

Following treatment guidelines for developmentally disabled adults

The invisible 3%

Nicholas Lennox, MBBS, BMEDSC, DIPOBST, FRACGP

Canada prides itself on being an inclusive society with policies that promote equity in provision of health care services. But some groups of people miss out.¹ People with developmental disabilities (DD) are one of these groups, and unlike other groups with serious unmet health needs, they receive virtually no attention in popular or medical literature. People with DD appear at times to be almost invisible to society and health services.

Why is this so? Perhaps they are too few in number. But at 1% to 3% of the population (325 000 to 975 000 Canadians), they are relatively numerous. The indifference is due to society's negative attitude, and more specifically with health care, the negative attitude of medical practitioners, toward patients with DD. Those of us who care for patients with DD find that some of our colleagues have little interest in our patients with DD.

Recognize humanity

What our colleagues fail to recognize is the humanity of patients with DD. Our colleagues seem to be blinded by the dysmorphology and various disabilities of these patients and do not see the real people and their abilities. These colleagues might be unable to appreciate the substantial improvement physicians can make in quality of life of adults with DD. Family physicians can help make developmentally disabled patients' lives better by first acknowledging people with DD as people and then by listening, observing, and empathizing with these patients. Physicians can take a holistic approach that both seeks a specific, albeit difficult to elucidate, diagnosis and remains cognizant of the broad context of the patient's life. Physicians need to think beyond the presentation and investigate what might be hidden. Too frequently, adults with DD are unnoticed, uncomplaining, and unheard; neglect and abuse are commonplace.

Adults with DD have lower life expectancies than those in the general population—up to 5 years for those with mild DD and up to 20 years for those with severe DD. Adults with DD rarely marry, have limited social networks, and are often poor; all factors associated with negative health outcomes. While this population is a heterogeneous group, even those with mild DD are at increased risk of poor health outcomes when compared with those in the general population.

Manage concurrent medical conditions

The medical literature indicates that adults with DD experience on average 5.4 medical conditions, half of which are unrecognized or poorly managed.² Many of these conditions (eg, epilepsy, mental disorders, sensory impairments, swallowing disorders, chronic constipation, reflux esophagitis, and dental disease) are more common in patients with DD than in the general population. These patients tend to become passive and compliant recipients of too many, or sometimes inappropriate, medications. Sometimes there is little indication for medication, and patients have infrequent reviews. Patients often experience serious and frequently unrecognized side effects of medications.

Patients with DD often do not receive health promotion or disease prevention maneuvers, such as immunizations. The situation is worsened by lifestyle problems such as poor diet, obesity, and inadequate physical activity. The challenges to good health and high quality health care for adults with DD are substantial and need to be addressed by social and health systems, by health professionals, and, most importantly, by family physicians. Family physicians are not only central to their health care, especially because of ongoing deinstitutionalization of adults with DD, but are also the health professionals these patients most commonly see.

Overcome communication and training barriers

At the core of good clinical assessment is patients' ability to recall and communicate detailed health history. Communicating with their patients with DD and obtaining health histories were identified as the 2 key barriers to high quality health care in a survey of family physicians.³ So it is not surprising that adults with DD receive inadequate health care. Other barriers identified by family physicians included lack of training and lack of experience of patients with DD; patients' poor compliance with management plans; consultation time constraints; difficulties in defining problems, especially if patients' baseline conditions and behaviour was not known; examination difficulties; poor continuity of care; and family physicians' inadequate knowledge of available services and resources. In spite of these challenges, family physicians were found to be interested

in opportunities for education and training in treating adults with DD.³

Use practice guidelines

To respond to the difficulties faced by family physicians, a group of health professionals and administrators experienced in the field of DD (eg, family physicians, nurses, psychologists, and psychiatrists) met in Toronto, Ont, in November 2005 to develop the "Consensus guidelines for primary health care of adults with developmental disabilities." These guidelines emerged from presentations of commissioned papers that were critiqued, discussed, and finally crafted into the guidelines document. These guidelines are published in this edition of *Canadian Family Physician* (page 1410).

The guidelines contain 24 considerations about the health and health care of adults with DD and recommend specific actions based on the best available evidence. They are the first Canadian guidelines to address the unmet health needs of adults with DD. The guidelines provide family physicians with approaches that need to be taken and areas that need particular attention with this population.

Integrating these guidelines into clinical practice is the next step. Research suggests family physicians are motivated to improve their care of patients with DD.³ Therefore, the explicit actions and approaches detailed

in the guidelines likely will be implemented by many physicians. While other innovative ways of improving the health and health care of adults with DD need to be tested and implemented, these guidelines are an important step to better health and health care for this often forgotten population.⁴

Dr Lennox is Director and an Associate Professor in the Queensland Centre for Intellectual and Developmental Disability (QCIDD) at the University of Queensland in Australia.

Correspondence to: Dr Nicholas Lennox, Community Services Bldg, Mater Hospitals, South Brisbane 4010, Australia; telephone 61 (0)7 3840-2413; fax 61 (0)7 3840-2445; e-mail n.lennox@uq.edu.au

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