources of knowledge that have informed the updated 2018 Canadian consensus guidelines for primary care of adults with intellectual and developmental disabilities (IDD).<sup>3</sup>

In recent years, many studies have generated knowledge about a range of patient perspectives. However, studies that focus on the perspectives of patients with IDD are still emerging.<sup>4</sup> People with IDD are known to have more-than-average health care needs.<sup>5-7</sup> Yet, the generic health care system is generally not well prepared to meet those needs,<sup>8,9</sup> resulting in problems accessing adequate health care.<sup>10</sup> Similarly, access to and assistance from generic mental health services

are limited,<sup>7</sup> even though mental health concerns are more prevalent among this group.<sup>11,12</sup> The imperative to include people with IDD in health care reform is supported by Canada's ratification of the United Nations' Convention on the Rights of Persons with Disabilities.<sup>13</sup> At the provincial level, in Ontario, there are efforts to increase patient engagement in improving the quality of health care, such as the Excellent Care for All Act<sup>14</sup> and, recently, the Patients First Act.<sup>15</sup>

This commentary summarizes what is known regarding the perspectives of patients with IDD, their health, and their health care. It highlights perspectives of people with IDD who have served as health advocates with several health care projects in Ontario.<sup>16,17</sup> The lessons learned should resonate with and be applicable to primary care settings across Canada and beyond.

If they don't actually discuss what about health with disability with actual people with disability, how would they know how to take care of us and the needs we need to stay healthy, because health is something that's really important, and, you know, we only live once. (Andrew Garcia, patient advocate)

### Patient advocates acting in health education videos



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### Andrew Garcia, patient advocate



### Inclusive health care for patients with IDD

The United Nations' Convention on the Rights of Persons with Disabilities urges societies to recognize that all people must be provided with opportunities to live to their fullest potential, with respect for their inherent dignity and autonomy.<sup>13</sup> While there is societal movement to include people with IDD in their communities, stigmatizing attitudes held by some members of the public still impede true social inclusion.<sup>18,19</sup>

Full social inclusion should cover equitable access to community-based and hospital-based health care. Health care professionals, however, are generally ill-equipped to provide such care fully, reporting inadequate training and limited experience related to the health care of people with IDD.<sup>20</sup> Also, as health care professionals face time pressures and multiple presenting problems (disabilities, previous diagnostic labels, long medication lists), they might miss the person in front of them and that person's pressing concerns.

Don't brush me off and say everything is good. Listen to us and what we have to say; make eye contact; look at us. (Lisa Woelfl, patient advocate)

**Lisa Woelfl, patient advocate**



### Presenting problems and patient engagement

Medical literature and training have often focused on describing and categorizing problems (eg, diagnosis, pathogenesis, pathology, and disability) and objectifying patient presentations. The physician-patient relationship forms the context for care and treatment, however, and should be responsive to each person's unique experience of his or her presenting problems.<sup>21,22</sup> It can be challenging to engage patients who do not communicate verbally and need more time or assistance, especially when they are experiencing ill health.<sup>23</sup> Family physicians can adapt already familiar interview practices, such as patient-centred interviewing.<sup>24-26</sup> Attending to various forms of communication and including in the discussion those who know the patient best can provide insights into the distress patients with IDD experience. In turn, this leads to options that provide more effective interventions that optimize their health and well-being.<sup>27,28</sup>

People need to take the time to really listen, even if a person cannot speak. (Andrew Kestenbaum, patient advocate)

### An “inside-out” perspective

Ontario patient advocate Kareem Elbard urges health care providers to adopt an “inside-out” versus the usual “outside-in” approach to clinical encounters with

**Andrew Kestenbaum, patient advocate**



patients with IDD.<sup>18</sup> This “inside-out” approach involves seeking out the patients' experiences of illness or suffering, engages them in collaborative decision making regarding interventions, and respects their personhood above all. Openly appreciating the thoughts and feelings of people living with disabilities can have a positive effect on primary care providers' attitudes and perceptions about disability. An “inside-out” approach involves being open to a better understanding of the patient from his or her perspective. He advises physicians to consider and incorporate the following into their practice:

- Treat me like an equal, include me and ask for and value my opinions.
- Give me the time to put these together and express them.
- If I have difficulty understanding you, be patient and find a way for us to communicate more successfully.
- Respect and recognize my skills....
- Please do not describe me as a disability, I have a name and am more than your label.
- I have many medical problems but I do not appreciate being told that they cannot be helped simply because I also have a developmental disability.<sup>18</sup>

Some physicians give up on people like me. This is not helpful. Understand that I have dreams and hopes; please help me to make them a reality. (Kareem Elbard, patient advocate)

### Patient perspectives inform practice

There has been an important worldwide movement of people with IDD “going public,” with many spokespeople effectively describing experiences of developmental challenges, sensitivities, overwhelming physical and emotional reactivity, alienation, and discrimination.<sup>28</sup> Some of them are also involved in medical education as teachers with IDD.<sup>1,2</sup> Patient narratives have been

Kareem Elbard, patient advocate



instrumental in shifting clinicians' frame of reference from a more pathology-centred to a more person-centred understanding.<sup>28,29</sup> Listening to the experiences of patients with IDD can provide important insights into how to adapt primary care practices.

Whether or not you have a disability, you want your doctor, nurse, social worker, lab technician, or whoever to listen to you and treat you with respect. (Victor Pereira, patient advocate)

Nick Herd and Victor Pereira, patient advocates



## Practices that improve experiences

Studies of health care consumer perspectives emphasize the importance of patients receiving humanizing, high-quality care that meets their health needs.<sup>30</sup> Consumer opinion studies reinforce the importance of inclusion and access; overcoming communication

barriers; treatment for health needs; help to navigate the system<sup>31</sup>; and continuity of care.<sup>32,33</sup> A recent Ontario focus group study involving adults with IDD echoed dominant themes of access to primary care, person-centred practices, helpful attitudes, communication tailored to the patient, health-promoting outcomes, continuity of care, and interprofessional collaboration.<sup>33</sup> These themes inform and reinforce recommendations in the updated Canadian consensus guidelines for primary care of adults with IDD.<sup>3</sup> Overall, these themes and recommendations should inform practices to improve the primary care experiences of both patients with IDD and their primary care providers.

## Conclusion

The need for accessible and appropriate primary care for people with IDD is real and pressing. The inclusion of consumer opinion literature and experience into the Canadian consensus guidelines for primary care of adults with IDD should improve health care access, interactions, and ultimately health outcomes for this population. The updated primary care guidelines<sup>3</sup> will be practised with people who are the best experts on themselves. Health care professionals can benefit from listening to and drawing on patients' experiences to inform the development and evaluation of guidelines and to improve health care encounters.

My advice to all you doctors and nurses out there:  
let's create a world where everyone belongs.  
(Nick Herd, patient advocate)

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### Competing interests

None declared

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