Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario

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Errata

The following corrections have been made to the online version of this publication:

Page 28 - In the table below the graph, "15,930" has been changed to "15,980."

Page 158 - In Note 2(f), last sentence, "300–314, 316" has been changed to "300–316."

Broken hyperlinks were fixed in several bibliographic references and their access date changed to September 10, 2014.

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About the Organizations Involved in This Atlas

About H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program whose primary goal is to enhance the overall health and well-being of people with developmental disabilities through improved health care policy and services. H-CARDD research is conducted by dedicated teams of scientists, policy-makers, and health care providers, working collaboratively under the direction of Dr. Yona Lunsky.

The H-CARDD research program was developed to address the disparities in health status and health care access faced by people with developmental disabilities. The complex health care needs of people with developmental disabilities are frequently met with difficulties in accessing appropriate services and health care providers with little knowledge of how best to serve them. To address these issues, H-CARDD is focused on enhancing the capacity of decision-makers to develop policy and monitor system performance and on using research to enable service providers to offer high-quality health care services.

H-CARDD's partners in the creation of this Atlas include the Ontario Ministry of Community and Social Services, the Ontario Ministry of Health and Long-Term Care, Surrey Place Centre, the University of Ontario Institute of Technology, the University of Ottawa and Queen's University, as well as ICES and CAMH. H-CARDD was funded for this work by the Partnerships for Health System Improvement Program of the Canadian Institutes of Health Research.

About CAMH

The Centre for Addiction and Mental Health (CAMH) is Canada's largest mental health and addiction teaching hospital, as well as one of the world's leading research centres in the area of addiction and mental health. CAMH combines clinical care, research, education, policy development and health promotion to help transform the lives of people affected by mental health and addiction issues.

CAMH is fully affiliated with the University of Toronto and is a World Health Organization/ Pan- American Health Organization Collaborating Centre in Addiction and Mental Health.

About ICES

Since its inception in 1992, the Institute for Clinical Evaluative Sciences (ICES) has played an important role in providing unique scientific insights to help policy-makers, planners and practitioners shape the direction of Ontario's health care system.

Key to ICES' work is its ability to link population-based health information, at the patient level, in a way that ensures the privacy and confidentiality of personal health information.

ICES receives core funding from the Ontario Ministry of Health and Long-Term Care. In addition, ICES scientists compete for peer-reviewed grants from federal funding agencies, such as the Canadian Institutes of Health Research, and receive project-specific funding from provincial and national organizations. The knowledge that arises from this research is always produced independent of the funding bodies, which is critical to ICES' success as Ontario's objective, credible source of evidence guiding health care.

Forewords

Message from Marni Brownell

Less than five years ago, I was asked to attend a planning and partnership forum exploring the potential for using linked provincial health and social services data in Ontario to identify individuals with developmental disabilities and document this population's use of health services. This was an incredibly ambitious yet important endeavour, given the dearth of population-level information on service use by individuals with developmental disabilities. I was asked to participate in this forum partly because of my research experience in the area of developmental disabilities but mostly due to my years of experience working at the Manitoba Centre for Health Policy (MCHP), a leader in both data linkage and collaborative partnerships between researchers and policy-makers. MCHP scientists frequently get asked to speak with researchers and policy-makers across the country, and around the world, about our data repository, how linkages are done in a confidential and secure manner, and how the data are used to conduct policy-relevant research. Many of the groups we speak with are daunted by the challenges they face in forging the relationships necessary for working with government representatives and legal departments in assuring that privacy and security of information are upheld while developing a valuable resource for policy-relevant research. But Yona Lunsky and her team on the Health Care Access Research and Developmental Disabilities (H-CARDD) Primary Care Project addressed these challenges head-on, and the result of their tremendously hard work is this important Atlas.

The population of individuals with developmental disabilities is one that urgently needs attention. Because their disabilities are often invisible, we tend not to notice what is happening with these individuals in terms of their health status and health care needs. Without this information, it is difficult to know how to improve services for this population. Working closely with experts in primary care and in developmental disabilities, from the scientific, clinical and policy realms, the H-CARDD team has produced an Atlas that provides this critical information regarding primary care—information that will be relevant for program developers and policy-makers not only in Ontario but also across Canada. The information in the Atlas is the first step in attaining the H-CARDD goal of enhancing "the overall health and well-being of people with developmental disabilities through improved health care policy and improved services." It is hoped that the Atlas will be simply a starting point for H-CARDD—that the next steps will consider primary care within the broader health care system, other service systems relevant to individuals with developmental disabilities, and the health care needs and health service use of seniors and children with developmental disabilities. The challenge ahead for the H-CARDD team is to ensure that the valuable evidence presented in the Atlas gets translated into policies to improve the health of adults with developmental disabilities. Knowing the team members, they are up to the task!

Congratulations to the H-CARDD team for producing this comprehensive and informative resource.

Marni Brownell, PhD
Senior Research Scientist, Manitoba Centre for Health Policy / *Associate Professor*, Department of Community Health Sciences, University of Manitoba

Message from Nick Lennox

On hearing of this Atlas, I wanted to shout, "Well done, Ontario!" For the first time, Ontario has captured health information about a large population of people with developmental disabilities and their use of primary health care services. Through this initiative, the authors aspire to help people with developmental disabilities become healthier and receive health care at the right time and in the right place. They have significantly added to our knowledge and mapped a way forward. This achievement needs to be acknowledged, welcomed and used to inspire other provinces and countries to continue to add to this picture.

The Atlas not only confirms that people with developmental disabilities have many unmet health needs and experience significant barriers to high-quality health care, but it adds a more detailed and nuanced understanding of the situation in Ontario. It specifies how Ontarians can build on Canada's already world-class health care system by using established guidelines and government initiatives and programs designed to improve the health of all citizens. The authors propose many ways to move forward: enhancing the integration of care; expanding interprofessional care across the health and disability sectors; improving connectedness to maximize opportunities for continuity of care; embedding clinical tools and guideline recommendations in health care practice; establishing processes to ensure ongoing monitoring of health care; and collecting more nuanced data to fill out the picture. As a sector, we need to find new ideas and ways to achieve the authors' admirable goals.

So, congratulations to the team that has added so much to our understanding of the health of people with developmental disabilities. I look forward to hearing how the Atlas becomes a map to guide implementation of the strategies detailed in Chapter 7. It is now the task of all those involved to ensure that they (and we) do not stop here.

Nick Lennox, MBBS, DipObst, FRACGP, PhD
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Executive **Summary**

The Issue

Ontario's Action Plan for Health Care[1] focuses on becoming healthier, with improved access to integrated family/primary care and a major emphasis on the provision of the right care at the right time and in the right place. These priorities are particularly relevant to individuals with developmental disabilities: research from other jurisdictions would suggest that they have higher rates of preventable diseases,[2] greater challenges obtaining guideline-recommended primary care[3] and higher associated health care costs.[4] However, the health status and health care of adults with developmental disabilities have not been well studied in Ontario, due to the absence of population-based data. The work of the *Health Care Access Research and Developmental Disabilities (H-CARDD) Program* is in direct response to Ontario's call to action through addressing this data gap. The first H-CARDD project, conducted in partnership with decision makers and clinicians from the health and social services sectors, has focused on primary care.

The Study

The *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* provides, for the first time in Canada, descriptive information on the health of adults with developmental disabilities in Ontario and examines the quality of their primary care relative to adults without developmental disabilities. Findings have relevance in Ontario and in other jurisdictions where there is interest in improving health care and the health status of those with developmental disabilities.

The Atlas has three main goals:

1. To provide prevalence estimates, demographic information and a description of the health status of adults with developmental disabilities in Ontario;

2. To examine their health care use relative to other adult Ontarians; and

3. To assess how consistent their care is with primary care guidelines.

Key Findings

Prevalence, demographic and disease profiles

- Through linked data from Ontario's social service and health sectors, the total number of adults between the ages of 18 and 64 years coded as having developmental disabilities between April 2009 and March 2010 was 66,484. This corresponds to a prevalence of 0.78%, an estimate that is somewhat higher than would be expected from previous reports relying on fewer data sources.
- Compared to adults without developmental disabilities, adults from the H-CARDD cohort were younger, a greater proportion were male, and they were more likely to live in poorer neighbourhoods and in rural areas. They also had higher rates of morbidity and were more likely to be diagnosed with a range of chronic diseases.

Health services utilization

- Despite comparable use of family physicians and similarities in continuity of care, adults with developmental disabilities were more likely to visit emergency departments and be hospitalized. Being older or having high morbidity increased the risk of visiting the hospital for adults with developmental disabilities to a level above what would be expected for adults without disabilities.
- Most adults with developmental disabilities were seeing physicians practicing in a primary care enrolment model. Although interprofessional care is recommended for this population, only 20% were receiving their care through interprofessional Family Health Teams.

Secondary prevention

- The periodic health examination—a key health care guideline for adults with developmental disabilities—occurred for 22% of adults with developmental disabilities over a two-year period, slightly less than the 26% for adults without developmental disabilities. The likelihood of this examination increased with neighbourhood income for both groups.
- Adults with developmental disabilities were less likely to undergo recommended screening for the three types of cancer studied. Income level did not affect cancer screening rates for adults with developmental disabilities, although it did affect those without developmental disabilities. The low uptake of preventive care among adults with developmental disabilities was consistent across all regions of Ontario.

Chronic disease management

- Among persons with diabetes, rates of eye examinations for adults with developmental disabilities compared favourably to those without disabilities.

- Rates of follow-up with either a family physician or psychiatrist within 30 days after a psychiatric emergency department visit were similar among adults with and without developmental disabilities.

- The proportion of adults who received bone mineral density testing within one year of experiencing a low-trauma fracture was lower among those with developmental disabilities than among those without developmental disabilities.

- The rate of preventable hospitalizations for those with developmental disabilities was much higher across age groups and neighbourhood income. This suggests a problem providing adequate primary care for this population.

Medication use

- Nearly one in two adults with developmental disabilities were dispensed multiple medications at one time, with one in five receiving five or more medications concurrently. Older persons with developmental disabilities, women and those with high levels of morbidity were more likely to be dispensed multiple medications. Regular follow-up visits with the same family physician did not take place for 32% of persons dispensed five or more medications at once.

- The most commonly prescribed medications were for mental health or behavioural issues, with antipsychotic medications being prescribed most frequently. Approximately one in five adults prescribed antipsychotics were dispensed two antipsychotics concurrently, putting them at risk for adverse reactions, including death.

Conclusion and Recommendations

The *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* reveals many gaps in the care of adults with developmental disabilities that need to be addressed if Ontario is to meet the standards set out in the *Excellent Care for All Act*.[5] While primary care providers are pivotal to achieving needed changes, the broader health care context that supports primary care provision also needs to be considered. We propose changes in three related areas:

1. **Improving quality of primary care based on best evidence and care standards.** This includes a balanced emphasis on mental and physical health issues and on the prevention and management of disease. Care requires an interprofessional approach with an emphasis on embedding guidelines and clinical tools into daily practice.
2. **Modifying broader health care system structures and processes.** This includes focusing on the development and maintenance of care plans, fostering collaboration and coordination across the health system, the inclusion of other relevant sectors and an emphasis on financial structures required to support collaborative care.
3. **Strengthening partnerships with patients, their families and paid caregivers.** To improve accessibility and quality of care, it is essential that the patient be at the centre of care and that those involved in supporting the individual, whether paid or unpaid, be recognized for the vital role they play.

Future research needs to expand beyond primary care to the broader health care system and should focus on those critical subgroups that experience the most significant difficulties in receiving optimal care. The *Primary Care Atlas for Adults with Developmental Disabilities in Ontario* provides an important starting point from which to identify gaps in primary care and approaches for addressing them. At the core of this future research will be the collaborative cross-sectoral relationships developed through this project.

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1 Primary Care of Adults with Developmental Disabilities in Ontario: An Overview

Inside

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MAIN MESSAGES

- Adults with developmental disabilities are at greater risk for health problems than other adults, but we have limited information on their health at the population level. The *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* aims to provide, for the first time, descriptive information on the health status of adults with developmental disabilities in Ontario and their patterns of primary care utilization.

- The Atlas follows primary care reform efforts targeting the general population, and primary care guidelines and training developed in Ontario, targeting adults with developmental disabilities. It addresses how closely health care providers are following recommended guidelines.

- To better understand health care issues related to developmental disabilities at the population level, data were linked between the health sector and the social services sector in Ontario at the Institute for Clinical Evaluative Sciences. The total number of adults coded as having developmental disabilities through this data linkage process was 66,484.

- The Atlas is divided into two sections. The first section describes the health status and health care patterns of the 66,484 adults with developmental disabilities relative to other Ontario adults. The second section evaluates the quality of primary care delivered, with a focus on preventive care, chronic disease management and medication use and monitoring. The conclusion to the Atlas synthesizes the findings from each chapter and proposes actions in three areas. It concludes with a brief section on data needs and directions for future research.

The H-CARDD Primary Care Project

Primary care is the cornerstone of the Ontario health care system. It includes health promotion and illness prevention, as well as the diagnosis and management of new symptoms and ongoing health conditions.[1,2] Primary care providers function as gatekeepers and system navigators, not only providing health care directly but also helping individuals to access broader health services. In recent years there has been an increased emphasis nationally[3,4] and provincially[5-7]on the role of primary care for vulnerable, disadvantaged or complex populations who experience disparities in the receipt of health care. One particularly vulnerable population that has received limited research attention in Ontario and Canada is those with developmental disabilities.[8,9] These individuals are more likely to have health problems and to need resource intensive health care; moreover, due to their cognitive impairments, they face particular challenges in navigating their way through our fragmented health care system.[10-12] This is why their primary care is so important. Nonetheless, most of the information regarding the health status and health inequities faced by those with developmental disabilities comes from other countries, where key policy papers[13-15] and national inquiries are leading to population data and monitoring initiatives (e.g., Scottish Learning Disability Observatory,[16] CDC National Center on

Birth Defects and Developmental Disabilities,[17] and Improving Health and Lives: Learning Disabilities Observatory[18]).

Health Care Access Research and Developmental Disabilities (H-CARDD) is a landmark research program in Ontario.[19] Its goal is to monitor and improve the health of individuals with developmental disabilities in Ontario through partnerships between scientists and stakeholders. The H-CARDD Primary Care Project explores the quality of primary care delivered to adults with developmental disabilities; it is funded by the Partnerships for Health System Improvement initiative of the Canadian Institutes of Health Research and by the Ontario ministries of Community and Social Services and of Health and Long-Term Care. The Primary Care Project is a partnership between Ontario policy-makers and health planners, clinicians and scientists focused on primary care and developmental disabilities.

Historical Context for The Atlas

It was not too long ago that individuals with developmental disabilities in Ontario received their health care in provincial institutions where many spent their entire lives. Community-based care, including health care, was the exception for this population. Since the 1970s, there has been a gradual shift away from an institutional model of care toward a community-based services and supports model.[20] Ontario's three remaining institutions serving people with developmental disabilities closed in 2009. Since 2004, the Ontario Government has been transforming services to better support adults with developmental disabilities in their efforts to live as independently as possible in the community and to facilitate their full inclusion in all aspects of society. These individuals now live in the community with their families and neighbours well into adulthood, and their health care needs are met by a primary care provider.

In 2006, ICES published *Primary Care in Ontario,*[2] an atlas describing, for the first time, patterns of primary care delivery across the province, and identifying system strengths and gaps through a series of indicators of health care quality. The influential atlas included a chapter devoted to disadvantaged populations, such as those living in poverty and immigrants, but made no mention of the health care needs or primary care use of persons with developmental disabilities. Also in 2006, the first Canadian primary care guidelines to focus on developmental disabilities were published in *Canadian Family Physician*[21] as part of the Developmental Disabilities Primary Care Initiative,[22] an Ontario-based program sponsored jointly by the Ministry of Health and Long-Term Care, the Ministry of Community and Social Services, and Surrey Place Centre to improve the primary care of adults with developmental disabilities. These guidelines (herein referred to as the Canadian Consensus Guidelines) were a series of 24 considerations with accompanying recommendations developed through consensus with leading experts from Canada, the

United States, Australia and the United Kingdom. Although written in Ontario, the Canadian Consensus Guidelines were informed primarily by research conducted in jurisdictions outside the province. Thus, both the atlas and the guidelines were limited because Ontario-based data on primary care and developmental disabilities were unavailable.

Following these two seminal publications, several important and converging developments have occurred in both primary care and developmental disabilities. Primary care in Ontario has undergone a

reformation: compensation models have been developed that encourage family physicians to provide comprehensive primary care services using a team approach, and the number of inter-professional primary care teams across Ontario has been expanded. Now, three-quarters of family physicians work in group practices offering greater physician availability after hours.[1] In addition, Ontario's Framework for Preventing and Managing Chronic Disease was released in 2007[23] and the *Excellent Care for All Act* was proclaimed in 2010.[24] Both address the need for intersectoral solutions for complex populations. Provincial initiatives to reduce disparities for vulnerable groups include the Health Equity Impact Assessment introduced in 2011[6] and Community Health Links introduced in 2012.[25] The Health Equity Impact Assessment is a tool to prevent health disparities by identifying and evaluating the potential health impacts that government policies or initiatives have on populations; Community Health Links aim to provide better and more coordinated care to patients with complex needs.

The Developmental Disabilities Primary Care Initiative spearheaded several efforts to improve primary care following publication of the 2006 Canadian Consensus Guidelines. These included targeted primary care training provided to over 200 Ontario clinicians, the development of primary care clinical tools for clinicians and caregivers, an update of the guidelines published in 2011,[26] and the establishment of clinical support networks with continuing medical education opportunities. The updated Canadian Consensus Guidelines and clinical tools were sent to every family physician in Canada, and each Ontario medical school was involved in a consultative process to clarify competencies and develop training resources in developmental disabilities for its family medicine residents.

In 2005, the Ontario Ministry of Community and Social Services established Community Networks of Specialized Care in order to coordinate a specialized service system for individuals with developmental disabilities and mental health issues, enhance service

WHAT ARE DEVELOPMENTAL DISABILITIES?

Under Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*,[20] *developmental disability* is an umbrella term for different disabilities that involve the person having "prescribed significant limitations in cognitive functioning and adaptive functioning and those limitations, (a) originated before the person reached 18 years of age; (b) are likely to be life-long in nature; and (c) affect areas of major life activity, such as personal care, language skills or learning abilities, the capacity to live independently as an adult or any other prescribed activity."

(The regulations supporting this *Act* are available at **www.e-laws.gov.on.ca/html/regs/english/elaws_regs_100276_e.htm**.)

As defined in the Act, *cognitive functioning* refers to "a person's intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences." *Adaptive functioning* speaks to "a person's capacity to gain personal independence, based on the person's ability to learn and apply conceptual, social and practical skills in everyday life."

Intellectual disability, autism spectrum disorders, Down syndrome and fetal alcohol spectrum disorders would all fit under this umbrella term. Developmental disabilities can be genetic in origin (e.g., fragile X syndrome or Williams syndrome) or caused by illness or injury either prenatally (e.g., maternal rubella or maternal alcohol consumption) or in early childhood (e.g., meningitis); in some cases, the cause is unknown. In Ontario, medical disabilities, such as cerebral palsy or epilepsy, and psychiatric disorders are not considered developmental disabilities unless they meet all of the criteria of the above definition.

Individuals with developmental disabilities are typically diagnosed as such by the elementary school years, and often much earlier. Most will have more difficulty problem solving than peers without developmental disabilities and will need support to live independently. The intensity of this support depends on many factors, including their cognitive ability, the activities they would like to do, the demands placed on them by society and their stage in life.

A WORD ABOUT LANGUAGE

In this Atlas, we use the term *developmental disabilities* because it is the term adopted in our provincial legislation. Other jurisdictions use different terminology to describe similar disabilities or conditions. For example, in the United Kingdom, the same population is often referred to as individuals with *learning disability*. In the United States, the term *developmental disabilities* has a broader connotation than it does in Ontario, including other types of disabilities that occur in the developmental period but do not include significant cognitive limitations. In medical settings, the term *mental retardation* was commonly used in the past. This term is now considered pejorative and has been removed from legislation in Ontario and the United States. It is also being removed from medical jargon. It has been replaced with *intellectual disability* in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5), and a proposal has been put forth to replace it in the next International Classification of Diseases (ICD-11) with the term *intellectual developmental disorder*.

In this Atlas, we use 'people first' language. We refer to adults with developmental disabilities, as opposed to developmentally disabled adults or the developmentally disabled. This is because having a disability does not define the person but is only one aspect of him or her.

delivery, and train and build capacity in the community. Through these networks, the role of the health care facilitator was created. Currently, 10 health care facilitators are working across social service and health sectors to promote the uptake of the Canadian Consensus Guidelines and clinical tools and to support primary care providers in the management of their patients with developmental disabilities.[27]

Now, several years into Ontario's primary care reform and the Developmental Disabilities Primary Care Initiative, it is time to take stock and examine at the population level how primary care is delivered to adults with developmental disabilities in Ontario. Research elsewhere points to continued disparities in health care between those with and without developmental disabilities, but it is not known if this is the case in Ontario.

The *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* aims to provide, for the first time, descriptive information on the health status of adults with developmental disabilities in Ontario and their patterns of primary care utilization. Findings have relevance both in Ontario and in other jurisdictions where there is an interest in improving health care for and the health status of those with developmental disabilities. It is hoped that this Atlas will highlight areas where appropriate health care is provided and flag areas where improvements are needed. The ultimate goal is to help those with developmental disabilities become healthier and to receive the right care at the right time and in the right place, as articulated in Ontario's Action Plan for Health Care.[28]

Creating the H-CARDD Cohort

Many jurisdictions, including Ontario, have difficulty forecasting future health needs and targeting interventions for adults with developmental disabilities because they do not know how many individuals have developmental disabilities or where they reside. This type of information is not well captured in large surveys, such as the Canadian Community Health Survey, because of the complexity of the survey process. In some jurisdictions, registries monitor who has a developmental disability over time; these include the IHAL Learning Disabilities Observatory in the United Kingdom,[18] the Australian Institute of Health and Welfare[29] and the Intellectual Disability Database in Ireland.[30] Such registries are particularly useful at the clinical level, although they tend not to include those individuals who are not receiving services.[31] Currently, there are no similar provincial or territorial registries in Canada. Therefore, determining who has a developmental disability in the Ontario population is difficult. The best alternative to survey or registry data is administrative health data that includes diagnostic information.[32] Because developmental disabilities may include several different diagnoses, any analysis of administrative data must include an agreed-upon list of diagnoses. One of the first tasks in creating a cohort of adults with developmental disabilities (henceforth referred to as the H-CARDD

cohort) was to develop such a list, based on input from government stakeholders combined with expert clinical opinion and a review of research conducted in other jurisdictions (*see the* Technical Appendix).

The next step in creating the H-CARDD cohort was the identification of appropriate data sources. One source of diagnostic information is the administrative data used to publicly manage universal health care in Ontario, including physician claims and hospital discharge abstracts. Administrative data are useful because they are individual level, have a unique person-specific identifier, include records that pertain to most publicly funded health care visits, are longitudinal with standardized data fields and are routinely collected. Previous research in Ontario and Canada has identified adults with developmental disabilities by reviewing diagnostic information held in these types of health care databases.[33-35] However, these data are not collected to answer a research question, and the problem with relying on health data alone is that the presence of a developmental disability is not always documented, particularly when the disability is not the reason for the health care visit. For example, when a patient with Down syndrome has a visit to monitor his diabetes, his health care provider will record the diagnostic information about diabetes management, but not necessarily the presence of Down syndrome, as part of the medical billing information for that appointment.

In Ontario and most other jurisdictions, information about the provision of care and support for individuals with developmental disabilities is spread across several government sectors and ministries that collect information to manage their service provision. For example, families of children with developmental disabilities in Ontario may receive special services at home or intensive behavioural interventions provided by the Ministry of Children and Youth Services. Students with developmental disabilities typically receive educational supports ("Special Education") through the Ministry of Education that are documented within Individual Education Plans. Adults with developmental disabilities may qualify for income support from the Ontario Disability Support Program (ODSP) of the Ministry of Community and Social Services. The different sectors collect diagnostic data to manage their programs but do not necessarily share or link those data.[5,36] To create a cohort of persons with developmental disabilities using administrative data, the ideal solution to the siloing of information would be to combine the data from all sectors that provide services and supports to these individuals. However, until H-CARDD, none of these sectors have had the capacity or taken the steps needed to share data.

To this end, the final step in creating the H-CARDD cohort was linking, on an individual level, health care and social services data. A database housed within the Ministry of Community and Social Services holds diagnostic information on all adults aged 18 to 64 years who receive ODSP income support. To qualify for these payments, applicants must undergo a financial eligibility test and a disability determination based on clinical documentation. Thus, because of financial ineligibility, some adults with developmental disabilities are not captured in the database. For each claimant, the database allows for the coding of up to two diagnoses relevant to the ODSP. As a result, some individuals with developmental disabilities and other qualifying disabilities could be included in the database but coded with two other diagnoses (not developmental disabilities).

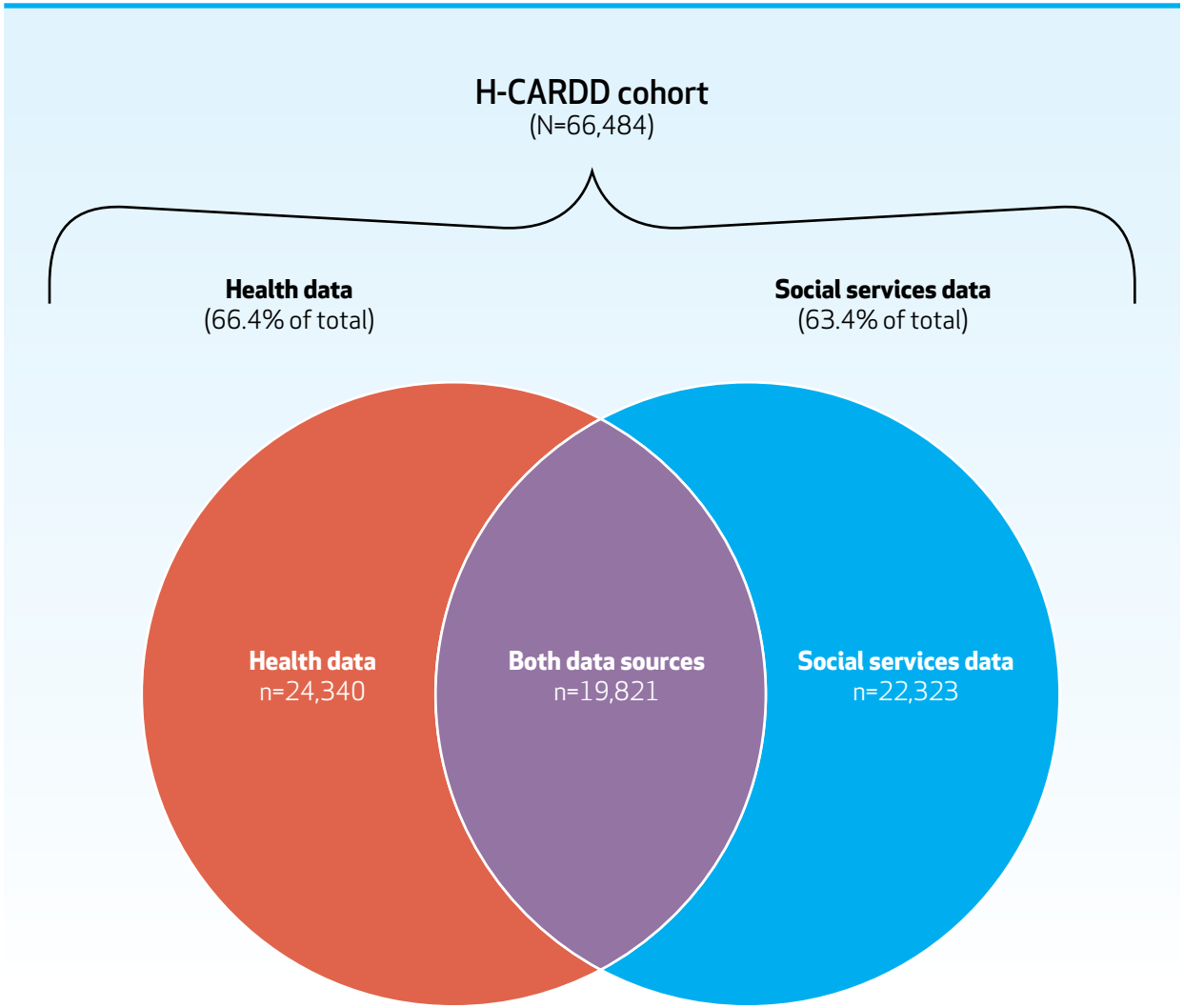
The ODSP data were considered to be the best and most feasible data to link with administrative health data because they combined a focus on adults—a population whose health care issues are the most problematic—with province-wide coverage, and a central location where both kinds of data could be housed. After several months devoted to writing a privacy impact assessment, engaging in legal consultations and negotiating terms of use, an agreement was signed between ICES and the Ministry of Community and Social Services to link the ODSP database with full-coverage, population-based administrative health data held at ICES.

By bringing these data sources together through this linkage, we could study a more complete group of individuals than if we had only used one set of data. We successfully linked the disability income information with health records for the purpose of creating a cohort of all adults aged 18 to 64 years with development disabilities living in Ontario between April 1, 2009 and March 31, 2010. Adults were included in our developmental disabilities cohort if any of the diagnoses from our list (*see the* Technical Appendix) appeared in either their health record or their disability income record. The total number of adults coded as having developmental disabilities

through the data linkage process was 66,484. Had we only been able to search records from one sector's data sources, more than 20,000 individuals (between 34% and 37%) would have been missed.

The chapters that follow describe the health status of and health care provided to the H-CARDD cohort of adults with developmental disabilities and, where possible, contrast them with a random sample of 20% of Ontario adults of the same age range without developmental disabilities. The cohort of over 66,000 adults is the largest available internationally and is a rich source of information on a group of individuals whose health issues have not been sufficiently studied in Ontario or other parts of Canada.

EXHIBIT 1.1 Number and proportion of adults with developmental disabilities who were captured by health and social services data sources, in Ontario, 2009/10



Atlas Objectives

The specific objectives of the *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* are to:

- Report on prevalence of developmental disabilities among adults in Ontario aged 18 to 64 years.
- Describe the population of adults with developmental disabilities in Ontario in terms of demographic characteristics and health status compared to a random sample of adults without developmental disabilities.
- Describe the extent to which adults with developmental disabilities used health care services that were provided by primary care providers in Ontario, specialists, emergency departments and hospitals compared to those without developmental disabilities.
- Describe the differences in primary care practice in the two groups with respect to a variety of health care indicators, some focused on secondary prevention and some on the management of chronic conditions.
- Describe medication use in adults with developmental disabilities.
- Highlight specific areas where more complete and robust data are needed.
- Provide policy and practice recommendations.

Atlas Contents

The Atlas is divided into two main sections, along with this overview chapter and a concluding chapter. Each chapter has a similar format: each is built around data exhibits and main findings using a variety of data sources, and concludes with a section on data needs, future research, and recommendations for primary care and developmental disabilities practice and policy. Main messages can be found on the first page of each chapter, and reflections from adults with developmental disabilities and their families regarding these main messages are dispersed throughout the chapter. Key technical terms are often defined in boxes in the chapter where they first appear, and there is a more exhaustive glossary found at the end of the Atlas. For readers who want more detail about methods than is provided in each chapter, we include a technical appendix outlining how indicators and other measures were calculated, which data sets and codes were used, which years the analyses assessed, and which exclusion criteria were applied.

Section 1

The first section of the Atlas addresses two key questions, each with its own chapter. Both chapters draw comparisons between adults with developmental disabilities and those without developmental disabilities.

Who are adults with developmental disabilities in Ontario and what do we know about their health?

What do we know about the health care received by Ontarians with developmental disabilities?

CHAPTER 2: PREVALENCE, DEMOGRAPHIC AND DISEASE PROFILES

Research and policy papers from other jurisdictions have highlighted the poorer health status of adults with developmental disabilities as compared to other adults, and this chapter provides this information for the first time in Ontario. This chapter presents the prevalence of developmental disabilities in Ontario adults and describes the distribution of adults with developmental disabilities by age, sex, urban/rural residence and neighbourhood income relative to adults without developmental disabilities. In addition, it provides percentages of key diseases and health problems monitored in the general population and relevant to adults with developmental disabilities.

CHAPTER 3: HEALTH SERVICES UTILIZATION

With regard to health care patterns, it is important to know which types of health services are used more and less frequently by adults with developmental disabilities relative to those without developmental disabilities. Chapter 3 addresses this gap by exploring, relative to those without developmental disabilities, the proportion who used various health care services and how often, the extent to which different compensation models and team approaches served adults with developmental disabilities during the period of study, and the level of continuity of primary care provided.

Section 2

The second section of the Atlas considers different aspects of primary care (screening for health issues and disease, management of chronic issues, and medication use and monitoring) provided to adults with developmental disabilities and is divided into three chapters, accordingly. When possible and relevant, their care is contrasted to care provided to those without developmental disabilities. Selected health performance indicators were informed by the 2006 Canadian Consensus Guidelines,[21] along with guidelines developed for the general population, in effect between 2009 and 2010.

Does primary care meet current guidelines set out for all Ontarians and those developed specifically for adults with developmental disabilities?

The 2006 Canadian Consensus Guidelines focus on 24 considerations, with accompanying recommendations, in the format of a preventive care checklist for adults with developmental disabilities. The first seven considerations focus on general issues in primary care, the next nine focus on physical health guidelines, and the final eight address behavioural and mental health guidelines. Updated guidelines were released in 2011 and we refer to these in the chapter discussion sections as relevant. We include relevant excerpts from both sets of guidelines in the chapters with a link to the full guidelines in the references.

In some sections of the three chapters comprising Section 2, the guidelines to be followed for those with developmental disabilities are the same as guidelines proposed for the general population and so those are the guidelines to which we referred. Cancer screening guidelines and diabetes management guidelines for the general population are examples of this. The Canadian Consensus Guidelines were not created to replace generic guidelines aimed at all adults; rather, they provide "additional recommendations and appropriate modifications to standard practice" as they relate to adults with developmental disabilities. The study of follow-up when multiple medications are prescribed is an example of this, whereby the guidelines studied are enhanced beyond what is considered in the general population. Finally, there are some unique guidelines that are specific to adults with developmental disabilities, such as the guidelines on crisis follow-up.

WHY WOULD WE DISCUSS GUIDELINES THAT ARE NOT CURRENT IN THIS ATLAS?

The reality is that guidelines are constantly evolving, based on research evidence and new policy or practice initiatives. Some of the guidelines referred to in this Atlas were modified during the course of our investigation. Other guidelines were being debated and perhaps revised at time of writing. In selecting our indicators, we only considered guidelines that were in effect at the time of our study (typically from April 1, 2009 to March 31, 2010, but sometimes extending to 2011 or 2012). Each guideline had to be in effect during the entire study period, so if a new guideline was introduced in 2010 or 2011, we commented on it in the discussion section of the chapter but did not evaluate how closely care was aligned with that guideline.

CHAPTER 4: SECONDARY PREVENTION

Screening for health problems is a very important part of primary care because it allows for identification and early management of major health issues. Such preventive efforts are even more relevant for those with developmental disabilities; they are at higher risk for some health conditions and their limitations in cognitive and adaptive functioning make them particularly vulnerable to poor recognition and underreporting of symptoms. This chapter includes four secondary prevention indicators—the periodic health examination and three types of cancer screening (colorectal, breast and cervical)—and presents rates for these procedures in adults with and without developmental disabilities by various demographic variables.

CHAPTER 5: CHRONIC DISEASE MANAGEMENT

Ongoing monitoring and management of chronic disease is an important aspect of primary care. It is particularly significant for adults with developmental disabilities, as many in this population have chronic and other health conditions. This chapter focuses on four indicators, three of which are specific areas of concern for those with developmental disabilities: osteoporosis management, diabetes management and the management of mental health issues. The fourth indicator examines the adequacy of primary care broadly by measuring how frequently individuals are hospitalized for conditions that could have been prevented or managed through primary care, known as ambulatory care-sensitive conditions.

CHAPTER 6: MEDICATION USE

The final chapter in this section focuses on medication use for both physical health and mental health issues. It presents descriptive information on adults with developmental disabilities being dispensed medications, and includes two indicators of the clinical care provided to those being dispensed multiple medications: one which focuses on a high-risk prescription combination (the use of multiple antipsychotics) and one which focuses on regular follow-up visits with a family physician.

CHAPTER 7: EXCELLENT CARE FOR ALL ADULTS WITH DEVELOPMENTAL DISABILITIES: CONCLUSION

The conclusion to the Atlas synthesizes the findings from each chapter and proposes actions in three areas. It concludes with a brief section on data needs and directions for future research.

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Section 1
Adults in Ontario with Developmental Disabilities

Who are adults with developmental disabilities in Ontario, what are their health concerns and which health services do they use?

Overview

This section provides a descriptive overview of adults with developmental disabilities between the ages of 18 and 64 years in Ontario, including their chronic disease profile and the health care services they use, with a focus on primary care. In each of the section's two chapters, we explain the relevance of this information, compare it to research conducted in other jurisdictions and describe how it is measured.

The data for Chapters 2 and 3 are presented in terms of the differences between adults with developmental disabilities and adults without. We also describe individuals with developmental disabilities and their service use patterns by demographic factors (age, sex, neighbourhood income) and geographic factors (region of residence, rural or urban residence). We have focused on adults aged 18 to 64 years, but in some cases we adopted a different age range where that made sense (e.g., diseases like congestive heart failure are more common in middle-aged and older adults).

Over the last decade, several primary care patient enrolment models have been introduced in Ontario. Designed to enhance care, these models vary in structure and in the incentives physicians are paid. In Chapter 3, we examine differences between adults with and without developmental disabilities in their enrolment in these models of care.

2 Prevalence, Demographic and Disease Profiles

Inside

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MAIN MESSAGES

- Policy development and service planning for adults with developmental disabilities in Ontario have relied until recently on information from other jurisdictions that may differ from Ontario in important ways. The H-CARDD cohort of 66,484 adults addresses this gap in knowledge, providing Ontario-relevant information to enable decision-making and service provision for this vulnerable population.
- To gain a better understanding of the adult population with developmental disabilities, H-CARDD has described the cohort in terms of age, sex, residence (urban or rural), health region (Local Health Integration Network), neighbourhood income and health status between April 2009 and March 2011, and compared the cohort to adults without developmental disabilities. We report on the total number of individuals with developmental disabilities and estimate their prevalence.
- The number of adults with developmental disabilities (66,484) corresponds to a prevalence rate of 0.78%, somewhat higher than would be expected from previous reports that relied on fewer data sources.
- Compared to adults without developmental disabilities, cohort members were younger, a greater proportion were male, and they were more likely to live in poorer neighbourhoods and rural areas. They also had higher rates of morbidity and were more likely to be diagnosed with a range of chronic diseases.
- Current policies and planning for adults with developmental disabilities should be reviewed to ensure that there is appropriate emphasis on particular subgroups, namely those living in the poorest neighbourhoods and those with higher rates of morbidity. While the scope of policy and planning activities should maintain a province-wide focus, specific attention to the Local Health Integration Networks that have prevalence estimates either much higher or much lower than the provincial average is needed to discern the underlying reasons for the differences.

Introduction

Canadians place a high value on universal and accessible health care. The stated objective of the 1984 *Canada Health Act* is to "protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers."[1] To ensure that this goal is accomplished for all Canadians, provincial health care systems—including Ontario's—need to pay attention to both the majority of their residents who are relatively healthy and to subgroups within their population who are more vulnerable to illness and disability.

This chapter describes one of these subgroups: adult Ontarians who have developmental disabilities. Although they are a relatively small percentage of the population, they are highly vulnerable to physical and mental health problems. The distressing fact is that, even though they are more likely to experience these problems, adults with developmental disabilities often receive insufficient or inappropriate care.[2,3]

The reasons for this group's increased vulnerability are many. Some are related to congenital conditions.[4-6] Others are due to lifestyle factors; individuals with developmental disabilities, whether through personal circumstance or lack of support, may lead a sedentary lifestyle which puts them at risk for obesity, diabetes and other physical health problems.[4,7] Still others may be a result of the medications they are taking (*see* Chapter 6).[8-10] Individuals with developmental disabilities are often

unable to advocate for themselves or communicate when they start to develop symptoms.[11] Finally, when they do attempt to access care, the health care system itself is confusing to navigate, and health care providers may not be equipped with the skill set required to interact with these individuals and address their particular needs (*see* Chapter 1).

Poor health has far-reaching and long-term consequences for individuals with developmental disabilities, for their families and for the larger society. In particular, over time poor health can lead to inefficient and costly use of the health care system.[12,13] It is important, therefore, to understand as much as possible about individuals with developmental disabilities, as well as the illnesses they are at risk for developing, in order to support more effective and efficient health care planning. Unfortunately, this information is often unavailable,[3] leaving a gap that has been noted in previous reports and articles.[6,14]

Although research has been conducted on developmental disabilities in Ontario, we have not had a province-wide cohort available for analysis until the present study. Therefore, previous policy and planning decisions have been based on information from other jurisdictions or on small clinical samples from Ontario. This is a serious concern, considering that other jurisdictions differ from this province in important ways that critically impact service planning, including different service philosophies, health care systems and social service policies.

This chapter addresses some of these information gaps using the H-CARDD cohort of 66,484 adults with developmental disabilities described in Chapter 1.

The main questions this chapter will answer are:

- Who are the adults with developmental disabilities in Ontario?
- Where do they live?
- What is their health status?
- How do they differ from adults without developmental disabilities?

Background

Prevalence and demographics

Most of what we know about the prevalence of developmental disabilities is based on research that has focused on children or adolescents, who are often easier to identify through education databases. A recent meta-analysis of the literature estimated the average prevalence of developmental disabilities among adults to be 0.49%.[15] The reported rates across the studies that were examined ranged between 0.26% and 0.70%.[15] This variation is partly a reflection of differences between the countries or populations being studied (e.g., low-income countries tend to have much higher prevalence rates than high-income countries). However, the main reasons for the variation can be attributed to the use of different data sources (e.g., education data versus household surveys) and different ways of defining and measuring developmental disabilities.

Studies comparing the demographic characteristics of those with and without developmental disabilities are surprisingly limited. The information that is available is based mostly on comparisons *within* the group with developmental disabilities. Two Canadian studies found that one-half to almost three-quarters of the individuals identified as having developmental disabilities were under the age of 20 years.[16,17] Persons with developmental disabilities are also more likely to be male than female, although some studies have found that this difference decreases with age.[16-18]

Other important characteristics of this population include socioeconomic status and geographic location. Socioeconomic status, specifically poverty, and the prevalence of developmental disabilities have been identified as a concern.[19] Geographic location, in terms of urban/rural residence, on the other hand, has received little attention.

To gain a better understanding of the adult population with developmental disabilities in Ontario, this chapter describes members of the H-CARDD cohort in terms of their age and sex, their area of residence (urban or rural), their health region (Local Health Integration Network), and their neighbourhood's average income. Mapping software (ArcGIS v.10.2) was used to show approximately where they live in Ontario.

For the entire H-CARDD cohort and for different subgroups (e.g., age group, sex), we report the total number of individuals with developmental disabilities and calculate the corresponding prevalence estimate.

We also compare our cohort of adults with developmental disabilities with a 20% random sample of adults aged 18 to 64 years without developmental disabilities.

For more detailed information about how specific measures were created, see the Technical Appendix.

Chronic disease and morbidity

It is recognized that adults with developmental disabilities are more likely to experience health problems than adults without developmental disabilities.[11,20-23] It has also been found that health issues are often underdiagnosed in this population, indicating that the high reported rates may be underestimates.[20] Given this recognition, there is surprisingly little literature that compares rates of specific diseases for adults with and without developmental disabilities.[20] In addition, the literature that does exist is sometimes contradictory.

Studies have found higher rates among individuals with developmental disabilities for a number of conditions, including seizure disorder, gastroesophageal reflux disease and dental disease.[11,24-27] Mental illness, a condition that has been extensively studied in this population, has also been found to have uniformly higher rates among individuals with developmental disabilities compared to those without.[17,28-30]

Reports for other diseases have been less consistent. For example, some studies have found much higher rates of diabetes among persons with developmental disabilities,[21,31-33] while others report similar or lower rates.[20,28,29] Similar contradictions exist in the literature for other diseases, such as asthma, heart disease, hypertension and chronic obstructive pulmonary disease.[20,21,24,31,32,34] It is therefore important to learn which diseases are more common among adults with developmental disabilities in Ontario so that we can ensure that appropriate care is being provided.

MORBIDITY Defined as a 'diseased state.'[35] Measures of morbidity show how close or far away a person is from a state of well-being or good health. In health care, high morbidity levels can signal a need for immediate or intensive treatment or a need for a combination of different kinds of care that are coordinated with each other.

It is also important to consider the *overall* disease burden (not just the rates of single diseases) experienced by adults with developmental disabilities. One term used for the overall level of ill health is *morbidity*, which is defined as a 'diseased state.'[35] Measures of morbidity show how close or far away a person is from a state of well-being or good health (*see the* Technical Appendix).

Morbidity has received less attention in the literature than rates of specific diseases. However, there is some evidence that individuals with developmental disabilities have higher levels of morbidity than adults without developmental disabilities.[21,36]

In this chapter, we compared adults with and without developmental disabilities in terms of the percentages who had any of six conditions: congestive heart failure, chronic obstructive pulmonary disease, diabetes, asthma, hypertension and psychiatric disorders. These conditions were chosen for two reasons. First, they are relatively common and can have a major impact on a person's well-being and ability to function. Second, they have been studied in other populations using the same data sources as our investigation and are thus easily measured and comparable to previous research (*see the* Technical Appendix *for details on how they were measured*).

We also compared the levels of morbidity in our cohort with the sample of adults without developmental disabilities by using a common measure of morbidity called the Resource Utilization Band (*see the* Technical Appendix *for an explanation*).

List of Exhibits

EXHIBIT 2.1 Geographic distribution of adults aged 18 to 64 years with developmental disabilities, in Ontario, 2009/10

Findings

- The prevalence estimate for adults aged 18 to 64 years with developmental disabilities was 0.78% in 2009/10, based on the H-CARDD cohort of 66,484 individuals.
- Like the overall Ontario population, adults with developmental disabilities tended to live in large and mid-sized urban communities but were also represented in more sparsely populated areas.

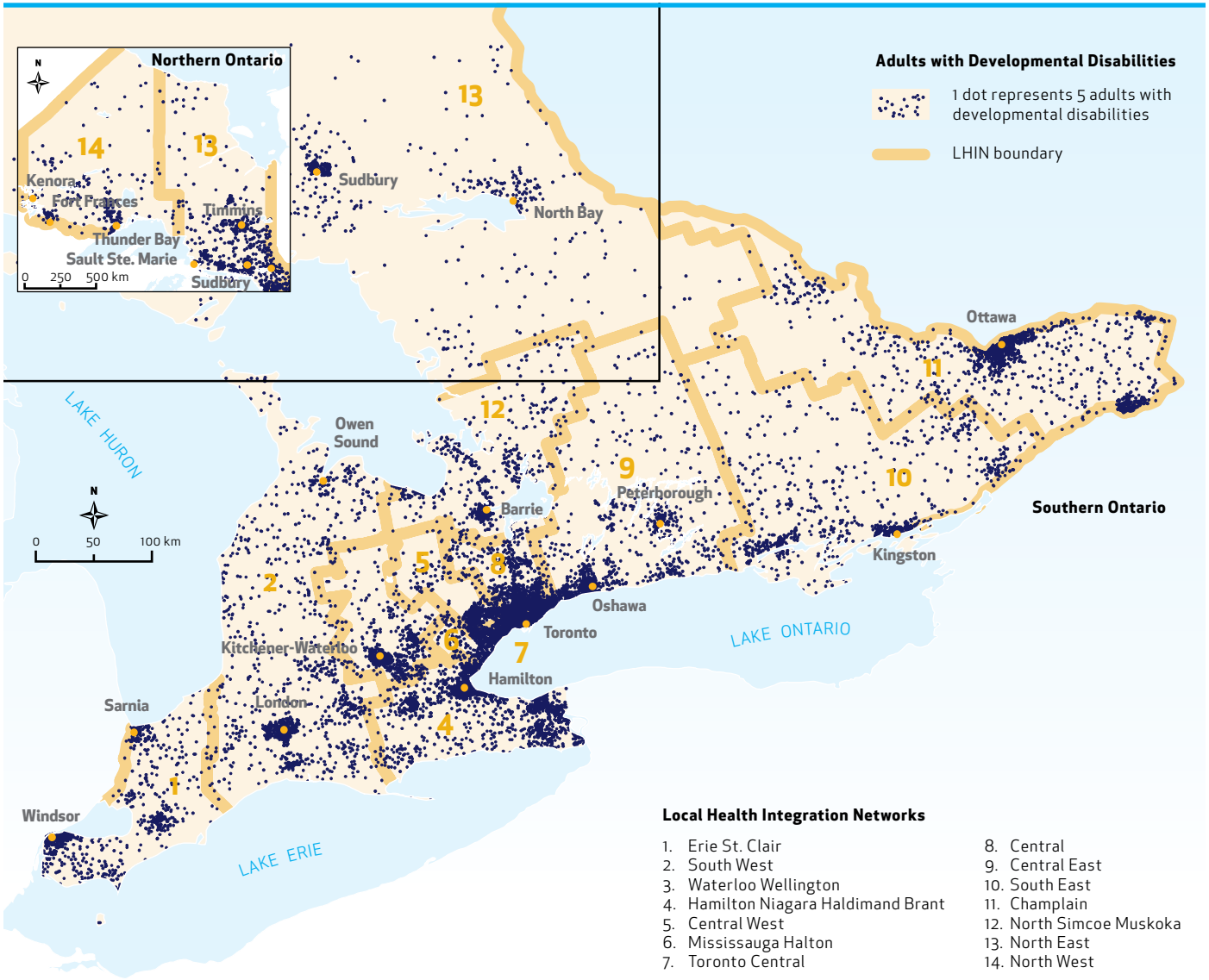


EXHIBIT 2.2 Number, prevalence and age- and sex-adjusted prevalence of adults aged 18 to 64 with developmental disabilities, by Local Health Integration Network and in Ontario, 2009/10

Findings

- There was wide variation across Local Health Integration Networks (LHINs) in the number of adults with developmental disabilities.
- The LHINs with the largest number of adults with developmental disabilities were Hamilton Niagara Haldimand Brant (9,158), Champlain (6,875) and Central East (6,702). Those with the smallest number were North West (1,828), Central West (2,321) and North Simcoe Muskoka (2,780).
- Prevalence estimates varied widely across LHINs, ranging from 0.42% to 1.44%.
- The highest prevalence estimates were evident in the South East (1.44%), North East (1.37%) and North West (1.15%) LHINs, while the lowest appeared in the Mississauga Halton (0.42%), Central West (0.45%) and Central (0.49%) LHINs.
- Adjusting for age and sex resulted in only small changes in the prevalence estimates for the LHINs, which suggests that the variation among LHINs was caused by something other than differences in their age and sex profiles. Furthermore, the pattern of prevalence estimates across LHINs was the same for both the unadjusted and adjusted estimates.

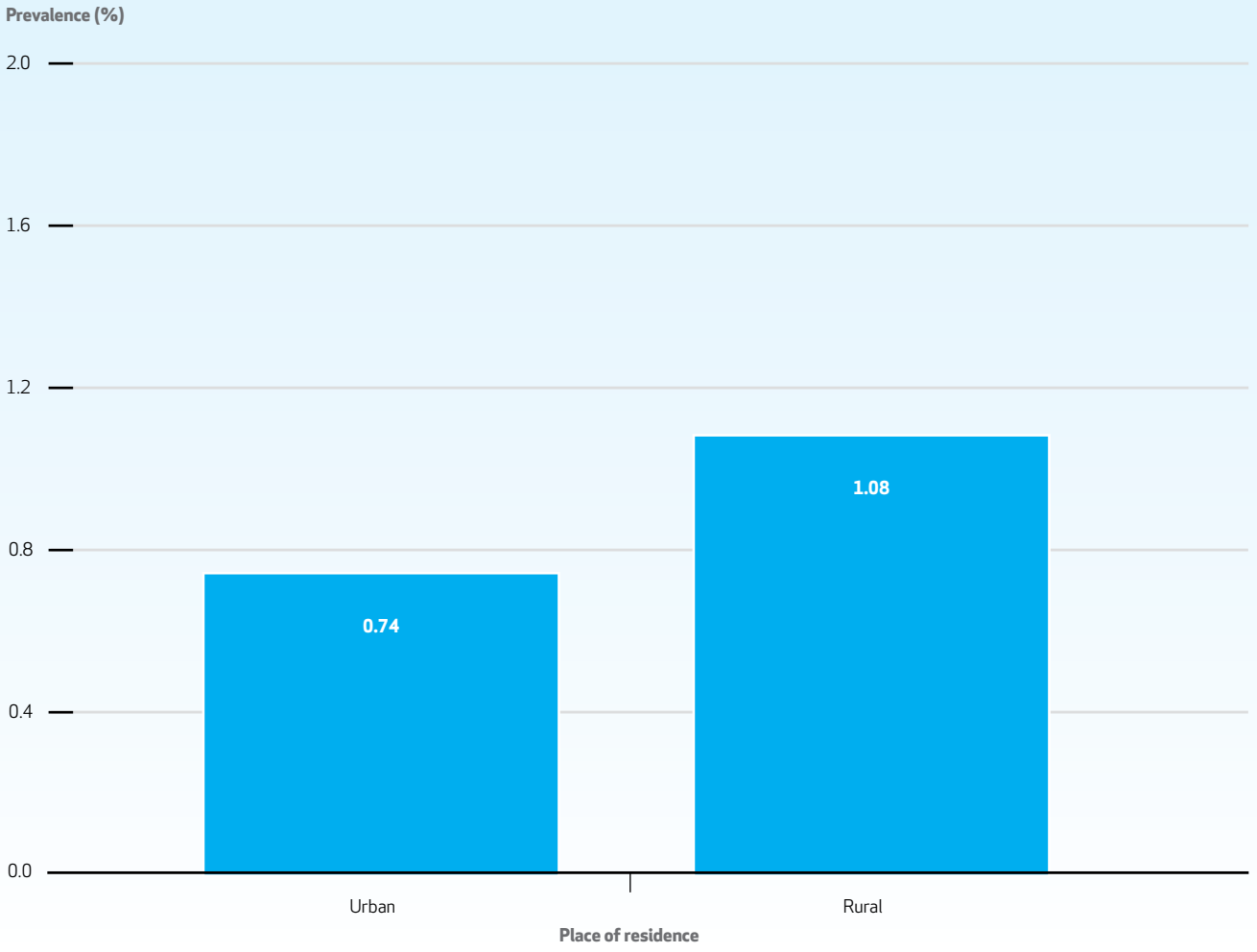
	Adults with developmental disabilities		
	Number	Prevalence	Age- and sex-adjusted prevalence*
Ontario	66,484	0.78	0.79
Local Health Integration Network			
1. Erie St. Clair	4,057	0.94	0.95
2. South West	6,242	1.01	1.03
3. Waterloo Wellington	3,267	0.67	0.68
4. Hamilton Niagara Haldimand Brant	9,158	1.01	1.05
5. Central West	2,321	0.45	0.46
6. Mississauga Halton	3,054	0.42	0.45
7. Toronto Central	4,575	0.56	0.57
8. Central	5,321	0.49	0.50
9. Central East	6,702	0.67	0.69
10. South East	4,610	1.44	1.51
11. Champlain	6,875	0.84	0.85
12. North Simcoe Muskoka	2,780	0.97	0.99
13. North East	5,194	1.37	1.43
14. North West	1,828	1.15	1.20

*Age and sex rates were standardized to the 1991 Canada population.

EXHIBIT 2.3 Prevalence and number of adults aged 18 to 64 years with developmental disabilities, by urban or rural residence, in Ontario, 2009/10

Findings

- Adults with developmental disabilities were an estimated 0.74% of the urban population (56,012 individuals) and an estimated 1.08% of the rural population (10,472 individuals).
- Adults with developmental disabilities were more likely to live in rural areas than adults without developmental disabilities (15.6% vs. 11.0%) (data not shown). This is equivalent to an urban-rural ratio of approximately 85:15 for adults with developmental disabilities versus approximately 90:10 for adults without developmental disabilities.

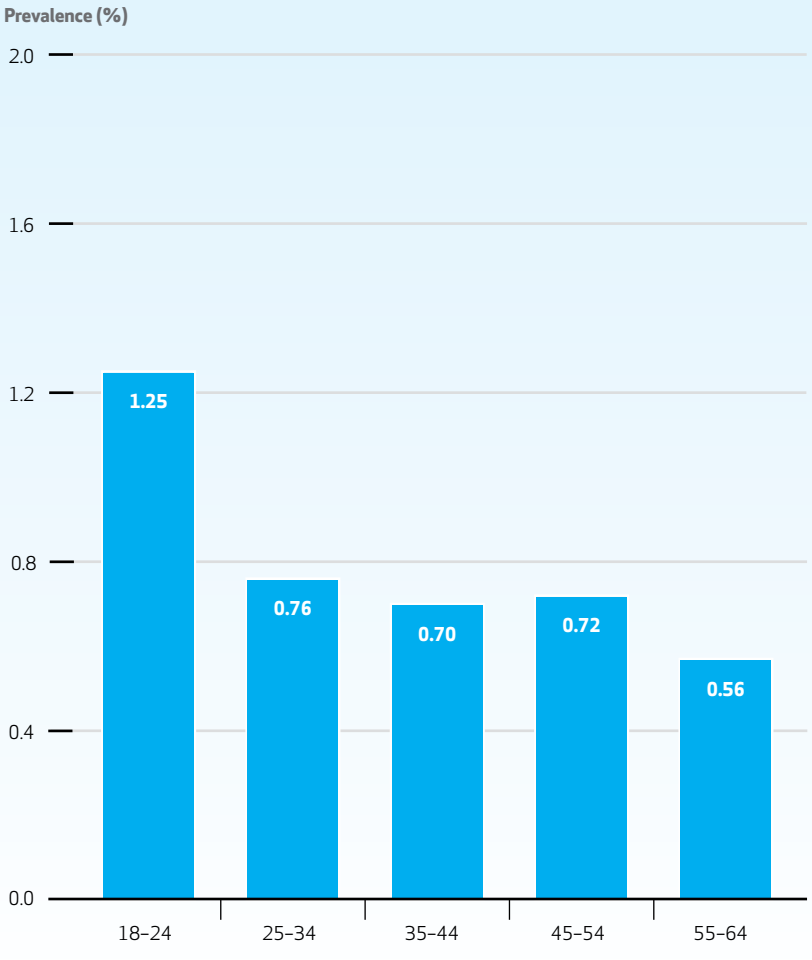


	Urban	Rural
Adults (n)	56,012	10,472

EXHIBIT 2.4 Prevalence and number of adults aged 18 to 64 years with developmental disabilities, by age group, in Ontario, 2009/10

Findings

- The prevalence estimate was highest among adults aged 18 to 24 years (1.25%), decreasing noticeably for those aged 25 to 34 years, and then decreasing at a lesser rate through the subsequent decades, reaching a low of 0.57% among those aged 55 to 64 years.
- When these prevalence estimates are translated to numbers, they range between 8,756 and 15,930 persons.
- When the age composition of adults with and without developmental disabilities are compared (data not shown), adults with developmental disabilities tend to be younger.
  - Adults aged 18 to 24 years accounted for 24.0% of adults with developmental disabilities but only 14.3% of adults without developmental disabilities.
  - By contrast, the oldest group (those aged 55 to 64 years) accounted for 18.0% of the comparison group but only 13.2% of adults with developmental disabilities.

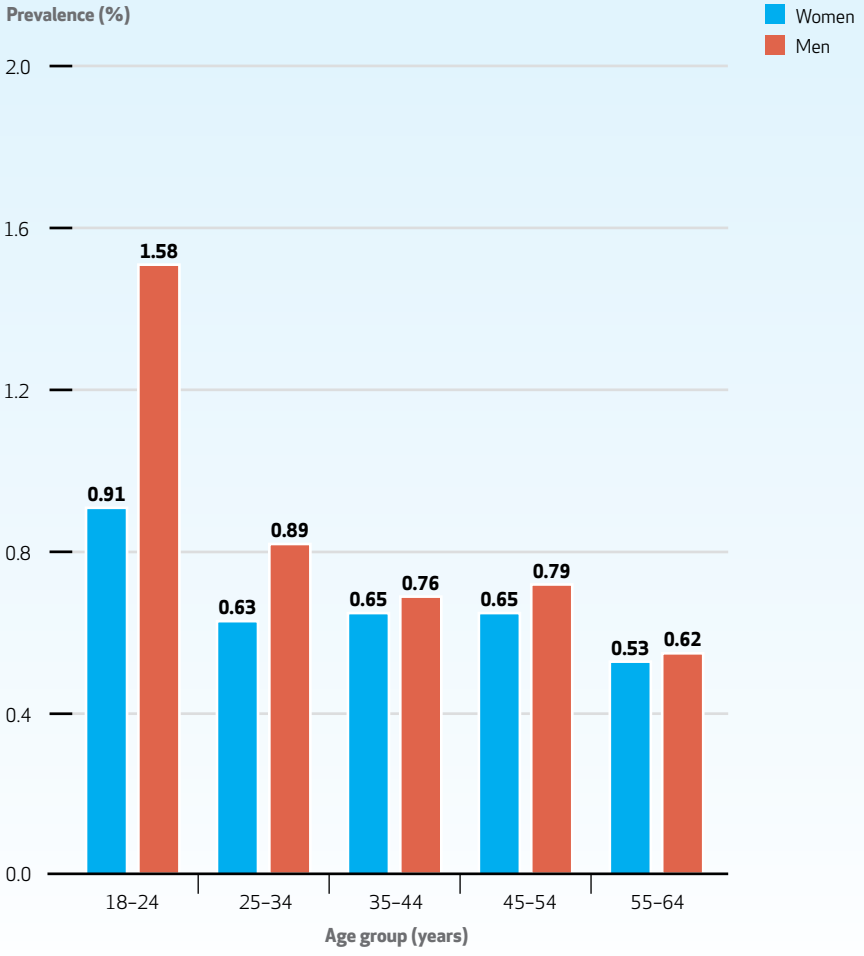


	18–24	25–34	35–44	45–54	55–64
Adults (n)	15,980	13,376	13,521	14,851	8,756

EXHIBIT 2.5 Prevalence and number of adults aged 18 to 64 years with developmental disabilities, by age group and sex, in Ontario, 2009/10

Findings

- In Ontario in 2009/10, the population of adults with developmental disabilities included 38,090 men and 28,394 women, with prevalence estimates of 0.89% and 0.66%, respectively (data not shown).
- This pattern of men having higher rates of developmental disabilities than women held true across all age groups.
  - The most dramatic difference in prevalence between men and women was among those aged 18 to 24 years (1.58% vs.0.91%, respectively).
  - The higher prevalence of men over women continued in the remaining age groups, but the difference was much smaller, with the least variation found in those aged 55 to 64 years (0.62% vs. 0.53%, respectively).
- Male-female ratios were different in the groups with and without developmental disabilities. Men comprised 57.3% of the developmental disabilities population while women made up 42.7%, almost a 60:40 male to female ratio. The group without developmental disabilities had a ratio closer to 50:50 (men, 49.1%; women, 50.9%).

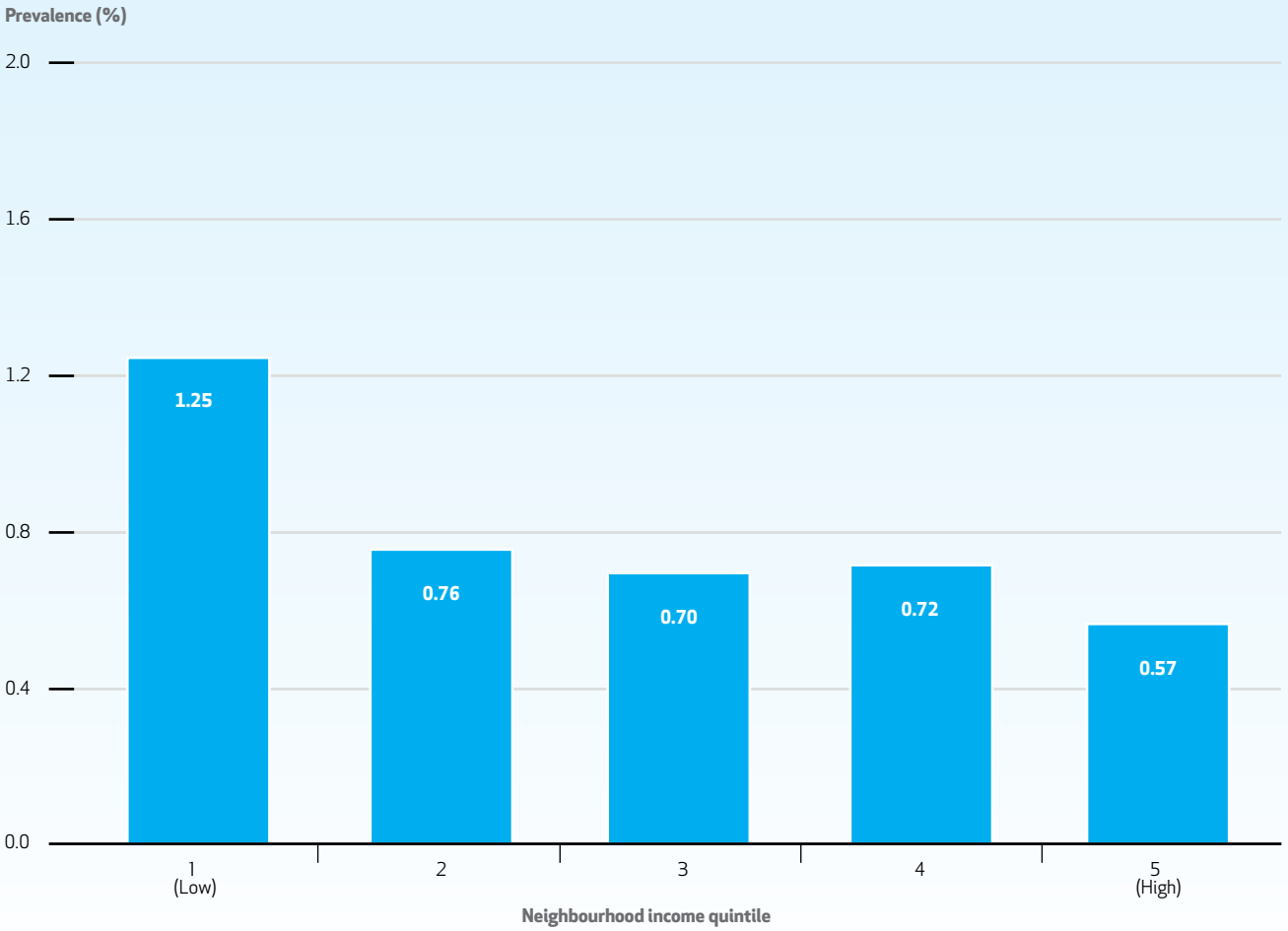


	18–24	25–34	35–44	45–54	55–64
Women (n)	5,694	5,622	6,221	6,718	4,139
Men (n)	10,286	7,754	7,300	8,133	4,617

EXHIBIT 2.6 Number and prevalence of adults aged 18 to 64 years with developmental disabilities, by neighbourhood income quintile, in Ontario, 2009/10

Finding

- Neighbourhood income quintiles divide the Ontario population into five groups, each consisting of 20% of the population. Adults with developmental disabilities were unevenly distributed across the income quintiles. More than twice the number of adults with developmental disabilities lived in the poorest neighbourhoods than in the wealthiest neighbourhoods (19,987 vs. 9,226). These numbers correspond to prevalence estimates of 1.25% and 0.57%, respectively.



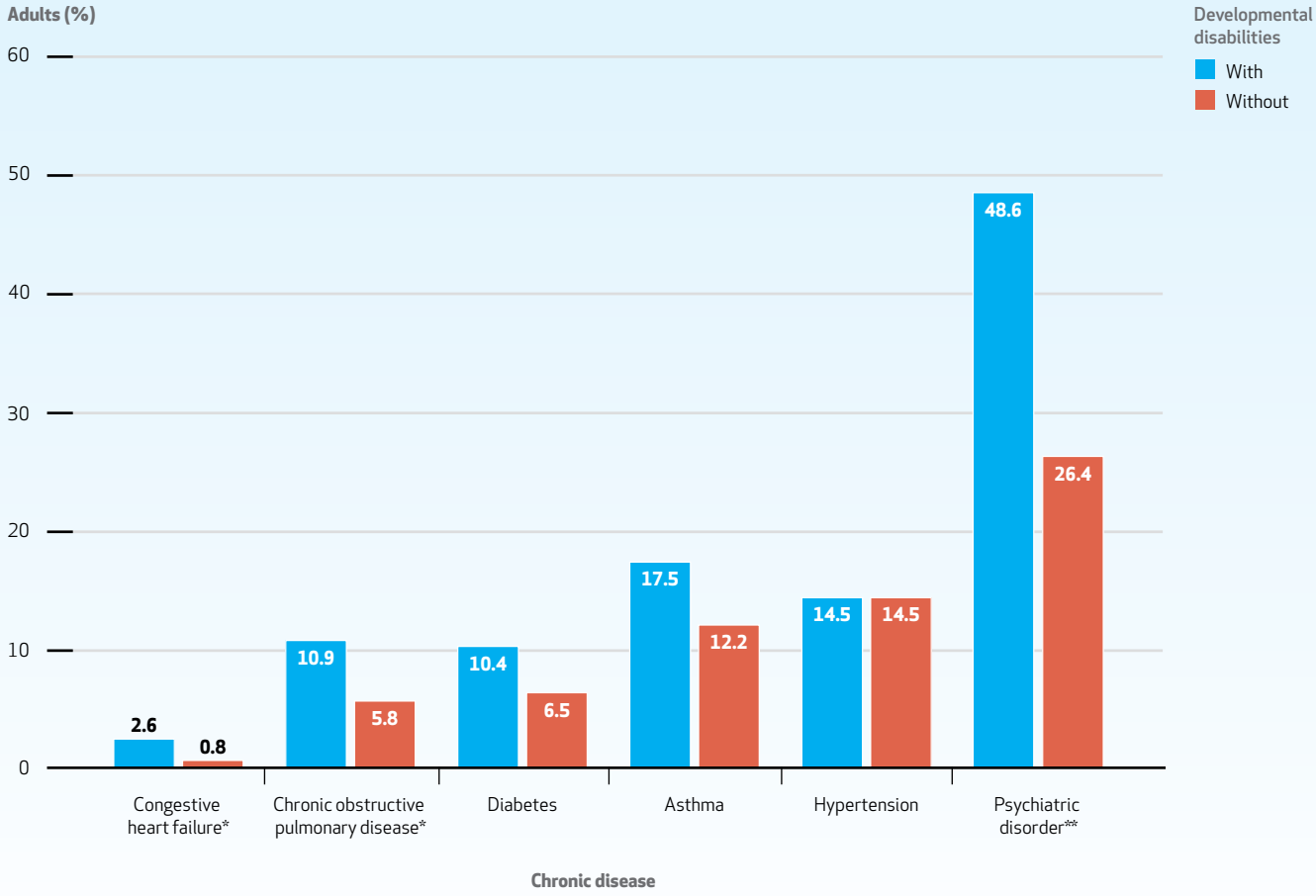
	1 (Low)	2	3	4	5 (High)
Adults (n)	19,987	14,181	11,610	10,635	9,226

Note: Excludes individuals for whom a postal code was missing.

EXHIBIT 2.7 Proportion of adults aged 18 to 64 years with or without developmental disabilities, by chronic disease, in Ontario, 2009/10

Findings

- Adults with developmental disabilities were more likely than adults without developmental disabilities to be diagnosed as having one of a range of chronic diseases.
- The most common disease among adults with developmental disabilities was psychiatric disorders, which affected almost half of this population (48.6%).
- Compared to adults without developmental disabilities, adults with developmental disabilities had more than three times the proportion of congestive heart failure and almost twice the proportion of chronic obstructive pulmonary disease and psychiatric disorders. They also had a 60% higher proportion of diabetes.

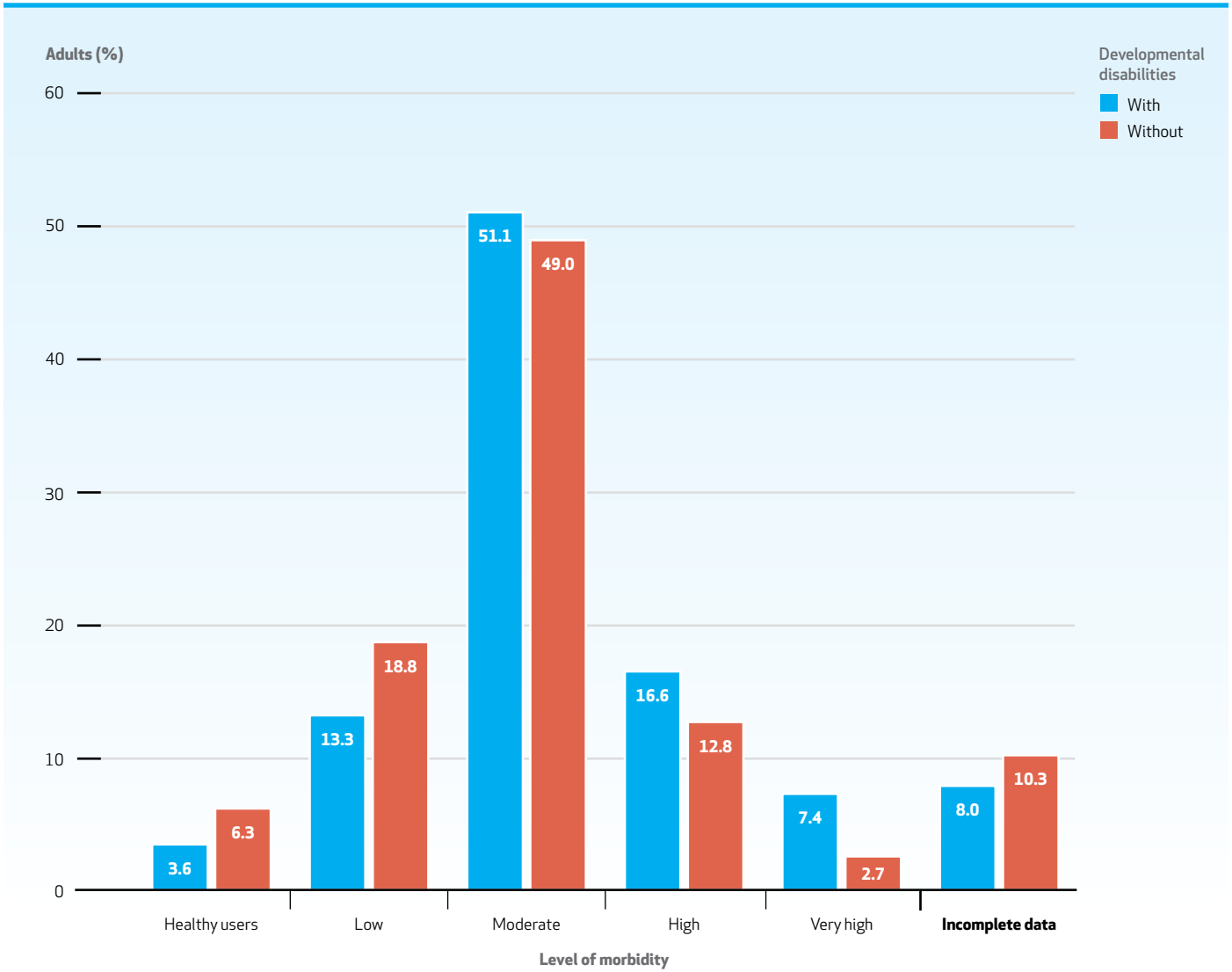


* CHF and COPD generally affect middle-aged and older adults. Consequently, rates for these diseases were calculated at age 40 for CHF and age 35 for COPD, rather than at age 18.
** Psychiatric disorder includes both chronic and episodic disorders.

EXHIBIT 2.8 Proportion of adults aged 18 to 64 years with or without developmental disabilities, by level of morbidity, in Ontario, 2009/10

Findings

- Adults with developmental disabilities were more likely to have moderate to very high levels of morbidity than those without developmental disabilities.
- In particular, adults with developmental disabilities were almost three times as likely to have a very high level of morbidity (7.4% vs. 2.7%) and more than half as likely to be in the healthy user group (3.6% vs. 6.3%) compared to adults without developmental disabilities.



Discussion

Estimating prevalence

Based on the H-CARDD cohort, the prevalence estimate of developmental disabilities for adult Ontarians is 0.78%. This is higher than the rates reported for adults in the scientific literature (0.49%),[15] and in the Canadian Participation and Activity Limitation Survey (0.6% for working-aged men, 0.5% for working-aged women).[37]

The most likely explanation for our higher estimate is that, unlike many previous studies, we were able to create a dataset by linking multiple data sources and thus capture a greater number of individuals with developmental disabilities. Other studies that used more than one source of information also found higher prevalence estimates than studies which relied on a single data source.[16,18,23]

What would be the impact of including even more sources of data on our prevalence estimates? While we would definitely be able to capture more individuals with developmental disabilities, previous reports suggest that the exact number depends on the source. The proportion of individuals with developmental disabilities who were added when more sources were available ranged between 0.3% to 38.0% in other studies.[16,18,23] The particular subgroups added through data linkage also varied, depending on the source (e.g., younger persons if the source was education records, older individuals if the source was long-term medication benefits).

Demographic profile

Adults with developmental disabilities live in every part of Ontario, from large urban centres to more sparsely populated rural areas.

They are not, however, evenly distributed across the province's 14 Local Health Integration Networks (LHINs). Among the LHINs, the highest prevalence estimate (1.44% in the South East LHIN) was more than three times larger than the lowest (0.42% in the Mississauga Halton LHIN). Very little of this difference in prevalence can be explained by differences in the age and sex of LHIN residents. There may be other possible explanations. For example, residents in some areas may be more exposed to social or other risk factors. The locations of the former provincial institutions for people with developmental disabilities may have influenced this population and their families to live in particular regions of the province.[38] It is also possible that doctors in some LHINs may be more experienced in recognizing, and thus making the diagnosis of, developmental disabilities which could influence who is captured in both the administrative health and disability income support data. We do not currently have enough information to allow us to judge which of these possible explanations might apply.

Consistent with previous reports, we found that adults with developmental disabilities in Ontario were more likely to be younger, male and residents of the lowest-income neighbourhoods.

Younger age may be a function of several factors. One is the method we used to identify individuals in the administrative health data (*see the* Technical Appendix). Another is the increasing prevalence of autism spectrum disorder over the past two decades.[39-41] This might also partly explain the larger male/female ratio that we found for the younger adults in the H-CARDD cohort, since boys are four times more likely to be diagnosed with autism spectrum disorder than girls.[42] A third possibility is that individuals with developmental disabilities have a shorter than average life expectancy[43] due in part to their higher rates of disease. However, because their life expectancy has been increasing,[44,45] their average age has also increased. This, combined with improved prevention and management of comorbidities, may increase prevalence estimates in the future.

The association between poverty and higher rates of developmental disability has been reported in several other studies.[19,46-48] A review of the literature suggests that this association may have two main causes.[19] Firstly, poverty exposes individuals to more environmental and psychosocial risk factors and increases their chances of having developmental disabilities. Secondly, developmental disabilities, because they can be barriers to employment and can make serious financial demands on families, lead to poverty. These two explanations are not mutually exclusive, and both may be operating in Ontario as well as in other regions.

Chronic disease and morbidity

Previous research on chronic disease has focused largely on conditions that are directly related to developmental disabilities (such as epilepsy). Few studies have considered more common chronic diseases.[20] We found that individuals in the H-CARDD cohort were more likely than adults without developmental disabilities to have a diagnosis of congestive heart failure, chronic obstructive pulmonary disease, diabetes or asthma. We also found that psychiatric disorders were nearly twice as common among adults with developmental disabilities (48.6%) compared to those without (26.4%). Generally, adults with developmental disabilities had higher levels of morbidity.

These Ontario findings are consistent with reports from other jurisdictions which found that individuals with developmental disabilities were more likely to have health problems in general, higher rates of specific diseases (such as asthma, diabetes, and psychiatric disorders) and higher levels of morbidity.[11,23,31,36,49] Our results also add to areas of research that need further exploration—for example, chronic obstructive pulmonary disease.

These higher morbidity levels emphasize the need for ensuring that policies and strategies for addressing chronic and other diseases include an awareness of the developmental disabilities population and the need to target management and prevention programs towards them. More investigation into the causes of higher morbidity, particularly in comparison to adults without developmental disabilities, is also needed to help tailor these programs.

Implications for policy and practice

Previously, planning for adults with developmental disabilities was informed by prevalence estimates that were not specific to Ontario (e.g., Statistics Canada's Participation and Activity Limitation Survey[50]) or that used data from only one sector. Information from this chapter, and indeed the entire Atlas, can be used to inform a review of current programs and policies to determine if they are still appropriate and adequate to address the numbers and needs of adult Ontarians with developmental disabilities.

The scope of policy and planning activities for adults with developmental disabilities should continue to be province-wide. However, specific attention may be necessary for those LHINs which have prevalence estimates that are either much higher or much lower than the provincial average.

Reasons for the higher estimates should be investigated to determine if they reflect increased individual or environmental risk factors (e.g., genetics, poverty), greater availability of specialized services or local provider practice.[51,52] Reasons for the lower estimates could include fewer risk factors but might also include poorer recognition by the health care and social service systems.

Current policies and planning that focus on developmental disabilities should also be evaluated to ensure they are targeting particular subgroups of adults with developmental disabilities, including younger adults, males and those who live in the lowest-income neighbourhoods. In addition, because the expected lifespan of individuals is increasing, greater attention to older adults with developmental disabilities is warranted.

The high rates of illness and especially the very high rate of psychiatric disorder in the H-CARDD cohort should continue to be a policy and planning concern. The steps that have been taken to meet the needs of these individuals (e.g., the Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis;[53] Community Networks of Specialized Care[54]) should be continued and developed more fully.

For chronic illnesses more generally, the conditions that we examined in this chapter are often preventable or can be successfully controlled if there are adequate and accessible services and supports. In particular, prevention and management should be important priorities. As well, there should be exploration of how coordination with social services and other service sectors might benefit this population.

Additionally, there is a need to expand policy and planning beyond the single-disease approach taken by many care guidelines. While there is a growing recognition of the need for program development for people living with multiple medical conditions,[55,56] this work should include vulnerable groups such as those with developmental disabilities. Similarly, the Canadian primary care guidelines that are focused on developmental disabilities also need to be further developed to cover the management of multiple health conditions.

Finally, policies and strategies developed for chronic diseases and for individuals with complex needs should be expanded to recognize the particular needs of those with developmental disabilities. Ontario examples relevant to adults with developmental disabilities include the Mental Health and Addictions Strategy,[57] the Chronic Disease and Management Strategy[58] and the Action Plan for Health Care.[59] These strategies address, respectively, the access to and quality of care for individuals with mental health and addictions, the needs of individuals with chronic diseases, and the needs of all Ontarians particularly in the context of an aging population.

Data needs

Because of the nature of the data sources that were linked to create the H-CARDD cohort, our focus has been on adults with developmental disabilities between the ages of 18 and 64 years. There are, however, both younger and older individuals who need to be included and described to obtain a more complete picture for Ontario.

We were able to examine some important chronic diseases in this chapter. However, other illnesses, such as seizure disorder, gastroesophageal reflux disease and dental disease,[11,24-27] also affect adults with developmental disabilities at high rates and can have long-term and significant impacts on functioning and quality of life. The development and validation of measures for these and other diseases would contribute to a more complete picture of the morbidity and needs of adults with developmental disabilities.

Finally, the developmental disabilities diagnostic information available in our data sources has not been rigorously validated. The fact that many of our findings (e.g., the demographic profiles) are consistent with those in other reports would seem to support their being relatively solid. However, is it quite likely that we missed some individuals who did have developmental disabilities and erroneously included others who did not. Validation studies will provide information on how many individuals we missed or included in error and increase our confidence in using both existing and new sources of information about individuals with developmental disabilities.

Future research

An important future direction to explore will be linking data from other sources to the data used to

create the H-CARDD cohort. Obvious information sources would include data from education, children and youth services, home care and long-term care facilities. This would allow more complete identification of adults with developmental disabilities, as well as children and youth and those aged 65 and older.

There are several areas where more investigation would help inform policy and planning. These include:

- Research that would help tease apart the contributions of social determinants, health-system factors and provider practices to the prevalence and care of persons with developmental disabilities;
- Further examination of how these factors, and personal circumstances, impact the morbidity profiles of adults with developmental disabilities;
- More finely grained descriptions of morbidity levels and rates of specific diseases by age, sex, and neighbourhood income level;
- Longitudinal studies to determine whether the results we have reported are consistent over time.

The results of this additional research could be used to help identify new areas where we need to improve our health care and social systems to better meet the needs of adult Ontarians with developmental disabilities. The more we learn about adults with developmental disabilities in Ontario—who they are, where they live and what illnesses they have—the better we are able to improve health and social services planning and ensure that this population receives adequate and equitable support.

Conclusion

This chapter presents the first province-wide information in Ontario describing adults with developmental disabilities and their health status. The linked dataset that we created allows us to provide a more comprehensive picture than had been available previously. It also provides a good starting point for answering other questions, such as what kinds of services are used by adults with developmental disabilities (*see* Chapter 3) and are they receiving appropriate care (*see* Chapters 4, 5 *and* 6).

Together, the information in this and the remaining chapters in this Atlas will help us to review and refine existing programs and policies, identify gaps and, ultimately, improve our ability to address the needs of adults with developmental disabilities.

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3 Health Services Utilization

Inside

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MAIN MESSAGES

- Adults with developmental disabilities are highly vulnerable to medically complex and co-occurring health problems that require greater coordination among primary care, specialist and hospital services. Knowledge about patterns of use of these services is needed to identify areas of underperformance in the health system and to inform system improvement.

- We compared adults with and without developmental disabilities in their use of family physicians, specialists and emergency departments between April 2009 and March 2010. We also looked at hospitalizations in that time period. The impacts of age, sex, morbidity, neighborhood income, urban/rural residence and regional differences on these aspects of health service use were reported. Continuity of care with family physicians and involvement in different models of family practice were also explored.

- Despite comparable use of family physicians and similarities in continuity of care, adults with developmental disabilities were more likely to visit emergency departments and be hospitalized. Being older or having high morbidity increased the risk of visiting the hospital for adults with developmental disabilities to a level above what would be expected for adults without. Most adults with developmental disabilities were seeing physicians practicing in a primary care enrolment model. Although interprofessional care is recommended for this population, only 20% were receiving their care through interprofessional Family Health Teams.

- Adults with developmental disabilities accessed primary care at equal to greater rates than those without developmental disabilities. It is important that primary care providers be aware of the vulnerability of adults with developmental disabilities to particular health problems so that appropriate specialist referral and care are provided. The reduction of avoidable emergency department visits and unnecessary inpatient visits is a shared goal of Ontario's newly introduced Community Health Links and the H-CARDD program. Expanding the focus of Community Health Links to include adults with developmental disabilities would be a positive step toward achieving this goal.

Introduction

There is limited information available on the use of health services by adults with developmental disabilities. Thus, it is difficult for policy-makers, managers and providers to make well-informed policy and planning decisions for this vulnerable population (*see* Chapter 1). Chapter 3 describes the extent to which adults with developmental disabilities use primary care, specialist care and hospital services. Service use is examined with respect to the proportion of the population that use the services and the frequency of that use. Data on continuity of care with a family physician are also presented. We explore the representation of adults with developmental disabilities in primary care patient enrolment models associated with payment incentives to increase comprehensive care. Interprofessional team practice through Family Health Teams is also considered.

The data presented are descriptive. This chapter aims to provide a broad overview of system utilization and, as such, there are no specific hypotheses, standards or benchmarks tested. There are, however, some basic expectations with respect to the overall utilization of health care services by adults with developmental disabilities.

There should be *equitable* access for all individuals.[1] Equitable access does not mean equal access; it means all individuals have the same access to care appropriate to their needs. Therefore, due to their higher levels of morbidity (*see* Chapter 2),

adults with developmental disabilities should be accessing health services more than adults without developmental disabilities, although how much more is unknown.[2] We would also hope to see good continuity of care with a single provider or team of providers, which would be particularly important for managing higher levels of morbidity. Related to this, being enrolled in a model of care where an interprofessional team of care providers can be accessed, such as a Family Health Team, would be consistent with recommendations for primary care of this population.

Finally, research has identified the negative effects of demographic risk factors on the health outcomes of persons with developmental disabilities.[3-7] Little is known, however, about how factors such as age, sex, geographic location, income and morbidity influence the use of health care services by persons with developmental disabilities relative to those without developmental disabilities. This chapter explores these issues.

Background

Physician visits, emergency department use and hospitalizations

The updated Canadian Consensus Guidelines on the Primary Care of Adults with Developmental Disabilities suggest that primary care providers are vital to efforts to ameliorate health care for individuals with developmental disabilities.[8] Those delivering primary care have been shown to be the most consistently available health care providers for these individuals and are active in consulting with their paid and family caregivers.[8]

Good access to primary care is particularly important to individuals with developmental disabilities for several reasons. First, due to their medical complexities (*see* Chapter 2), adults with developmental disabilities are more likely to need specialty care requiring referral from their family physician. For example, adults with developmental disabilities have higher rates of psychiatric, seizure, gastrointestinal, feeding and respiratory disorders; thus, they are more likely in need of specialists who can address these issues such as psychiatrists, neurologists, gastroenterologists and respirologists.[8-12] Second, poor access to primary care is linked to emergency department use[13] and preventable hospitalizations[14] in the general population. While we need more research into the nature of these links with respect to individuals with developmental disabilities, existing research has shown that they are more likely to visit an emergency department[15] or experience unnecessary hospital admissions[16] compared to individuals without developmental disabilities.

PRIMARY CARE There are several attributes that differentiate primary care from specialty care. Primary care is distinguished by being the first point of contact within the health care system, providing continuity of care, providing comprehensive care and coordinating care across the health care sector.[17] Currently, family physicians are the main providers of primary care in Canada.[18] However, nurse practitioners are increasingly providing primary care to some populations.[19,20]

Given the links between primary care, specialist care, emergency department use and hospitalizations, it is important to examine all these types of services when exploring health care utilization. We looked at several measures among adults aged 18 to 64 years with developmental disabilities during the period April 1, 2009 to March 31, 2010. We calculated the proportion who (1) made at least one visit to a family physician, (2) made at least one visit to selected specialists, (3) made at least one visit to an emergency department, and (4) were hospitalized at least once. For individuals who did use these services, we also looked at the frequency of use. We compared their service utilization to that of adults aged 18 to

64 years without developmental disabilities. For both groups, we examined the impact of age, sex, neighbourhood income, urban/rural residence and morbidity on health service use (*see the* Technical Appendix *for descriptions of these variables*).

Continuity of care

It is not only the type of providers accessed and the frequency of visits that are important to the health needs of persons with developmental disabilities; continuity of care is another important aspect of their care that should be evaluated. Evidence has shown that, in the general population, good continuity of care with a single provider, or a team of providers, is associated with high levels of patient and provider satisfaction.[21,22] It has also been shown to be correlated with reductions in emergency department visits and avoidable hospitalizations, and with better prescribing practices among physicians.[23-25] Research specific to adults with developmental disabilities has shown that primary care continuity in this population is associated with decreased emergency department use.[25]

CONTINUITY OF CARE reflects consistency in seeing a specific provider over time.[26]

As an indicator of continuity of care, we used the Usual Provider Continuity (UPC) Index which measures continuity of care with family physicians.

Vicki, Petra's mother: "*My experience in going with Petra to the doctor has been that communication with the doctor is easier when you have a doctor that you see from year to year.*"

The UPC Index is calculated as the proportion of all visits that a person made to their usual family physician divided by total visits to all family physicians over a two-year period.[27] For a UPC Index score to be calculated, a person must make at least three visits to his or her family physician during the two years. In this report, we looked at the period from April 1, 2009 to March 31, 2011, calculated the average UPC Index score for adults with developmental disabilities and for a random sample of adults without developmental disabilities, and sorted them into high, medium and low categories by score (*see the* Technical Appendix *for definitions of the categories*).

Primary care patient enrolment models

Patient enrolment models were introduced in Ontario in 2001 by the Ministry of Health and Long-Term Care in an effort to improve access to primary care, comprehensive primary care delivery, and continuity of care. This concept of service delivery was introduced in several care models which addressed different combinations of how physicians practiced (solo, in physician groups or in interprofessional teams) and how they were reimbursed (fee for service or some form of capitation payment). In all of these models, patients sign an agreement to receive all of their primary care from a specific physician (referred to as enrolment). These models were introduced in 2001 with the **Family Health Network,** followed by the **Family Health Group** in 2003, the **Comprehensive Care Model** in 2005 and the **Family Health Organization** in 2007. Of these models, only the Comprehensive Care Model is a solo practice; the remainder are group practice models.

Physicians in Comprehensive Care Models and Family Health Groups are paid through fee-for-service (FFS) with some incentives/bonuses (called enhanced FFS), while physicians in Family Health Networks and Family Health Organizations are funded through capitation with an expanded menu of incentives/bonuses (called blended capitation). The incentives and bonuses are meant to promote patient access, comprehensive care, and continuity of care. For example, incentives are provided for diabetes and heart failure management and preventive services which target comprehensiveness and continuity of care. Continuity is also encouraged by a bonus provided to physicians in the blended capitation models which is reduced each time an enrolled patient seeks primary care outside of the practice. Incentives for enrolling patients looking for a family physician and those with serious mental health problems, as well as requirements for extended office hours and on-call arrangements are examples of access-oriented incentives (*see the* Technical Appendix *for details on the different models*).

Family Health Teams are Family Health Networks or Family Health Organizations (i.e., blended capitation models) that receive additional funds to establish an interprofessional team of care providers (e.g., registered nurse, nurse practitioner, pharmacist, mental health worker, social worker) whose skills sets reflect the needs of the community they serve.

Appropriate access and high levels of continuity and coordination of care—which are a focus of the patient enrolment models—are crucial to meet the varied and complex needs of persons with developmental disabilities. We investigated the extent to which adults with and without developmental disabilities were receiving care in one of the enrolment models described above. The updated Canadian consensus guidelines on primary care for adults with developmental disabilities emphasize the need for interprofessional care.[8] Therefore, we were particularly interested in Family Health Teams, which are characterized by interprofessional collaboration.

There is a small proportion of patients receiving care in these practices, but who are not formally enrolled, or "rostered." This means that their care is reimbursed as fee-for-service and they are not included in the capitation funding. There may be a variety of reasons why a specific patient is not enrolled. In some cases, patient complexity may make it more cost-effective for physicians not to enroll patients. In other cases, the reason may be purely administrative; for example, there may be an intention to enroll a patient but because the process can be time-consuming, it has not been done.[28] Patients may also refuse enrolment. Whether or not the presence of a developmental disability is related to nonenrolment is addressed subsequently in this chapter.

CAPITATION A method of payment whereby a physician is paid a set amount of money for each patient enrolled with the practice, whether the patient visits or not.

List of Exhibits

EXHIBIT 3.1 Proportion of adults aged 18 to 64 years with or without developmental disabilities who used primary care, visited an emergency department or were hospitalized, in Ontario, 2009/10

Findings

- Among adults with developmental disabilities, 76.1% visited a family physician at least once, similar to the 74.5% of adults without developmental disabilities who did so.
- A much larger proportion of adults with developmental disabilities (33.9%) visited the emergency department at least once compared to adults without developmental disabilities (20.2%).
- A higher proportion of adults with developmental disabilities were hospitalized (7.5%) compared to adults without developmental disabilities (4.4%).

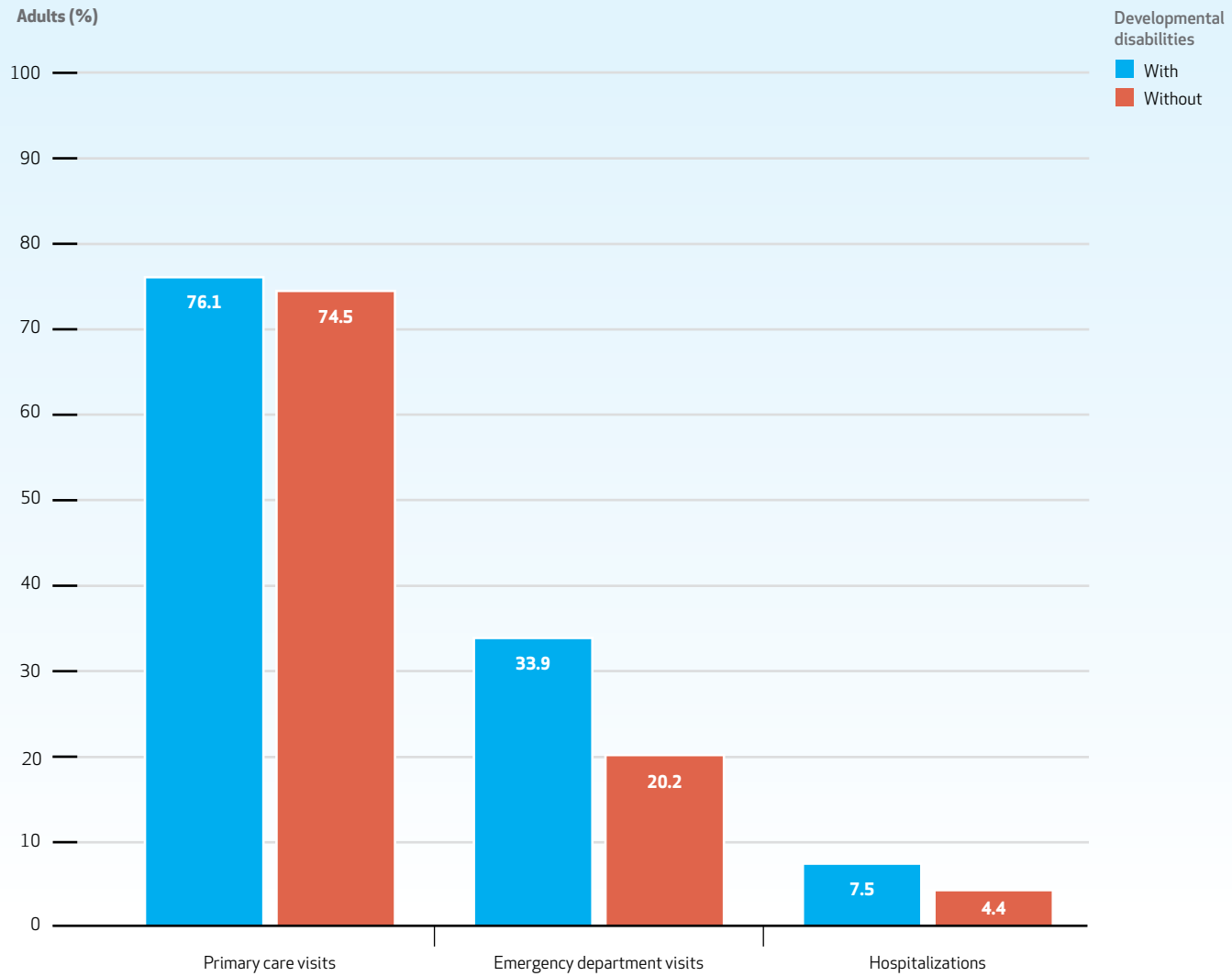
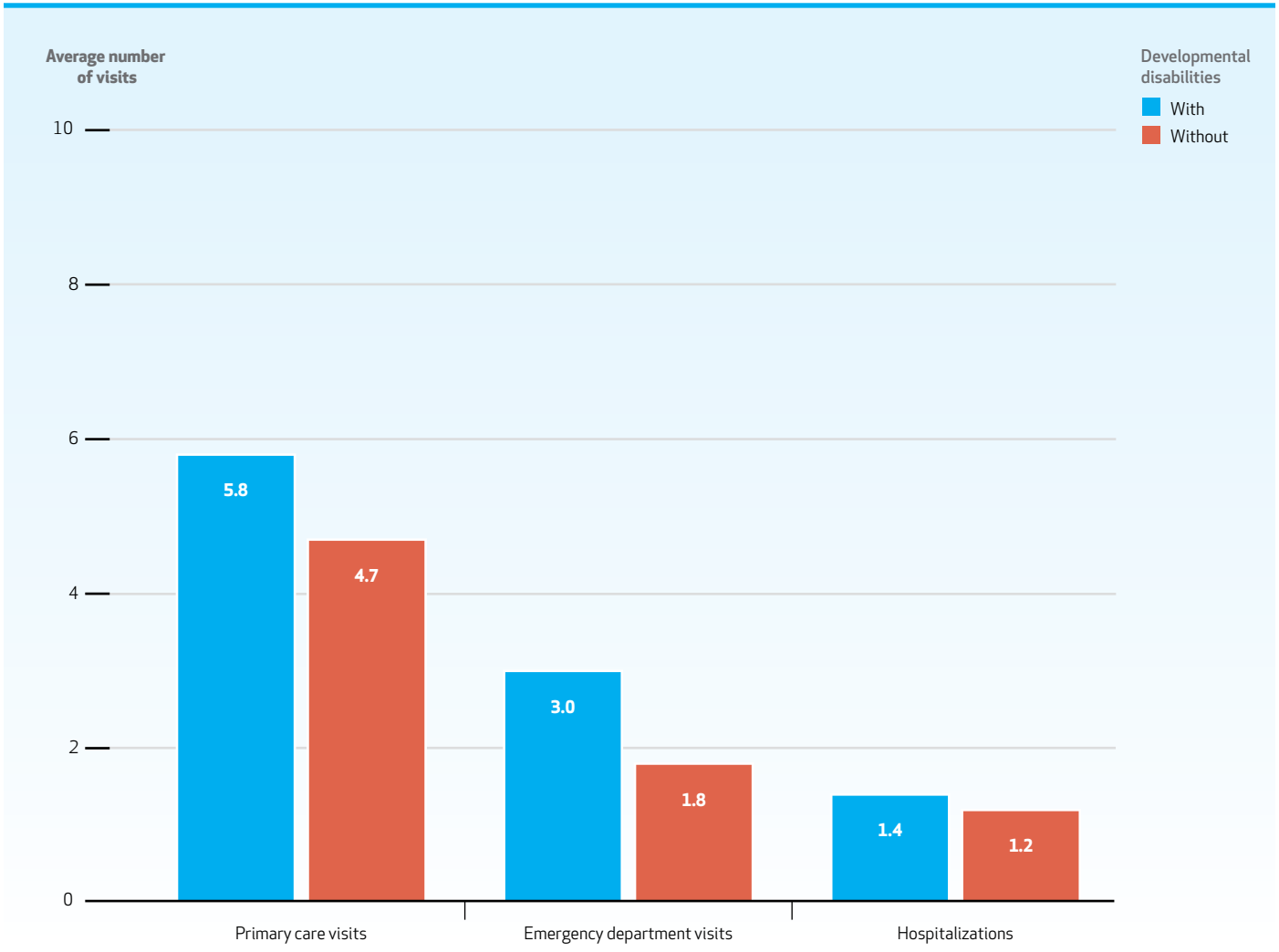


EXHIBIT 3.2 Average number of primary care visits, emergency department visits or hospitalizations for adults aged 18 to 64 years with or without developmental disabilities, in Ontario, 2009/10

Findings

- Those adults with developmental disabilities who visited their family physician tended to do so more frequently than adults without developmental disabilities.
- On average, adults with developmental disabilities who visited the emergency department did so almost twice as frequently as adults without developmental disabilities.
- On average, adults with developmental disabilities who were hospitalized had a similar number of admissions compared to adults without developmental disabilities.



Note: For each category, the calculation of the average number of visits was based on those patients who made at least one visit.

EXHIBIT 3.3 Proportion of adults aged 18 to 64 years with or without developmental disabilities who visited a specialist, overall and by type of specialist, in Ontario, 2009/10

Findings

- Adults with developmental disabilities were more likely to visit a specialist compared to adults without (42.0% and 35.7%, respectively).
- A larger proportion of adults with developmental disabilities visited a psychiatrist (14.9%) or neurologist (6.0%), while a smaller proportion visited surgical specialists (19.3%) compared to adults without developmental disabilities (3.1%, 2.1% and 22.5%, respectively).
- A similar proportion of adults with developmental disabilities visited other types of medical specialists (15.4%) compared to adults without developmental disabilities (16.1%).

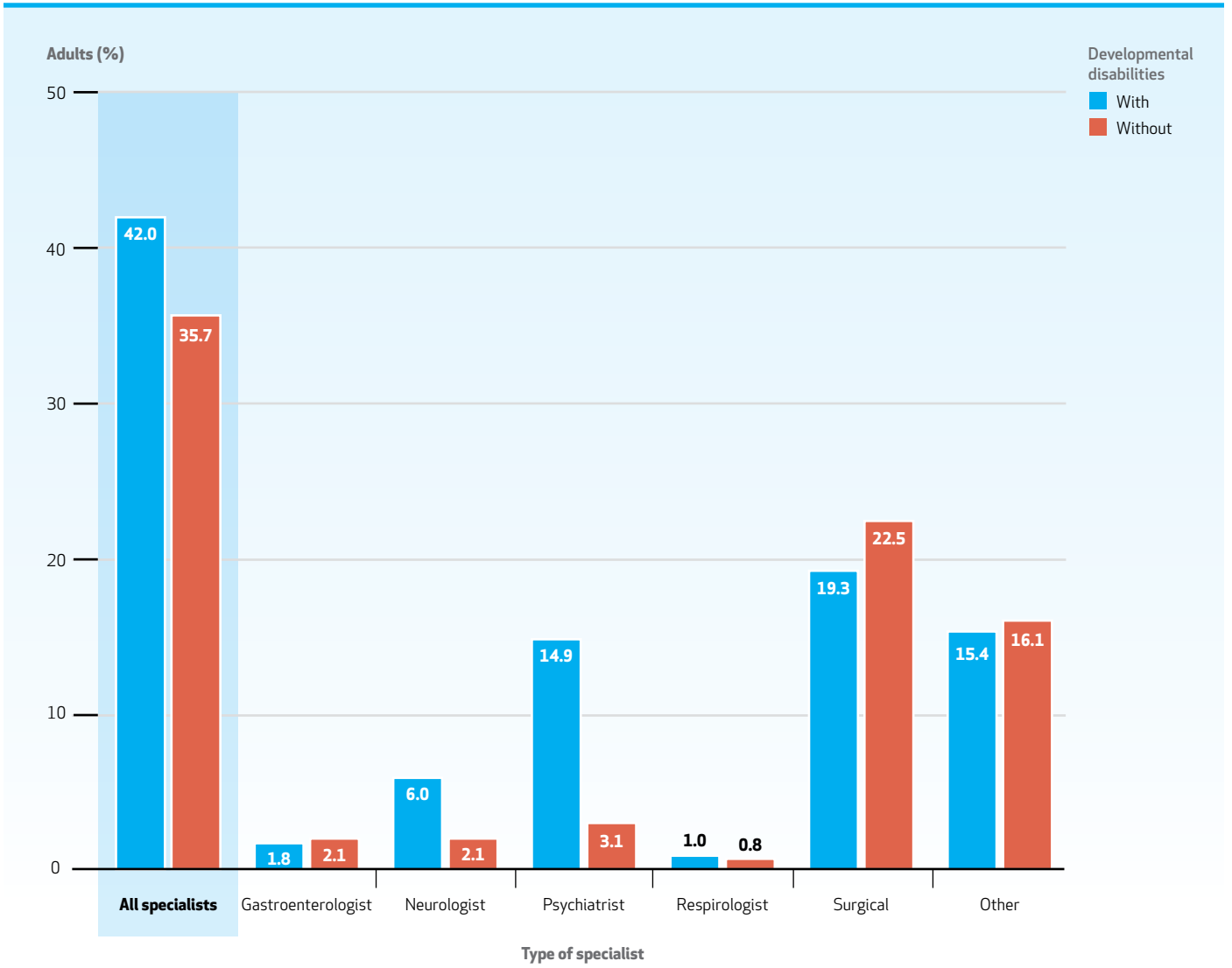
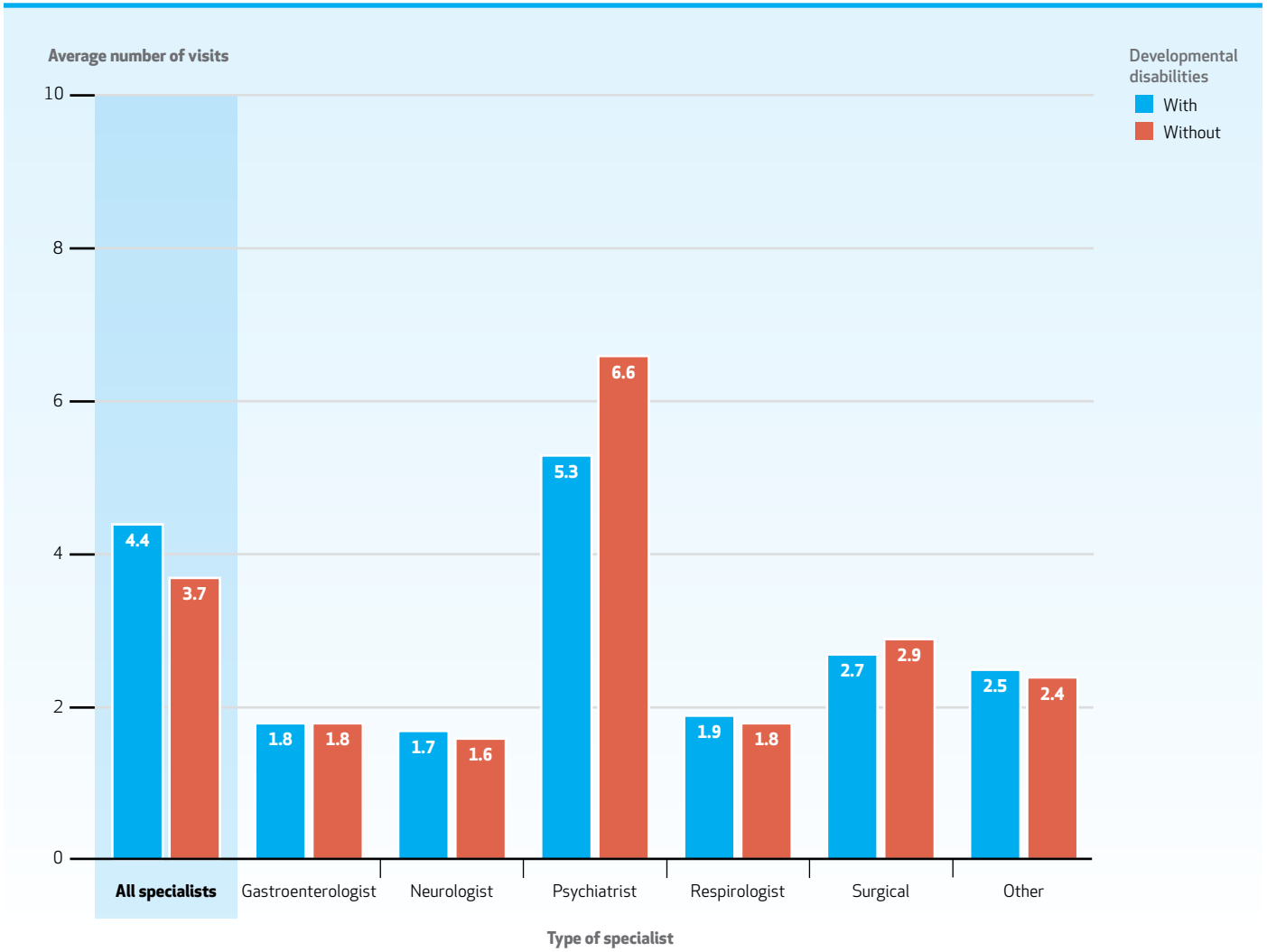


EXHIBIT 3.4 Average number of visits to specialists by adults aged 18 to 64 years with or without developmental disabilities, overall and by type of specialist, in Ontario, 2009/10

Findings

- During 2009/10, adults with developmental disabilities had more visits with specialists compared to adults without developmental disabilities (4.4 visits vs. 3.7 visits, respectively).
- Adults with developmental disabilities had fewer visits to psychiatrists than those without developmental disabilities (5.3 visits vs. 6.6 visits).



Note: For each category, the calculation of the average number of visits was based on those patients who made at least one visit.

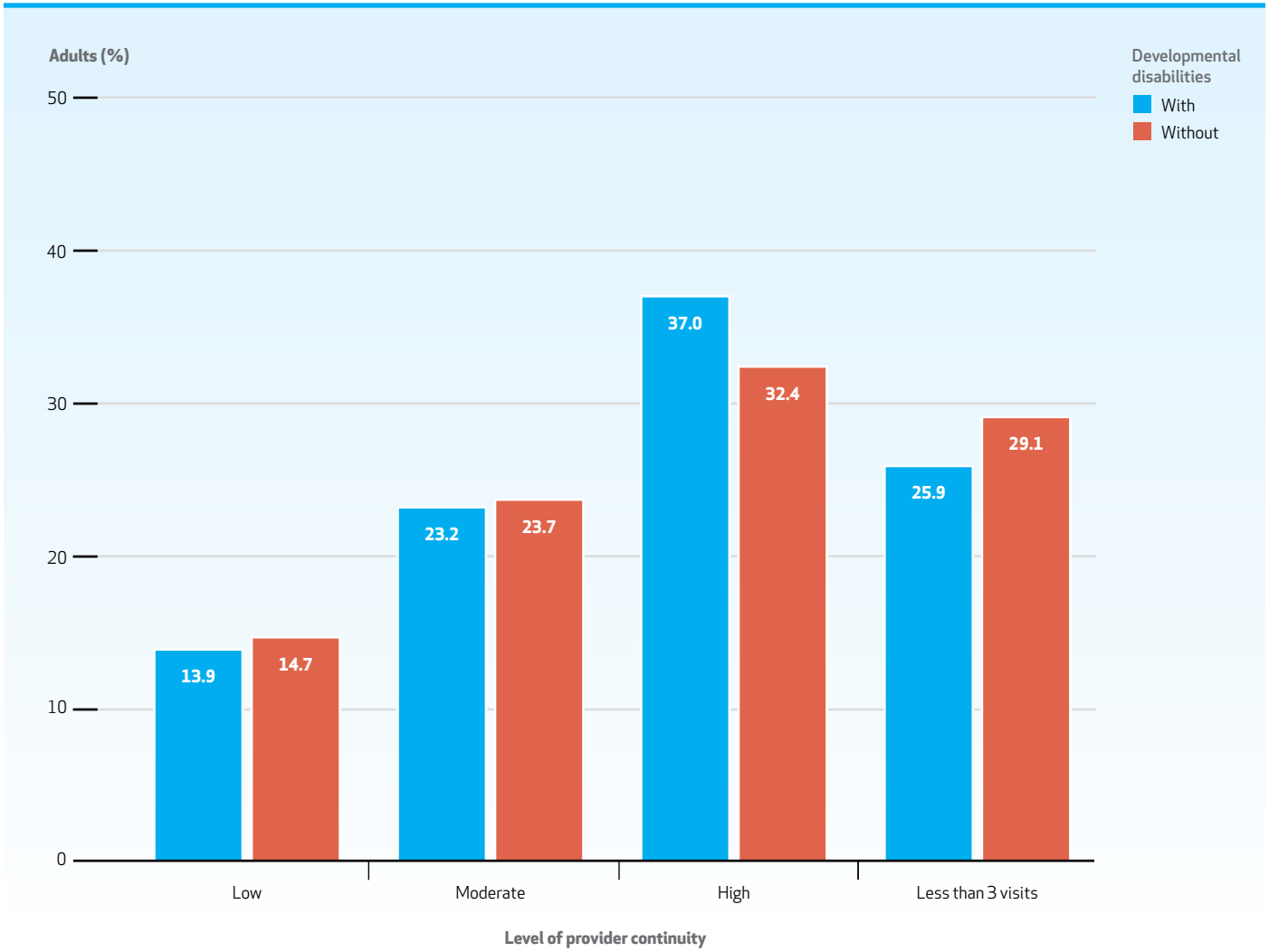
Summary of utilization by demographic variables in 2009/10 (data not shown)

- Health care service use by persons with and without developmental disabilities varied in similar ways across **sex, neighbourhood income** and **urban or rural location**. In both groups:
  - Women were more likely to visit a family physician or emergency department or be hospitalized than men.
  - The proportion of persons visiting family physicians was higher among those living in higher income neighbourhoods.
  - The proportion of individuals who visited an emergency department or were hospitalized decreased as neighbourhood income level rose.
  - Individuals living in rural areas made less use of primary care services but were more likely to visit an emergency department or be hospitalized than urban residents.
- Patterns of variation in health care service use by **age** and **morbidity** differed between those with and without developmental disabilities. Overall, there was a tendency for greater use of primary care and hospital services among older adults in both groups. However:
  - The likelihood of adults with developmental disabilities using the emergency department increased with age; for adults without developmental disabilities, it decreased.
  - Adults with developmental disabilities aged 35 to 64 years were more likely to be hospitalized than their same-age peers without developmental disabilities. This difference was not observed in the younger age groups.
  - In both groups, those with higher morbidity levels (i.e., those further from a state of well-being or good health) were more likely to use primary care and be hospitalized than those with lower levels of morbidity. However, the proportion of persons with high levels of morbidity who visited an emergency department was 20% higher for adults with developmental disabilities compared to those without. This difference was only about 5% in those who were healthy or had low levels of morbidity.

EXHIBIT 3.5 Proportion of adults aged 20 to 64 years with or without developmental disabilities, by level of provider continuity for family physicians, in Ontario, 2009/10 to 2010/11

Findings

- Overall, the continuity of care for adults with and without developmental disabilities was similar.
- Over a quarter of individuals in both groups visited physicians fewer than three times over the two-year period and therefore could not be assigned a value on the index used to measure continuity of care.



Note: Level of provider continuity was measured with the Usual Provider Continuity Index (see definition in the Technical Appendix).

EXHIBIT 3.6 Proportion of adults aged 18 to 64 years with or without developmental disabilities who were enrolled with or seeing a physician belonging to a primary care patient enrolment model, by type of practice model, in Ontario, 2009/10

Findings

- The proportion of adults with developmental disabilities enrolled with or seeing physicians in the enhanced fee-for-service model was smaller compared to those without developmental disabilities (40.2% and 47.5%, respectively).
- The proportion of adults with developmental disabilities enrolled with or being seen by physicians in the blended capitation model was larger compared to those without (37.4% and 31.2%, respectively).
- Similar proportions of individuals with and without developmental disabilities were seeing physicians in one of the defined practice models but were not enrolled (12.7% and 11.3%, respectively).
- Similar proportions of individuals with and without developmental disabilities were seeing physicians who were not practicing within a defined patient enrolment model during the time frame of analysis (22.5% and 21.5%, respectively) (data not shown).

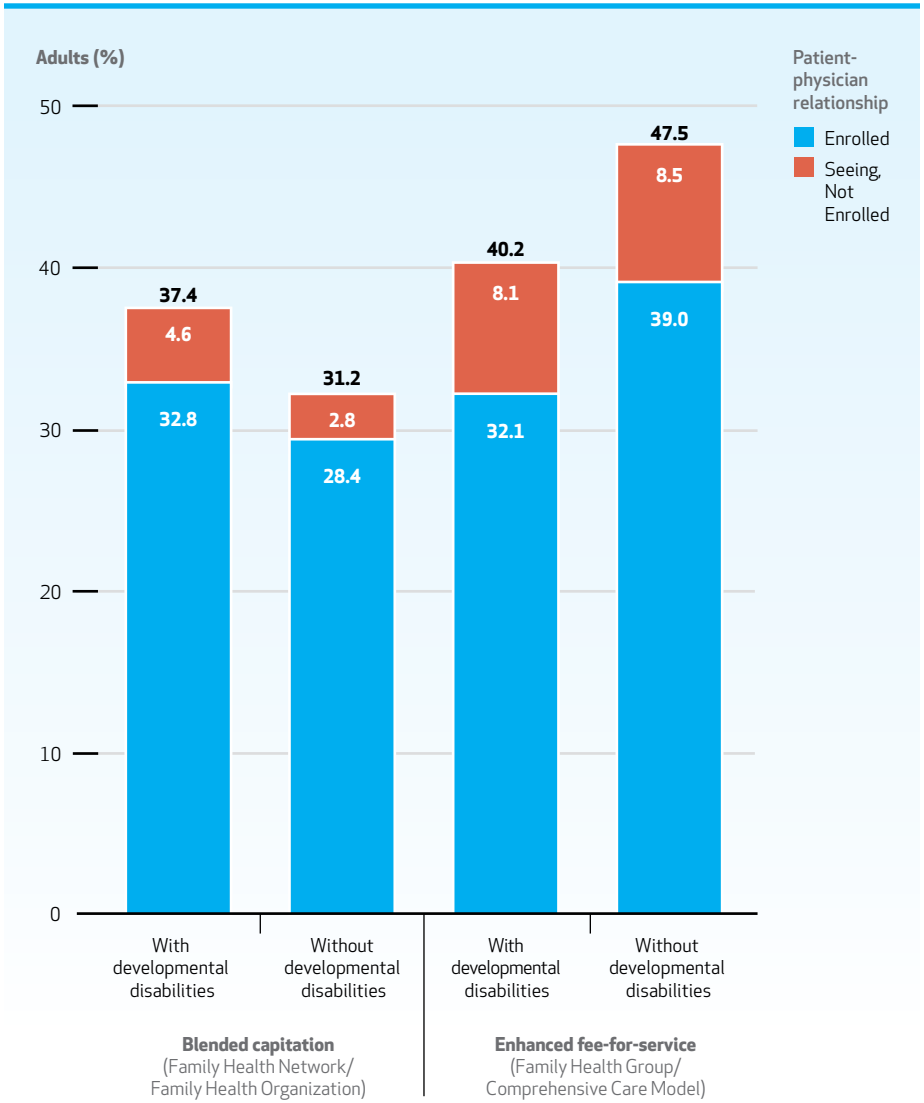
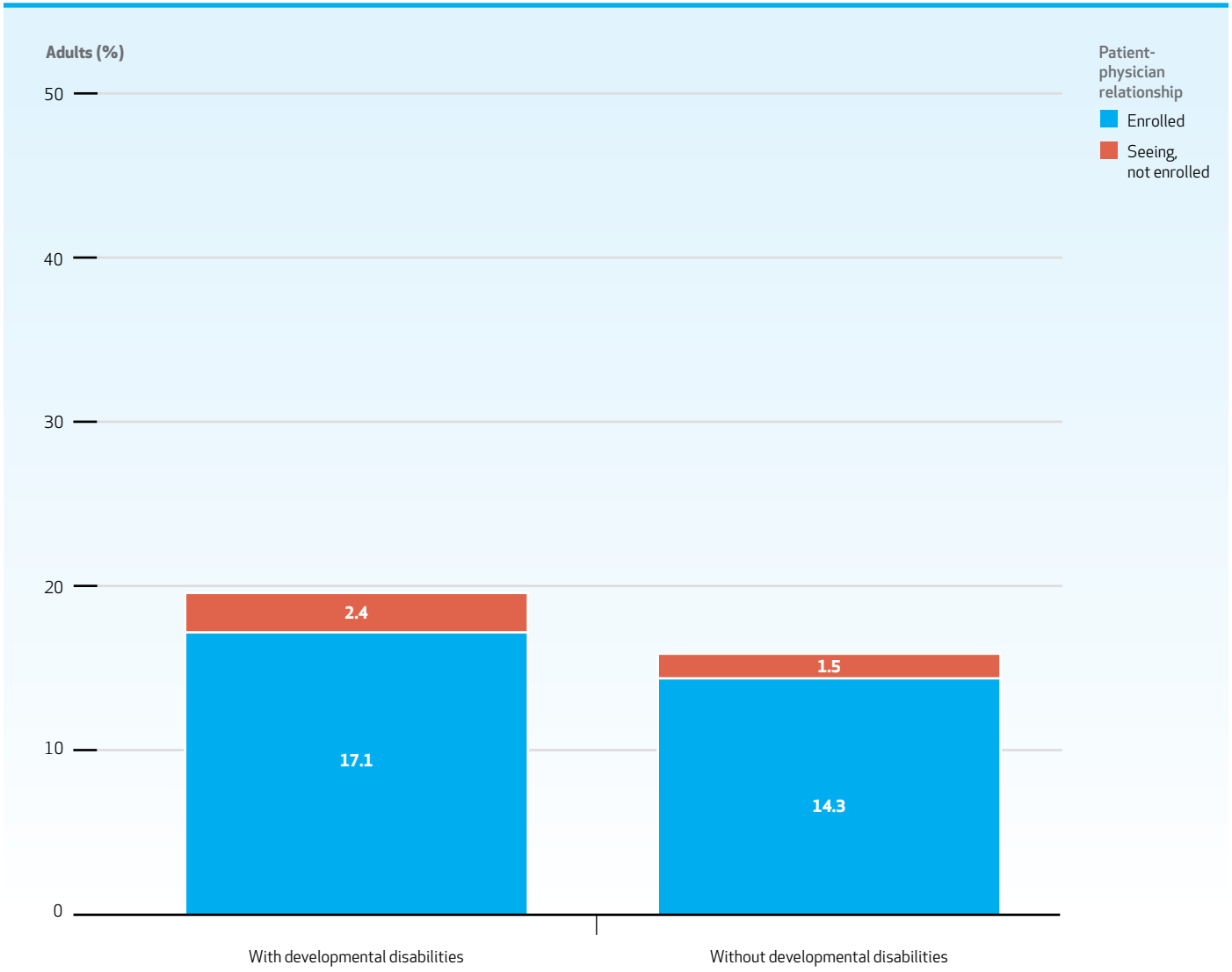


EXHIBIT 3.7 Proportion of adults aged 18 to 64 years with or without developmental disabilities who were enrolled with or seeing a physician belonging to a Family Health Team, in Ontario, 2009/10

Findings

- During the period of study, 19.5% of adults with developmental disabilities were being seen by Family Health Teams, compared to 15.8% of adults without developmental disabilities.
- A similar proportion of adults with and without developmental disabilities were seeing physicians practicing in Family Health Teams but were not enrolled (2.4% and 1.5%, respectively).



Discussion

Physician visits, emergency department use and hospitalizations

Adults with developmental disabilities were using primary care at levels comparable to adults without developmental disabilities. Over one-third of adults with developmental disabilities had a high level of continuity of care with their family physician. A higher proportion of adults with developmental disabilities, compared to those without, visited psychiatrists and neurologists.

However, greater use of primary care did not result in fewer emergency department visits or hospitalizations for adults with developmental disabilities. In particular, those who were older seemed to be at an increased risk for visiting an emergency department or being admitted to hospital, compared to adults of the same age without developmental disabilities. In addition, adults with developmental disabilities and high morbidity were more likely to visit an emergency department compared to adults without developmental disabilities who also had high morbidity. One explanation may be that the medical management of older adults with developmental disabilities, particularly those with high morbidity, is different from adults without developmental disabilities. Also, access to health services other than primary care may not be adequate to deal with their health needs.

One area that may be lacking for adults with developmental disabilities is access to specialist care. While adults with developmental disabilities are much more likely to visit a psychiatrist or neurologist than adults without developmental disabilities, this was not the case for other types of specialists. For example, we would expect that a significantly higher proportion of adults with developmental disabilities would be seeing a respirologist, given their higher rates of asthma[9,29] (*see* Chapter 2), but this did not occur. Optimal chronic disease management includes access to specialist physicians when required.[30] This access not only improves health outcomes but also leads to less frequent use of emergency departments and fewer admissions to hospital.[31,32]

There may be several reasons for the low use of some specialists by adults with developmental disabilities. These include poor coordination of care between primary care and specialist care; shortage of specialists, particularly in more rural areas; lack of training and education and thus inadequate knowledge about developmental disabilities on the part of physicians and other health care providers; issues with patient transportation or communication; and lack of support from caregivers. Each of these issues would hinder the ability of adults with developmental disabilities to navigate the health care system well enough to receive good preventive care, have early recognition and diagnosis of acute conditions and avoid exacerbations of chronic health conditions. Currently in Ontario, programs such as Community Health Links (CHLs) are being developed to improve the coordination of patient care among all types of providers in the community.[33] The first step of CHLs is focused on frequent users of the health care system and patients with complex needs (i.e., patients with multiple health conditions who access the system frequently and at multiple access points). A goal of CHLs is to reduce unnecessary and inappropriate care, such as avoidable emergency department visits and unnecessary inpatient admissions. It is important to specifically consider how CHLs might benefit individuals with developmental disabilities. This issue is discussed further in Section 2 of the Atlas.

> **Jeremy, a patient:** *"I know it's really, really hard for someone who's living alone to go see the doctor by themselves. I heard that the doctor gets paid for the first 10 minutes, not for the half hour or however long you are there. For people who have trouble talking, it's really hard for them to say what the problem is if they go by themselves. We need to sponsor people and have more time with the doctors. People are afraid to go alone."*

While age and morbidity seem to be associated with increased visits to the hospital among adults with developmental disabilities above what would be expected among adults without developmental disabilities, it is important to note that neighbourhood income quintile, sex and rural residence had similar effects in both populations. Living in higher income neighborhoods was associated with greater use of primary care services, less use of emergency department services and

fewer hospitalizations. Women with and without developmental disabilities were more likely than men to visit a family physician, visit an emergency department or be hospitalized. Living in rural areas was associated with a greater likelihood of visiting an emergency department or being hospitalized among both those with and without developmental disabilities. It is important to be aware of, and address, equity issues beyond or in combination with developmental disabilities.

Primary care patient enrolment models

Twenty percent of adults with developmental disabilities were enrolled with a physician in a Family Health Team. This is encouraging as it may provide better access to health care providers, such as nurse practitioners, nutritionists, pharmacists, psychologists and home care coordinators. Still, 80% of adults with developmental disabilities were not enrolled with a Family Health Team and therefore may have had limited access to these health care professionals. While the updated primary care guidelines for adults with developmental disabilities recommend interprofessional care,[8] the degree to which Family Health Teams meet the needs of persons from this population is still to be determined. This issue is addressed in Chapters 4 and 5, which examine indicators of secondary prevention and chronic disease management according to Family Health Team enrolment status.

The majority of individuals with developmental disabilities (over 77%) visited family physicians practicing in either enhanced fee-for-service or capitation-based primary care models. In Ontario, there has been a movement toward these funding models for everyone.[34,35] Currently, family physician capitation payments are based on a patient's age and sex. Capitation payments are not adjusted for a patient's comorbidity or complex care requirements. Other jurisdictions in Canada and the United States include comorbidities in their capitation rates,[36-38] and this may act as an incentive for family physicians to increase the number of vulnerable patients in their practice. However, the impact of financial incentives on care needs to be examined further.

Implications for policy and practice

Health care structures need to improve the coordination of care for persons with complex needs to include those with developmental disabilities.

Planners of programs such as Community Health Links need to recognize that many individuals with developmental disabilities are frequent users of the health system or at risk of becoming so. As with patients helped by Community Health Links, these individuals would benefit from improved coordination of care. Another way to address this issue would be to establish minimum competencies for all primary care providers, including family physicians, psychologists, social workers, physiotherapists and community care coordinators, to better meet the needs of adults with developmental disabilities. Additionally, access to appropriate specialist care for adults with developmental disabilities needs to be improved. Seeing the right provider who can provide the right care at the right time should ultimately have an impact on the overall quality of health care and associated costs, such as reducing emergency department visits and inpatient admissions. The coordination of health care with education, housing, employment and social services also needs to be further examined.

> **Joi, a mother:** *"I always thought that if we met as a team—the family, all of the agencies working with my daughter—with the doctor spearheading the team, we could have everyone on the same page with respect to Danielle's life. Our doctor was very receptive to this idea and agreed to do it even though it is a big thing for her. Sometimes my daughter has a hard time with change, and during those times we meet once a month. When things are going well, we meet every two months. The doctor gives us a minimum of an hour and doesn't say "Time's up, you have to leave" at the end. With her mediating and being in charge of this meeting, it has the two agencies communicating with one another. This wasn't really happening before. This model of having staff, families, and the family doctor as the lead could be a new way to provide primary care for people with developmental disabilities."*

Data needs

To further identify the needs of adults with developmental disabilities and opportunities to improve their care, information on the utilization of services delivered by other health care providers is required. This should include encounter data from community health centres (which provide care to vulnerable populations),[39] as well as data from home care providers and other health care professionals (e.g., nurses, dentists, geneticists, nutritionists, social workers, physiotherapists, occupational therapists, speech therapists, behavior therapists, rehabilitation therapists, psychologists and pharmacists). This information is housed in multiple sources, such as electronic health records or databases in other sectors including education and social services.

Future research

A more comprehensive examination of health care use by adults with developmental disabilities—one that includes interactions with all of their formal and informal health care providers—would necessitate partnering across multiple sectors to access the data described above. Within the context of such partnering, future research should focus not only on describing utilization of a wider range of services, but should also provide a more in-depth analysis of factors that affect service use. For example, beyond the demographic and clinical factors (such as age and morbidity), could system factors (such as care provided by a Family Health Team, or continuity of care) also influence the likelihood of emergency department use?

Research should also focus on service processes at the provider level. For example, the updated Canadian consensus guidelines[8] for care of adults with developmental disabilities encourage access to interprofessional care (such as that provided by Family Health Teams). Research on how these teams should function to improve care for persons with developmental disabilities needs to be undertaken.

Conclusion

Adults with developmental disabilities visited family physicians more often than adults from the general population. They had good continuity of care with their family physician and were more likely to see psychiatrists and neurologists, as was expected. However, adults with developmental disabilities, specifically those who were older and/or living with several medical conditions, visited the emergency department more often than those without developmental disabilities. Specialist care may not be as accessible to adults with developmental disabilities as it should be, given their higher levels of morbidity. Currently, the benefits of receiving care in models of primary care that facilitate access to a range of health care providers, such as physiotherapists, social workers and community care coordinators, are unknown. This interprofessional approach, however, is consistent with care guidelines for this population. Health system structures are needed to improve the coordination of care for this vulnerable population.

This chapter has provided a broad overview of health care service use by adults with developmental disabilities. While the results do point to some possible inadequacies in the care provided, information assessing what is actually happening in physicians' offices or in hospitals is lacking. Using a set of guidelines-based indicators, the chapters in Section 2 address this issue by evaluating the care received by adults with developmental disabilities.

APPENDIX A3.1 Health Care Service Use and Continuity of Care Indicators

Proportion of adults aged 18 to 64 years with or without developmental disabilities who used selected health services (2009/10) and their mean level of provider continuity (2009/10 to 2010/11), by Local Health Integration Network and in Ontario

	Adults (%)									Mean Level of Provider Continuity*		
	Visited family physician			Visited emergency department			Were hospitalized					
	Developmental disabilities			Developmental disabilities			Developmental disabilities			Developmental disabilities		
	With	Without	Difference	With	Without	Difference	With	Without	Difference	With	Without	Difference
Ontario	76.1	74.5	1.6	33.9	20.2	13.7	7.5	4.4	3.1	0.76	0.75	0.01
Local Health Integration Network												
1. Erie St. Clair	75.7	74.2	1.5	36.7	23.5	13.2	8.0	4.8	3.2	0.77	0.75	0.02
2. South West	74.1	71.2	2.9	40.3	28.2	12.1	8.5	4.8	3.7	0.80	0.79	0.01
3. Waterloo Wellington	75.7	71.5	4.2	30.5	18.9	11.6	6.9	4.3	2.6	0.79	0.78	0.01
4. Hamilton Niagara Haldimand Brant	77.7	74.9	2.8	34.1	22.0	12.1	7.5	4.8	2.7	0.76	0.76	0.00
5. Central West	83.8	82.3	1.5	26.8	16.6	10.2	5.9	4.5	1.4	0.73	0.71	0.02
6. Mississauga Halton	81.7	80.0	1.7	24.4	15.6	8.8	6.1	4.1	2.0	0.75	0.73	0.02
7. Toronto Central	77.1	74.3	2.8	30.2	16.3	13.9	6.7	4.0	2.7	0.72	0.72	0.00
8. Central	83.2	79.7	3.5	27.0	15.1	11.9	6.4	3.9	2.5	0.74	0.73	0.01
9. Central East	79.3	78.5	0.8	30.4	19.2	11.2	6.6	4.2	2.4	0.76	0.75	0.01
10. South East	72.1	69.6	2.5	37.6	28.2	9.4	6.7	4.6	2.1	0.82	0.80	0.02
11. Champlain	76.3	74.2	2.1	34.5	20.2	14.3	7.5	4.2	3.3	0.76	0.73	0.03
12. North Simcoe Muskoka	76.9	72.8	4.1	38.3	26.0	12.3	7.7	5.1	2.6	0.78	0.76	0.02
13. North East	71.1	68.6	2.5	41.5	31.8	9.7	10.5	6.3	4.2	0.75	0.76	-0.01
14. North West	63.7	63.2	0.5	45.2	33.8	11.4	11.3	6.3	5.0	0.77	0.76	0.01

* Level of provider continuity was measured using the Usual Provider Continuity Index (see definition in the Technical Appendix).

APPENDIX A3.2 Characteristics of Primary Care Patient Enrolment Models

Characteristics of primary care patient enrolment models, by type of practice model, in Ontario, 2009/10

	Blended Fee-for-Service Model		Blended Capitation Model		
Characteristics	**Comprehensive Care Model**	**Family Health Group**	**Family Health Network**	**Family Health Organization**	**Family Health Team**
Date of establishment	2005	2003	2001	2007	2005
Maximum number of physicians	Solo	3+	3+	3+	3+ and interprofessional team
Formal enrolment with family physician	Yes	Optional	Yes	Yes	Yes
Requirements	Extended hours, on-call arrangements	Extended hours, on-call arrangements with Telephone Health Advisory Service			
Reduction in bonus payment for outside primary care use	No	No	Yes	Yes	Yes
Financial incentives*	1, 3–11, 14	1–13	1, 3, 4, 6, 7, 9–19	1, 3, 4, 6, 7, 9–19	1, 3, 4, 6, 7, 9–19

Source: Based on data compiled by Maude Laberge, PhD(c), Institute of Health Policy, Management and Evaluation, University of Toronto, October 2012.

***List of financial incentives**[40-42]

1. Patient registration incentive: one-time payment for formal enrolment of patient.
2. Comprehensive Care: applies to Family Health Group only; for assessment, consultation, supportive care.
3. Comprehensive Care Management Fee: payment per enrolled patient.
4. After-Hours Care: fee per enrolled patient receiving after-hours care.
5. Palliative Care: annual payment per patient receiving palliative care.
6. Diabetes Management Incentive: payment for coordination, provision and documentation of care provided to a diabetic patient.
7. Heart Failure Management Incentive: payment for coordination, provision, and documentation of care provided to a heart failure patient.
8. Cumulative Preventative Care Management Payment: bonus for Pap smears, mammograms, influenza vaccination, childhood vaccination.
9. Colorectal Screening Payment: bonus for colorectal screening of patients aged 50 to 74 years.
10. Smoking Cessation Counseling Fee: payment per enrolled patient receiving counseling.
11. New Graduate–New Patient Fee: payment per new patient enrolled by a physician who graduated in the past three years.
12. Primary Health Care of Patients with Serious Mental Health Illness: annual payment for each patient with bipolar disorder or schizophrenia.
13. New Patient Premium: payment for enrolment of new patients presently without a family physician.
14. Unattached Patient Fee: fee for enrolment of new patients without a family physician who were inpatients at an acute care hospital within the past three months.
15. Group Management and Leadership Payment: fee paid to a health care organization for each enrolled patient.
16. Preventive Care Management Service Enhancement: payment for each patient recalled to receive specific preventive care.
17. Targeted Medical Education Service Enhancement: a fee for continuing medical education.
18. Special Payments (Premiums): payment for an in-office procedure, prenatal care, obstetrical coverage, nonpalliative home visit.
19. Newborn Care Episodic Fee: payment for up to eight well baby visits per enrolled patient.

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Section 2
Primary Care and Developmental Disabilities

How responsive is the Ontario health care system to the primary care needs of adults with developmental disabilities?

Overview

This section evaluates how consistently health care providers are following guidelines when it comes to the primary care of adults with developmental disabilities. The specific content areas focus on secondary prevention, chronic disease management, and medication use and monitoring. We selected guidelines based on their relevance to this population and also on the feasibility of measuring them using health data that is available for adults with and without developmental disabilities between the ages of 18 and 64 years. Although some guidelines apply to adults older than 65 years, we focus here on those 64 years and younger. In each chapter, we provide an overview of why selected guidelines are relevant, define indicators and evaluate the extent to which these guidelines are followed.

Indicator data for Chapters 4 and 5 are presented in terms of the differences between adults with developmental disabilities and adults without. Differences were examined for each indicator by demographic factors (age, sex and neighbourhood income) and geographic factors (Local Health Integration Network of residence, rural/urban residence). Differences were also examined by enrolment in a Family Health Team because we were interested in the role that interprofessional collaboration, a key feature of this enrolment model, played on the difference in indicator performance between adults with developmental disabilities and those without. An examination of differences observed in the various patient enrolment models described in Chapter 3 was considered beyond the scope of this Atlas. Given the importance of patient enrolment models from a policy perspective, we consider evaluating the differences in these indicators among all models to be an important future research direction. Chapter 6 includes descriptive information on medication use by demographic factors (age, sex and neighbourhood income) and geographic factors (LHIN of residence, rural/urban residence). Medication data are not available for adults without developmental disabilities younger than 65 years unless they are receiving income support; therefore, none of the indicators could be examined in this population.

4 Secondary Prevention

Inside

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MAIN MESSAGES

- As their life expectancy increases, adults with developmental disabilities are at greater risk for age-related illnesses. They also experience high rates of concurrent, treatable health conditions. With improved secondary prevention, these conditions could be detected at an earlier stage. Significant, known barriers at the individual and systems levels make adults with developmental disabilities vulnerable to experiencing gaps in preventive care.

- This chapter examines the extent to which secondary prevention occurs for adults with developmental disabilities compared to adults without developmental disabilities. It also examines the impact of age, sex, neighbourhood income and urban/rural residence on secondary prevention. Finally, regional differences and patterns for those receiving care through Family Health Teams are reported. The aspects of secondary prevention care studied include the periodic health examination for all adults, colorectal cancer screening for adults aged 50 to 64 years, breast cancer screening for women aged 50 to 64 years, and cervical cancer screening for women aged 20 to 64 years.

- The periodic health examination—a key health care guideline for adults with developmental disabilities—occurred for 22% of adults with developmental disabilities over a two-year period, slightly less than the 26% for adults without developmental disabilities. The likelihood of this examination increased with neighbourhood income for both groups.

- Adults with developmental disabilities were less likely to undergo recommended screening for the three types of cancer studied. Income level did not affect cancer screening rates for adults with developmental disabilities, although it did affect those without developmental disabilities. The low uptake of preventive care among adults with developmental disabilities was consistent across all regions of Ontario.

- Multiple steps at the policy and practice levels need to be taken to reduce the barriers to secondary prevention. These include:

  — providing incentives to primary care providers for the provision of comprehensive annual health assessments to adults with developmental disabilities;

  — creating information campaigns aimed at adults with developmental disabilities and their caregivers;

  — augmenting the education and training of health care providers and technicians to include consideration for this vulnerable group; and

  — adapting cancer screening strategies to reflect the needs of and risks for adults with developmental disabilities.

Introduction

Secondary prevention involves the early detection of disease while it is asymptomatic in order to prevent its progression. It is part of a comprehensive approach to preventive health care that has been promoted in primary care. For adults with developmental disabilities, secondary prevention is critical as they may not have the ability to recognize the early signs and symptoms of disease. When comprehensive health assessments were undertaken in other jurisdictions, they often revealed high rates of concurrent treatable conditions.[1,2] As it is clear that adults with developmental disabilities experience most health-related problems at similar or higher rates than those without developmental disabilities (*see* Chapter 2), they should receive at least the same array of secondary prevention services.[3,4]

Yet, in general, health screening for persons with developmental disabilities requires significant improvement.[5] A New Zealand study found that prevention activities such as regular health checks and cancer screening were among the most common unmet health care needs in adults with developmental disabilities.[6]

The limited uptake of secondary prevention programs does not result from a choice on the part of adults with developmental disabilities. Known barriers to uptake such as lower education and income, lack of awareness and skills, and physical limitations make adults with developmental disabilities particularly vulnerable to experiencing gaps in preventive care.[7,8] For individuals with developmental disabilities who rely on caregivers to assist in such activities, the caregivers' attitudes, knowledge and skills further influence the decision to participate in secondary prevention activities.[9,10] Knowledge and attitudes of primary care providers also contribute to low uptake.[11-13]

SECONDARY PREVENTION involves the early detection of disease while it is asymptomatic and before it progresses.

With regard to secondary prevention, the Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities[14] highlight the need to consult general guidelines in periodic health examination checklists for average-risk adults in the general population. These focus on the early detection of cancer, osteoporosis, diabetes, hearing impairment, cardiovascular disease and sexually transmitted infections.[15] Sullivan et al.[14] also draw attention to additional and enhanced secondary prevention guidelines specific to the care of adults with developmental disabilities. The additional guidelines relate to the early detection of neglect and abuse, visual impairment, thyroid disease, dysphagia, aspiration, gastroesophageal reflux disease, constipation and *H. pylori* infection. Enhanced guidelines relate to earlier and targeted screening for hearing impairment and osteoporosis.[16]

In this chapter, we explore the extent to which the primary care received by adults with developmental disabilities in Ontario corresponds to four secondary prevention guidelines. The selected guidelines relate to the periodic health examination and early detection of colorectal, breast and cervical cancer or precancerous lesions. The chapter also examines disparities in secondary prevention related to these guidelines for adults with developmental disabilities compared to those without developmental disabilities in Ontario. Finally, the chapter considers factors associated with low uptake and observed disparities.

Background

Periodic health examination

The periodic health examination—also known as the annual health examination—provides an opportunity for primary care providers to ensure that preventive care and early disease detection are regularly undertaken. It may include an examination of the whole body, discussion of health behaviours, immunization updates, and screening tests. It is a time to discuss health issues not addressed during regular appointments directed to specific, new symptoms or concerns of the patient, or to follow up and manage chronic diseases.

Although there continues to be debate in Canada and elsewhere about the utility of the periodic health examination,[17-21] the evidence specific to adults with developmental disabilities suggests that without a dedicated approach in primary care to a comprehensive health assessment, inadequate care will result.[22] A 2006 Welsh study revealed the ability of the health check to identify previously undiagnosed health problems among adults with developmental disabilities.[23] Subsequently, a cluster randomized trial in Australia demonstrated that structured, comprehensive health assessments in adults with developmental disabilities led to the early identification of health issues and prevention of more complex difficulties.[2] A recent study conducted in Scotland demonstrated that these health exams were inexpensive and had lower associated caregiver costs in the year following than caregiver costs for those receiving usual care.[24] Furthermore, though not yet demonstrated, the periodic health examination in adults with developmental disabilities may have important benefits similar to those found among older adults, such as reduced hospitalization and long-term care admissions.[25]

CONSENSUS GUIDELINES FOR PRIMARY HEALTH CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Primary health care providers should consult… more general guidelines in periodic health examination checklists for average-risk adults in the general population.[14]

In effect during the period of study; updated in 2011.

For the purpose of this Atlas, we defined the periodic health examination as a general assessment of an individual. It includes a full history (medical, family and social) and an examination of all body parts. It may include instructions to the patient and/or caregivers regarding health care. Referred to as the annual health or physical examination, this family or general practice service is funded under the Ontario Health Insurance Plan. During the period from 2009 to 2011, physicians in Ontario could bill for this service no more than annually for their adult patients.[26] We selected the periodic health examination as our first indicator because of its ability to detect early stages of disease and the evidence supporting its relevance to this population. We used the physician billing code for the procedure over a two-year period to identify uptake of the periodic health examination.

Cancer screening

As the life expectancy of individuals with developmental disabilities increases,[27] suboptimal screening practices may contribute to a greater cancer burden in this population.[28] Adults with developmental disabilities are particularly vulnerable to inequitable access to cancer screening; they tend to be poorer, have limited literacy and communication skills, and often do not understand the procedure and its benefits.[29,30]

Colorectal cancer screening

Colorectal cancer is the third most common cancer diagnosed in Canada, the second leading cause of cancer deaths among Canadian men and the third leading cause among Canadian women.[31] Removal of adenomatous polyps, the precursor lesion for most colorectal cancers,[32] has been shown to reduce cancer incidence by 76% to 90%.[33] Effective population-based screening therefore provides the opportunity to greatly reduce colorectal cancer morbidity and mortality.

A study that linked records for 9,409 individuals with developmental disabilities to the Western Australian Cancer Registry found that women with developmental disabilities had an increased risk of colorectal cancer compared to their counterparts in the general population.[34]

In 2008, Ontario instituted the first population-based colorectal cancer screening program in Canada, ColonCancerCheck.[35] Biennial screening with the guaiac fecal occult blood test (FOBT) is recommended for individuals aged 50 to 74 years who are at average risk of colorectal cancer, followed by colonoscopy for those with an abnormal FOBT. For persons at increased risk because of a family history of the disease, screening by colonoscopy is recommended (beginning at age 50 or 10 years earlier than the age at which the relative was diagnosed, whichever occurs first).[35] The FOBT requires the collection of stool samples over a period of several days. FOBT kits to collect samples at home are available through primary care providers' offices, pharmacies and TeleHealth Ontario.

CANCER CARE ONTARIO RECOMMENDATION

A fecal occult blood test every two years for individuals aged 50 to 74 years.[35]

In effect since 2008 as part of the provincial ColonCancerCheck screening program.

To allow for a better understanding of the proportion of the age-eligible population which remains truly unscreened, in 2010 Cancer Care Ontario introduced an indicator it called 'up-to-date with colorectal tests.' We used this indicator to measure uptake of colorectal cancer screening among individuals aged 50 to 64 years. Individuals were considered up-to-date with colorectal tests if they had one of the following:

- a FOBT in the previous two years;
- a sigmoidoscopy in the previous five years; or
- a colonoscopy in the previous 10 years.[35]

Breast cancer screening

Breast cancer is the most common cancer diagnosed in women in Canada, representing 26.1% of new cancer cases in women and ranking second among cancer causes of death among women.[31] Breast cancer screening relies on mammography, the study of the breast using a low-dose X-ray to produce images of breasts showing abnormal areas of density, mass or calcification that may indicate the presence of cancer.[36]

Several studies have reported that participation in breast cancer screening programs is lower among women with developmental disabilities compared to women without such disabilities.[37-39] In the United States, the proportion of women with developmental disabilities who were not screened was found to be 2.1 times that of women without developmental disabilities,[38] while an Australian study suggested that the proportion of women with developmental disabilities not receiving mammograms was 1.4 times that of women in the general population.[39]

The Ontario Breast Screening Program (OBSP), which was established in 1990, provides biennial mammograms for women aged 50 years and older. As an organized screening program, the OBSP sends recall notices, communicates screening results to women, and helps initiate specialist care for women with abnormal mammograms.

CANCER CARE ONTARIO RECOMMENDATION

A mammogram every two years for women aged 50 to 74 years.[40]

In effect from 1990 onward as part of the Ontario Breast Screening Program.

We counted as screened for breast cancer those women aged 50 to 64 years who had received at least one mammogram over a two-year period. We excluded women identified in the Ontario Cancer Registry as having a diagnosis of breast cancer because they were more likely to have had a mammogram for reasons other than screening.

Cervical cancer screening

New cases of cervical cancer are diagnosed in seven per 100,000 women annually in Canada.[31] Human papillomavirus (HPV) infection, which is sexually transmitted, appears to be a necessary factor in the development of almost all cases of cervical cancer.[41]

The Papanicolaou test (also called a Pap test or Pap smear) is used to detect pre-malignant and malignant lesions early so that they can be treated.[42] It requires the collection of cells from the outer opening of the cervix. Pap tests are conducted by family physicians or other health care providers during women's regular physical examinations. Cervical cancer incidence and mortality have been on the decline since the widespread, regular use of the test.[36]

Cervical cancer screening has been reported to be three to five times lower among women with developmental disabilities compared to women without such disabilities.[37,38,43]

CANCER CARE ONTARIO RECOMMENDATION

A Pap test within three years of initiation of sexual activity and annually until three negative tests, then every two to three years to age 70.[44]

In effect during the period of study; updated in 2012.

The Ontario Cervical Screening Program was launched in 2000. Until 2012, the program followed the 1994 guideline from the Canadian Task Force on Preventive Health Care, which recommended that women undergo screening within three years of sexual activity initiation and have a Pap test repeated every three years thereafter.[45]

We counted as screened for cervical cancer those women aged 18 to 64 years who had at least one Pap test over a three-year period. We excluded women identified in the Ontario Cancer Registry as having a gynaecological cancer diagnosis because they were more likely to have received a Pap test for diagnostic purposes; also excluded were women who had undergone a hysterectomy.

In this chapter, we present the proportion of eligible Ontario adults with and without developmental disabilities for each of the four indicators. We examine the impact of age and sex (where appropriate), as well as neighbourhood income, and urban or rural residence. Finally, we explore differences in uptake for those with and without developmental disabilities by Local Health Integration Network, and we present the same comparisons for the subset of adults receiving their care through Family Health Teams.

Bill, a family physician: *"At least 40 percent of the behaviour issues that my colleagues and I see have a medical basis. The preventive care assessment is an opportunity to address these proactively. It is the most important health intervention for adults with developmental disabilities."*

List of Exhibits

EXHIBIT 4.1 Proportion of adults aged 18 to 64 years with or without developmental disabilities who received at least one periodic health examination, overall and by age group, in Ontario, 2009/10 to 2010/11

Findings

- In the period from 2009/10 to 2010/11, 22.0% of adults with developmental disabilities had a periodic health examination compared to 26.4% of adults without developmental disabilities. This difference between the two groups increased with age.
- In both groups, men were less likely than women to undergo the periodic health examination (data not shown). However, women with developmental disabilities were considerably less likely than women without developmental disabilities to undergo the examination (24.7% and 32.0%, respectively), while rates for men were similar among those with and without developmental disabilities (19.9% and 20.5%, respectively) (data not shown).

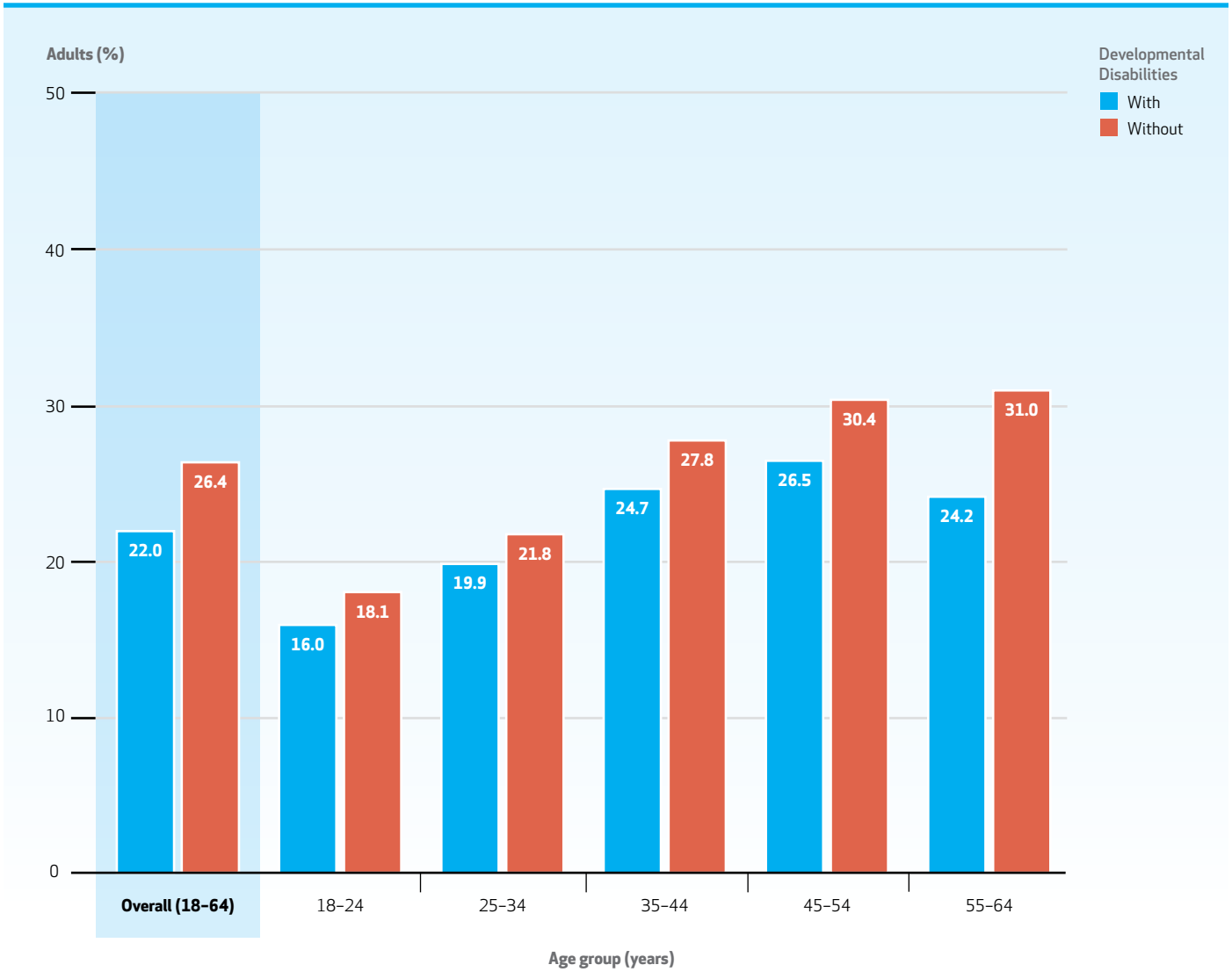
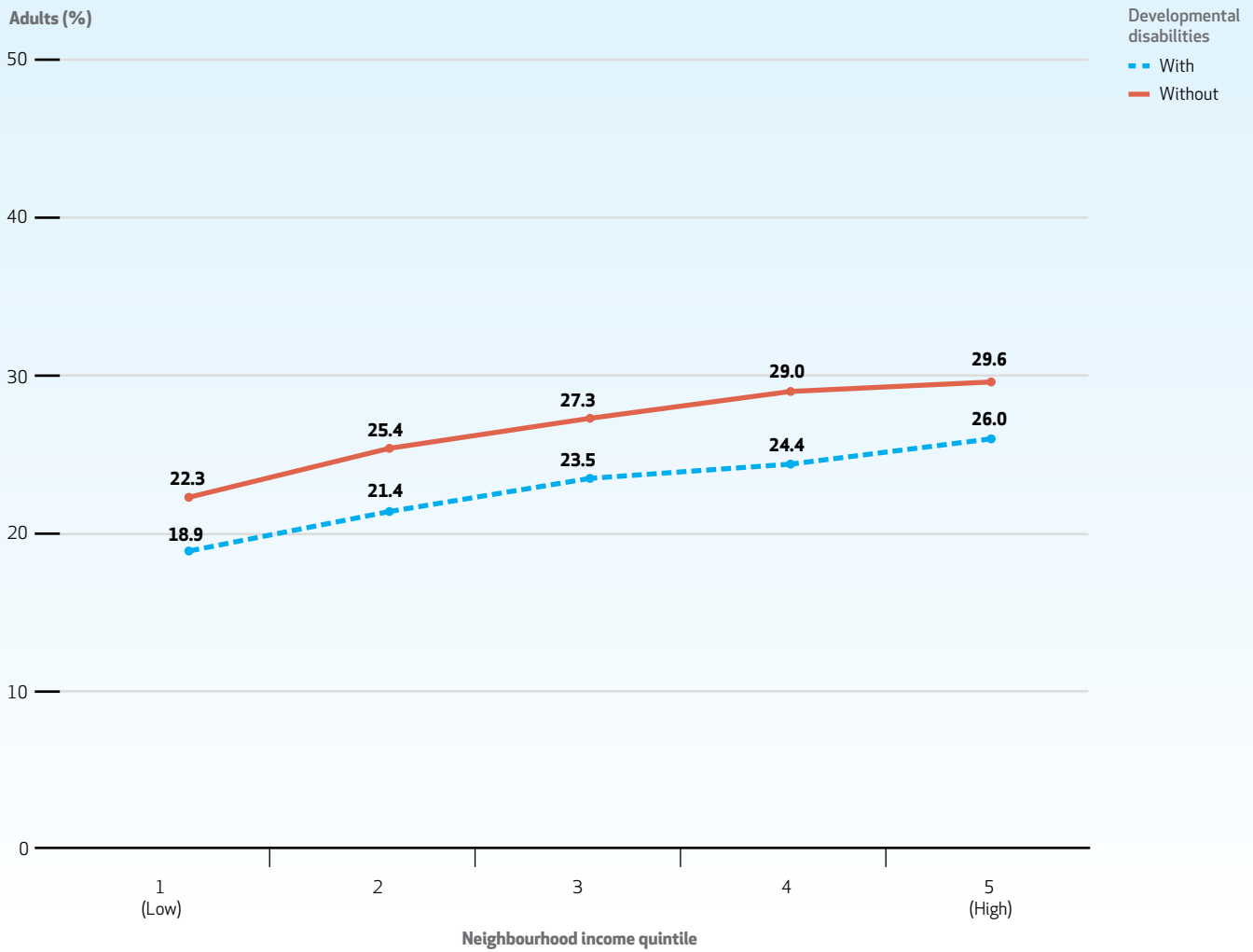


EXHIBIT 4.2 Proportion of adults aged 18 to 64 years with or without developmental disabilities who received at least one periodic health examination, by neighbourhood income quintile, in Ontario, 2009/10 to 2010/11

Findings

- The proportion of adults who had a periodic health examination increased for both groups according to neighbourhood income.
- A marked difference between adults with and without developmental disabilities was exclusive to those living in urban settings (respectively, 22.7% and 27.2%), with rates in rural settings being similar (respectively, 18.0% and 19.5%) (data not shown).

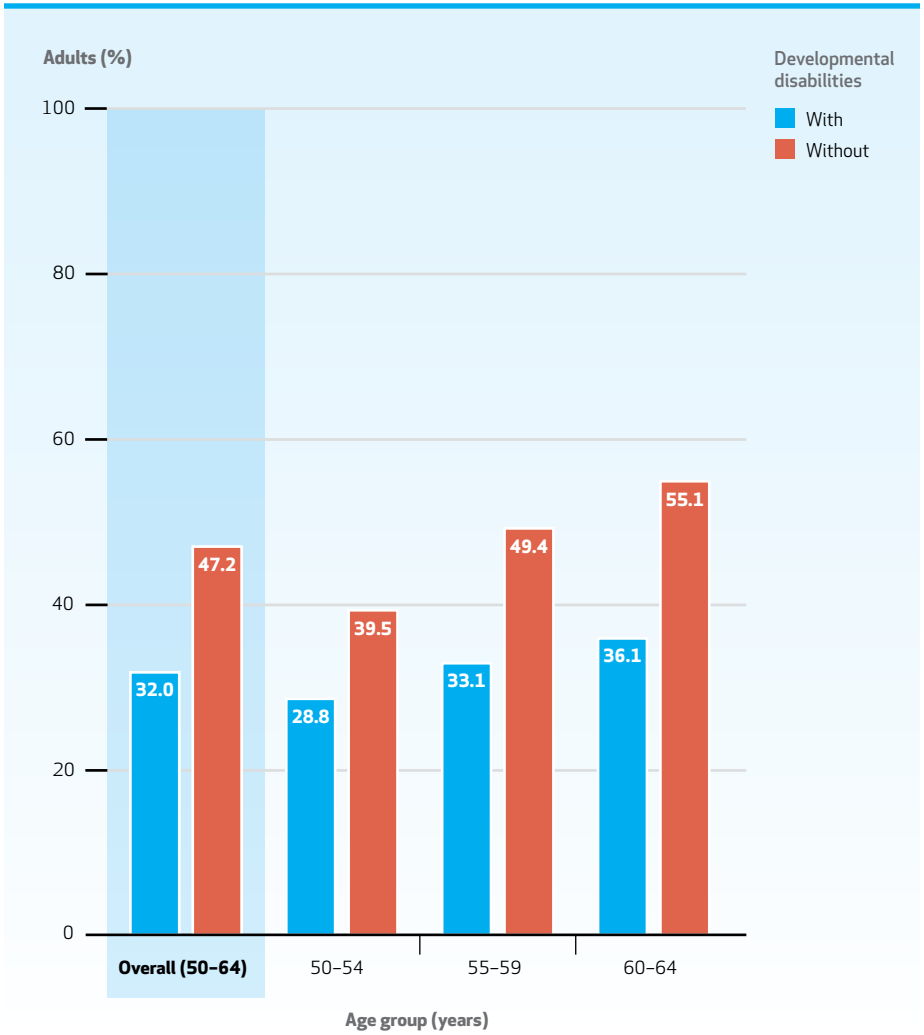


Note: Excludes individuals for whom a postal code was missing

EXHIBIT 4.3 Proportion of adults aged 50 to 64 years with or without developmental disabilities who were up-to-date with colorectal tests, overall and by age group, in Ontario, 2010

Findings

- Fewer of the 15,791 adults with developmental disabilities aged 50 to 64 years were up-to-date with colorectal tests (32.0% vs. 47.2% for adults without developmental disabilities).
- Screening increased with age in both adults with developmental disabilities and those without, but the gap between the two groups widened as age increased.
- In both groups, colorectal cancer screening was more common in women than men: respectively, 34.6% vs. 29.7% among adults with developmental disabilities and 50.1% vs. 44.1% among adults without developmental disabilities (data not shown).
- The observed difference in colorectal cancer screening between adults with and without developmental disabilities existed for both the fecal occult blood test (18.3% vs. 26.4%) and colonoscopy (17.1% vs. 27.2%) (data not shown).

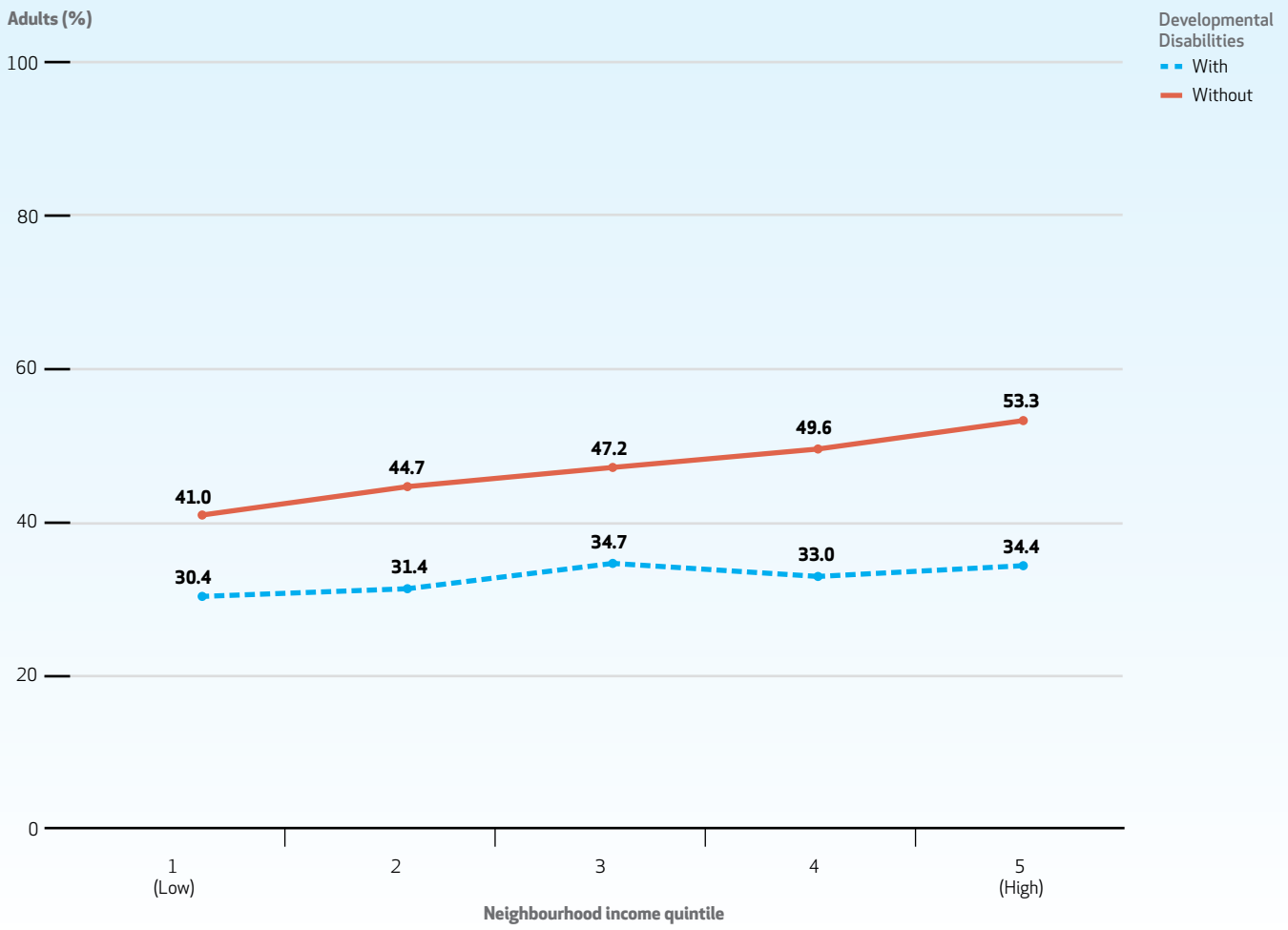


Note: Up-to-date with colorectal tests is defined as one of the following: a fecal occult blood test in the previous two years, a sigmoidoscopy in the previous five years or a colonoscopy in the previous 10 years.

EXHIBIT 4.4 Proportion of adults aged 50 to 64 years with or without developmental disabilities who were up-to-date with colorectal tests, by neighbourhood income quintile, in Ontario, 2010

Findings

- Adults without developmental disabilities who lived in higher-income neighbourhoods were more likely to be up-to-date with colorectal tests. No such income gradient was seen among adults with developmental disabilities.
- Adults without developmental disabilities who lived in urban areas were more likely to be up-to-date with colorectal tests (47.5% in urban areas vs. 44.9% in rural areas), but this difference was not seen among adults with developmental disabilities (31.3% vs. 32.1%) (data not shown).



Notes: 1. Excludes individuals for whom a postal code was missing.
2. Up-to-date with colorectal tests is defined as one of the following: a fecal occult blood test in the previous two years, a sigmoidoscopy in the previous five years or a colonoscopy in the previous 10 years.

EXHIBIT 4.5 Proportion of women aged 50 to 64 years with or without developmental disabilities who had a mammogram, overall and by age group, in Ontario, 2009/10 to 2010/11

Findings

- Of women with developmental disabilities who were eligible for breast cancer screening (n=7,022), only 52.2% had a mammogram, compared to 70.7% of women without developmental disabilities.
- In both groups, the uptake of mammography increased with age.

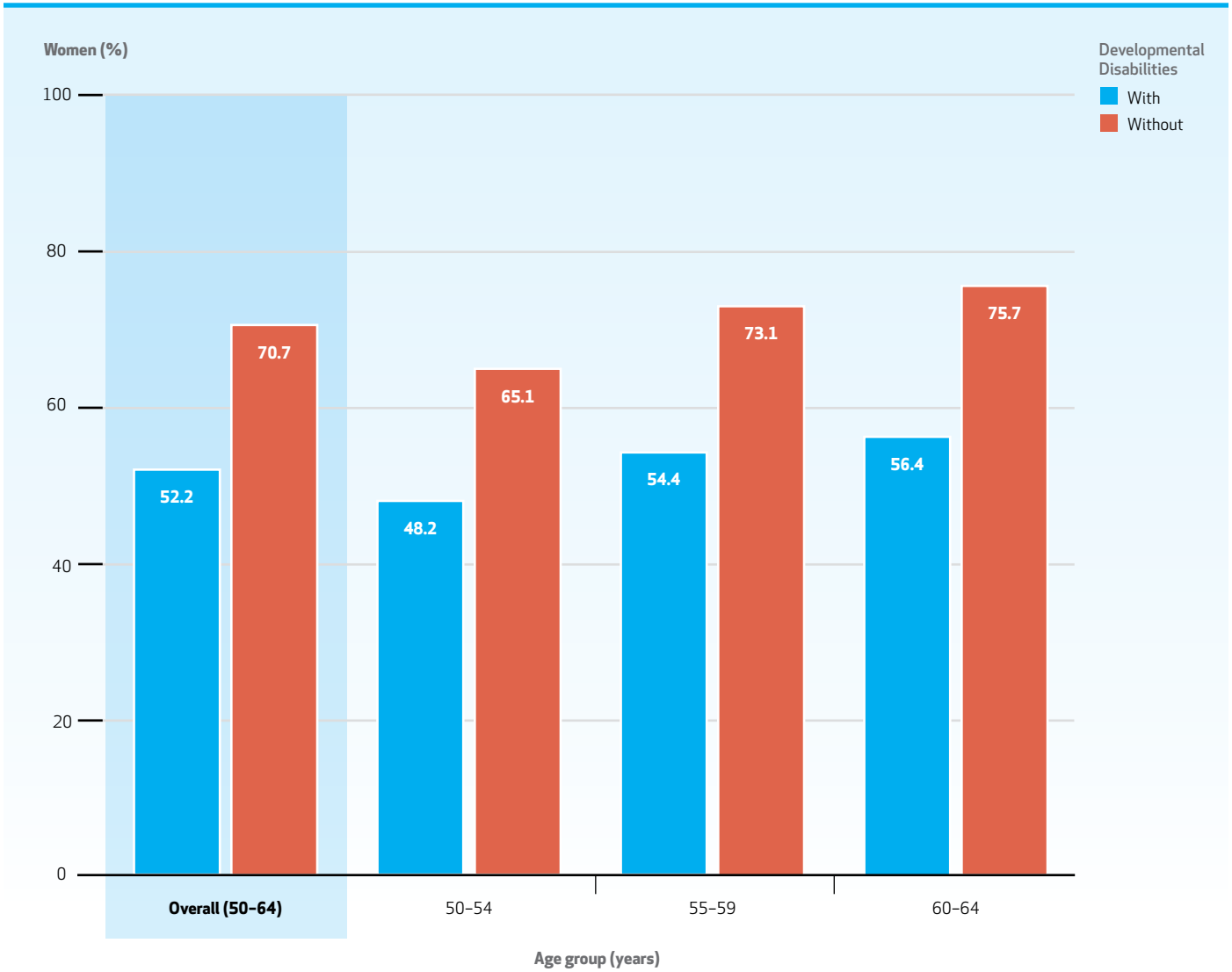
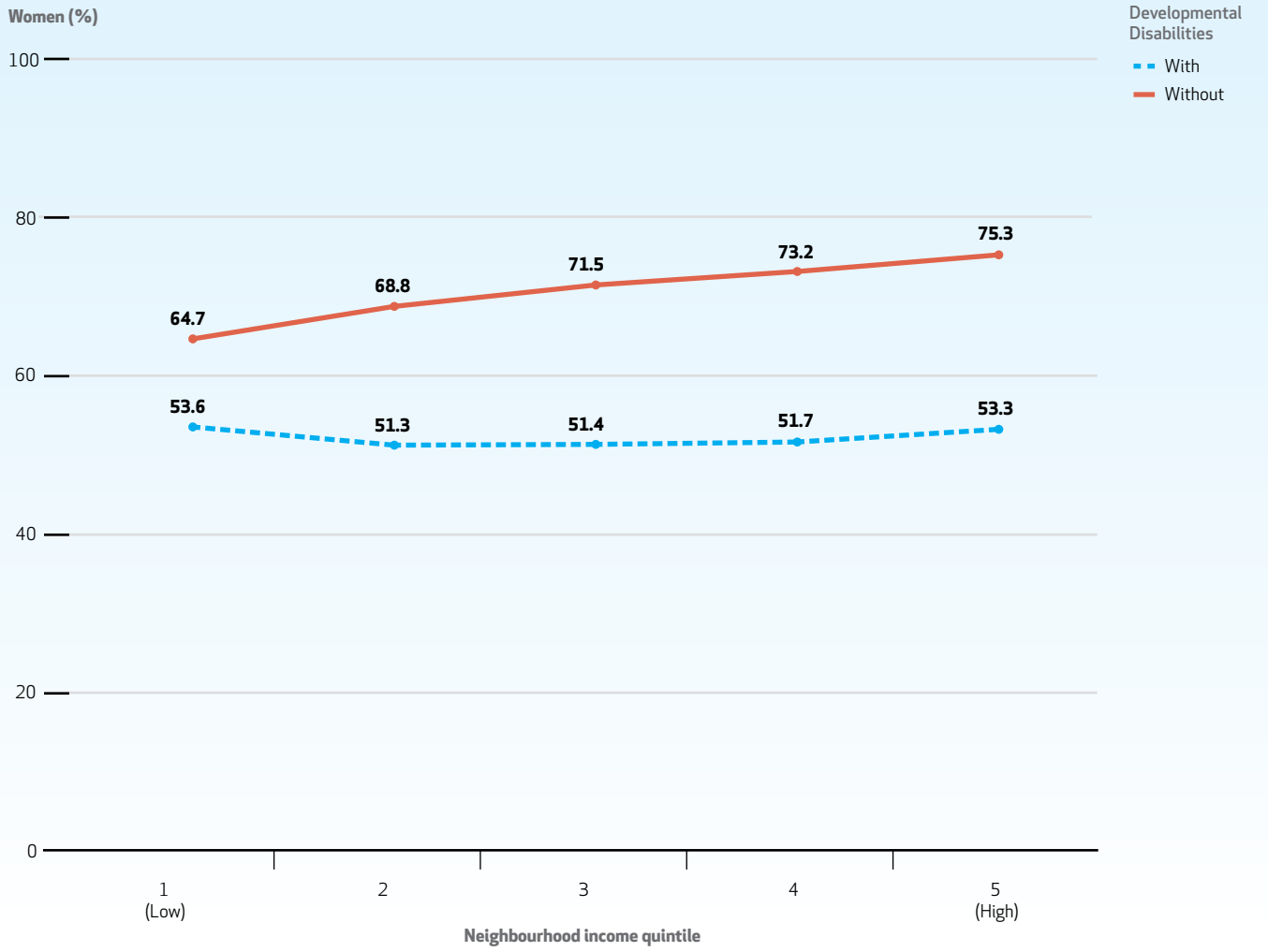


EXHIBIT 4.6 Proportion of women aged 50 to 64 years with or without developmental disabilities who had a mammogram, by neighbourhood income quintile, in Ontario, 2009/10 to 2010/11

Findings

- Uptake of mammography was higher in women without developmental disabilities living in the wealthiest neighbourhoods (gradual increase from low to high neighbourhood income quintile). This income gradient was not present for those with developmental disabilities.
- No urban-rural differences in mammography uptake were observed for either group (data not shown).



Note: Excludes individuals for whom a postal code was missing

EXHIBIT 4.7 Proportion of women aged 18 to 64 years with or without developmental disabilities who had at least one Pap test, overall and by age group, in Ontario, 2009/10 to 2011/12

Findings

- Among women with developmental disabilities who were eligible for screening (n=26,301), 33.7% had a Pap test between 2009/10 and 2011/12 compared to 66.7% of women without developmental disabilities.
- The same age pattern was observed among women with and without developmental disabilities, with the highest proportion screened being those aged 25 to 44 years.

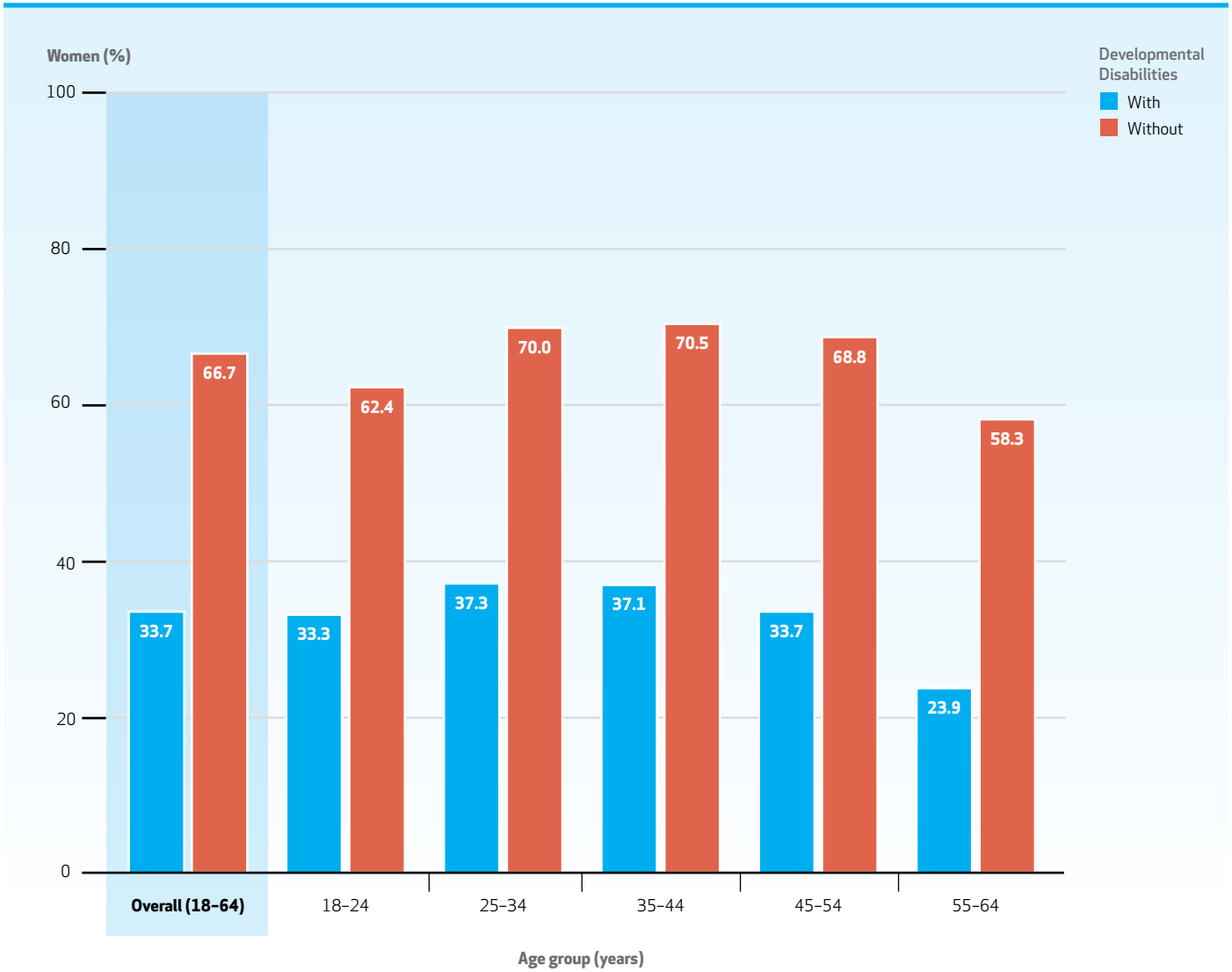
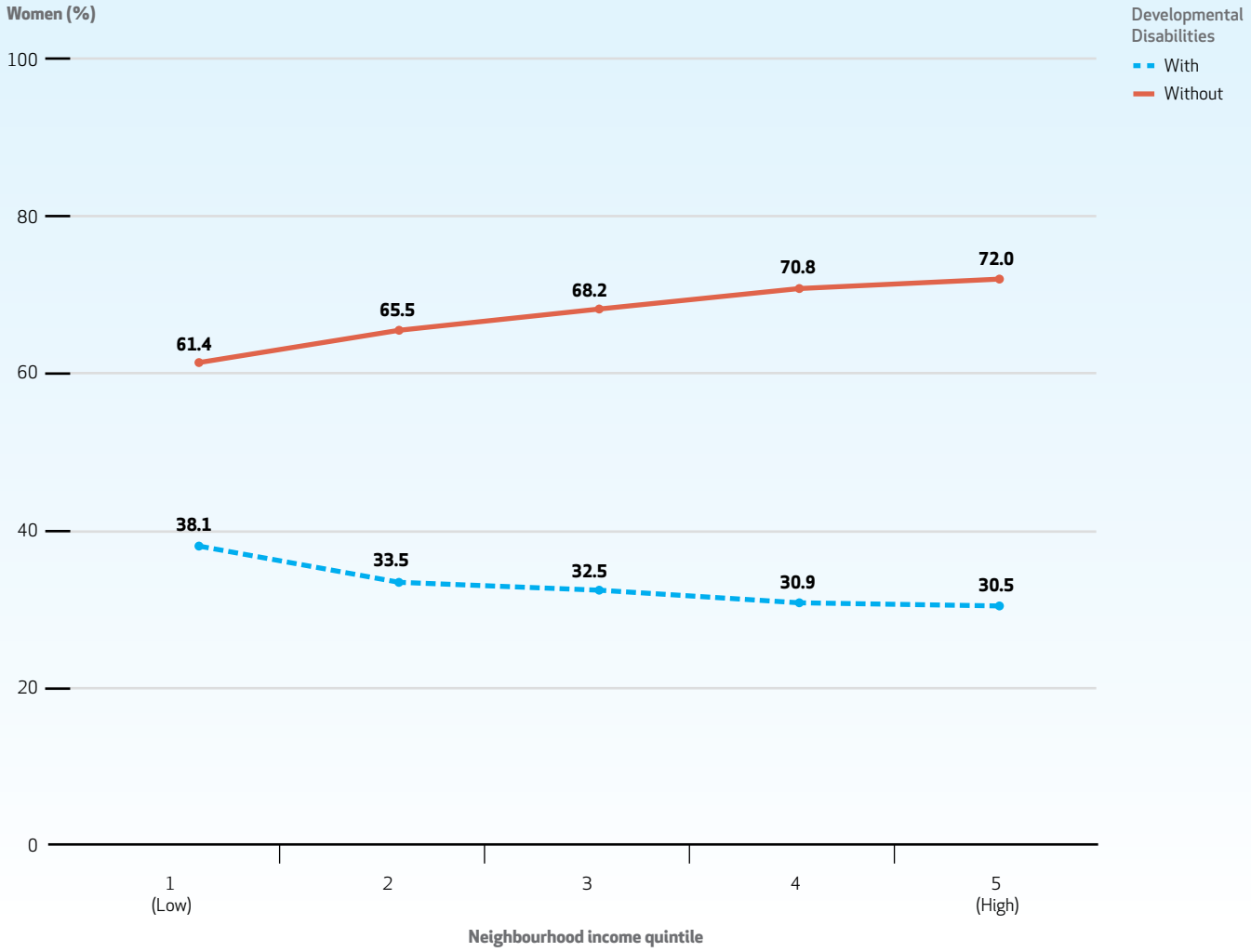


EXHIBIT 4.8 Proportion of women aged 18 to 64 years with or without developmental disabilities who had at least one Pap test, by neighbourhood income quintile, in Ontario, 2009/10 to 2011/12

Findings

- Among women with developmental disabilities, a higher uptake of cervical cancer screening was observed among those living in the lowest income neighbourhoods.
- Among women without developmental disabilities, uptake increased with neighbourhood income while the reverse was seen for women with developmental disabilities.



Note: Excludes individuals for whom a postal code was missing

EXHIBIT 4.9 Proportion of eligible adults with or without developmental disabilities who had a periodic health examination or screening for colorectal cancer (2010), breast cancer (2009/10 to 2010/11) or cervical cancer (2009/10 to 2011/12), by Local Health Integration Network and in Ontario

Findings

- Across LHINs, the proportion of adults with developmental disabilities who received a periodic health examination was similar to or lower than the proportion of adults without developmental disabilities who received this service.
- The proportion of adults with developmental disabilities who were up-to-date with colorectal tests was consistently lower across all LHINs. Twelve of the 14 LHINs had differences of greater than 10%.
- The proportions of women with developmental disabilities who were screened for breast and cervical cancer were consistently lower across LHINs. The majority of LHINs had differences of 15% to 20% for breast cancer screening and 29% to 35% for cervical cancer screening.

	Eligible adults (%)											
	Periodic health examination			Screening								
				Colorectal cancer*			Breast cancer			Cervical cancer		
	Developmental disabilities			Developmental disabilities			Developmental disabilities			Developmental disabilities		
	With	Without	Difference	With	Without	Difference	With	Without	Difference	With	Without	Difference
Ontario	22.0	26.4	-4.4	32.0	47.2	-15.2	52.2	70.7	-18.5	33.7	66.7	-33.0
Local Health Integration Networks												
1. Erie St. Clair	22.1	22.9	-0.8	30.7	47.1	-16.4	52.6	71.4	-18.8	30.2	64.2	-34.0
2. South West	20.3	23.8	-3.5	32.4	43.5	-11.1	56.2	73.1	-16.9	33.5	67.9	-34.4
3. Waterloo Wellington	23.3	23.2	0.1	38.7	47.9	-9.2	53.8	70.7	-16.9	34.7	69.7	-25.0
4. Hamilton Niagara Haldimand Brant	22.9	25.3	-2.4	31.5	45.2	-13.7	50.3	70.2	-19.9	35.7	68.5	-32.8
5. Central West	28.1	30.8	-2.7	37.4	44.8	-7.4	47.9	66.3	-18.4	29.6	65.5	-35.9
6. Mississauga Halton	30.1	33.2	-3.1	34.6	47.8	-13.2	52.4	70.7	-18.3	32.0	68.1	-36.1
7. Toronto Central	22.2	27.0	-4.8	29.2	47.1	-17.9	51.3	66.1	-14.8	33.9	65.3	-31.4
8. Central	32.1	33.8	-1.7	38.1	52.7	-14.6	57.8	73.7	-15.9	34.3	68.8	-34.5
9. Central East	23.4	29.1	-5.7	34.9	49.5	-14.6	50.0	70.1	-20.1	33.3	67.6	-34.3
10. South East	14.5	17.7	-3.2	29.2	45.5	-16.3	53.9	71.7	-17.8	40.1	70.1	-30.0
11. Champlain	20.1	25.0	-4.9	31.7	47.8	-16.1	49.0	71.9	-22.9	34.4	71.0	-36.6
12. North Simcoe Muskoka	23.6	23.8	-0.2	29.3	46.9	-17.6	51.6	73.0	-21.4	32.5	67.9	-35.4
13. North East	14.9	15.3	-0.4	31.0	46.1	-15.1	57.4	74.4	-17.0	31.7	61.4	-29.7
14. North West	12.5	15.6	-3.1	24.0	43.2	-19.2	43.9	72.6	-28.7	33.7	63.2	-29.5

*Represents individuals who were up-to-date with colorectal cancer screening in 2010.

EXHIBIT 4.10 Proportion of eligible adults with or without developmental disabilities who had a periodic health examination or screening for colorectal cancer (2010), breast cancer (2009/10 to 2010/11) or cervical cancer (2009/10 to 2011/12), among patients seeing a Family Health Team physician and in Ontario

Findings

- Disparities in secondary prevention persisted when only individuals receiving the majority of their primary care through Family Health Teams were considered.
- Among adults receiving care in Family Health Teams, the gap in the periodic health examination uptake between those with developmental disabilities and those without was lessened, while the disparity in cervical cancer screening increased.
- Women seen by Family Health Team physicians were more likely to have had a mammogram. This finding was observed among both women with and without developmental disabilities.

	Eligible adults (%)											
	Periodic health examination			Screening								
				Colorectal cancer*			Breast cancer			Cervical cancer		
	Developmental disabilities			Developmental disabilities			Developmental disabilities			Developmental disabilities		
	With	Without	Difference	With	Without	Difference	With	Without	Difference	With	Without	Difference
Ontario	22.0	26.4	-4.4	32.0	47.2	-15.2	52.2	70.7	-18.5	33.7	66.7	-33.0
Family Health Team only	22.2	23.7	-1.5	36.2	51.5	-15.3	59.7	77.5	-17.8	36.8	73.0	-36.2

*Represents individuals who were up-to-date with colorectal cancer screening in 2010.

Discussion

Periodic health examination

The proportion of adults with developmental disabilities receiving a periodic health examination is low yet not very different from what is observed in the general population (22.0% versus 26.4%). Age, sex and income patterns for this indicator are similar across the two groups. Still, the low uptake raises concerns given the vulnerabilities to poor health and health care previously documented among adults with developmental disabilities.[46]

In light of the internationally-growing literature in support of the periodic health examination for adults with developmental disabilities, Australia and Wales instituted specific funding to physicians as an incentive to perform annual health assessments for adults with developmental disabilities in 2006.[47,48] In 2009, the practice was extended across the United Kingdom.[49] There is currently no incentive in Ontario for physicians to perform such annual health assessments for adults with developmental disabilities.

In Wales, when combined with notifications of the importance of the examination being sent to adults with developmental disabilities and their caregivers, this incentive resulted in the uptake of the annual health assessment in this population increasing from 27% in 2007 to 42% in 2009.[50]

Of note, in 2011 the Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities[16] were updated to include more specificity around the recommendation regarding the periodic health examination. This recommendation is particularly relevant in light of recent changes to the Schedule of Benefits for Physician Services in Ontario.[51]

UPDATED CANADIAN CONSENSUS GUIDELINES FOR THE PRIMARY CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Perform an annual comprehensive preventive care assessment including physical examination and use guidelines and tools adapted for adults with developmental disabilities.[16]

In effect since 2011.

Not only are there no incentives for the annual health assessment for adults with developmental disabilities in Ontario, but effective January 1, 2013, the periodic health examination, as defined in this Atlas, has been replaced by the periodic health visit.[52] Physicians can now bill for an annual visit which does not necessarily include a complete medical history and physical examination or routine laboratory tests. The fee for adults aged 18 to 64 years has been reduced to reflect lower complexity in the preventive care required by adults in this age group. The redefined service is not consistent with Canadian primary care guidelines that are focused on developmental disabilities or with developments in other countries requiring more thorough annual health assessments for all adults with developmental disabilities.[14,16]

The new fee schedule in Ontario does however allow for more comprehensive assessments of patients with chronic diseases. Moving forward, it will be important that the comprehensive assessments be conducted with adults with developmental disabilities and not the briefer periodic health visits. The extent to which this can or will be applied to adults with developmental disabilities will require careful monitoring.

Cancer screening

Our analyses clearly show that adults with developmental disabilities are disadvantaged when it comes to cancer screening. Differences in the proportions of adults with and without developmental disabilities who were screened ranged from 15.2% for colorectal cancer to 33.0% for cervical cancer. The finding that screening does not increase according to neighbourhood income for adults with developmental disabilities suggests that the disadvantage in screening created by the disability is similar to the disadvantage in screening created by socioeconomic status.

Previous research has highlighted the lack of knowledge and training among health care professionals and technicians on the health and support needs of adults with developmental disabilities.[30] One important issue is the belief that this group is not at risk for cancer and thus screening is not required; this is particularly the case with respect to breast and cervical cancer. However, men and women with developmental disabilities are living

longer and are at risk for age-related diseases. A recent study in Western Australia reported a 50% survival probability of 66.7 years for men and 71.5 years for women with developmental disabilities.[53] While a lower incidence of solid tumours has been reported in individuals with Down syndrome,[30,54-56] it is expected that the disparities in screening reported are too large to be explained solely by this factor. Individuals with Down syndrome make up less than 20% of the population of adults with developmental disabilities.[57]

An important barrier to cancer screening is the challenge of seeking valid consent from individuals with developmental disabilities.[58] While less has been written about colorectal cancer, women with developmental disabilities report a lack of knowledge of breast and cervical cancer screening, and that fear and embarrassment prevent them from accessing these programs.[29,59,60] Interventions tailored to the communication skills of adults with developmental disabilities are required in order to increase their knowledge of the procedures and their benefits, decrease their anxiety, and thus allow them to give informed consent.[61-64] The role of family caregivers and paid staff is crucial in providing information about cancer screening, supporting the individual during the procedure and reporting any potential symptoms of cancer to health professionals.[65,66] Information and training are required to support caregivers and staff in this role.

Finally, the specific cancer screening procedures present unique challenges and risks that require consideration. These are described below.

Colorectal cancer screening

In 2009/2010, more than two-thirds of adults with developmental disabilities aged 50 to 64 years went unscreened for colorectal cancer. Recognizing that the uptake of colorectal cancer screening in 2009/2010 remained below established targets, in 2010 ColonCancerCheck launched an invitation system to increase screening participation. Recall letters were sent to those who were due for their biennial repeat screening (two years after a normal fecal occult blood test [FOBT]), and invitations were sent to newly screen-eligible Ontarians. In its 2010 Program Report, ColonCancerCheck also stated that it was planning to send invitations to all eligible residents who were under-screened or who had never been screened.[35] This may increase uptake among adults with developmental disabilities. However, to be effective in increasing uptake, the strategy needs to consider the unique barriers experienced by those with developmental disabilities and tailor interventions accordingly.

Both the FOBT and the colonoscopy rely on at-home preparation to ensure the quality of the screening test. The FOBT requires dietary restrictions while the colonoscopy requires complete cleansing of the colon (using stimulants and osmotic agents). Furthermore, the FOBT requires at-home specimen collection. The latter involves obtaining two specimens each from three separate stools. Most adults with developmental disabilities will need to rely on others (family members or paid caregivers) to support them in these tasks. One U.S. study reported inadequate preparation in 45.6% of adults with developmental disabilities presenting for colonoscopy.[67] To ensure compliance, targeted awareness and education campaigns must be directed at these caregivers, in addition to adults with developmental disabilities.

While a colonoscopy might appear to be more appropriate for use among those whose disability could make the FOBT specimen collection challenging, it is not without risk. The preparation for a colonoscopy poses a risk to individuals who are unable to consume at least three liters of clear liquids per day and to those with digestive motility disorders, constipation and seizures—all comorbidities commonly seen in adults with developmental disabilities.[67] The colonoscopy itself also carries a small risk of complications, such as perforation of the intestine, bleeding and incontinence. In adults with developmental disabilities, there are also added risks associated with sedation, as deeper sedation may be needed to ensure successful completion of the screening test.[67]

Without adequate knowledge of the risk of colorectal cancer in adults with developmental disabilities, it is difficult to assess the risk-benefit of screening. Further research is needed to ascertain prevalence beyond the one study carried out in Australia.[34]

Breast cancer screening

Since the introduction of breast cancer screening to routine preventive care, media campaigns have increased public awareness regarding its relevance. Observed differences in the uptake of breast cancer screening between those with and without developmental disabilities calls for more intensive and group-specific or individually tailored awareness and

education strategies for women with developmental disabilities in Ontario.[68]

Our finding that nearly half of the eligible women with developmental disabilities were not screened compared to nearly one-third of the women without developmental disabilities also calls for consideration of the barriers to access. Other jurisdictions have identified logistical and practical barriers including issues related to transportation to the health care facilities,[30] the need to adapt techniques used with persons who have a physical disability,[28,30] and the requirement for technicians and health professionals to spend more time with women with developmental disabilities to accommodate their needs and provide information on the procedure.[29] The relevance of these factors should be studied in Ontario.

Cervical cancer screening

Pap smears are only recommended for women who have been sexually active,[69] but women with developmental disabilities might find it difficult to communicate their sexual history and may have experienced nonconsensual sexual activity that they cannot or will not report.[43] Neither this study nor previously published studies showing differences in cervical cancer screening uptake among women with developmental disabilities have been able to control for this factor. However, it is documented that women with developmental disabilities do experience sexual relationships,[43,70,71] and thus the observed difference in screening is unlikely to be fully explained by a lower proportion of women with developmental disabilities having been sexually active.

Joi, a mother: *"We've had lots of cancer in my family. There have been people who have had colon cancer, cervical cancer, and many women in our family have had breast cancer. I eventually found a doctor who was trained to give Pap tests to women with developmental disabilities. I am very relieved and grateful that the doctor was able to give [my daughter] a Pap test more than once to make sure she was okay. I think it is important to receive appropriate screening no matter what your ability or IQ. Cancer can happen to anybody. However, if doctors aren't trained to do proper physicals, then we won't find it. If lives have value, people should have proper physical examinations and care regardless of their disability status."*

Adapted information, education and support are needed to ensure women with developmental disabilities are appropriately protected (HPV immunization) and screened for cervical cancer. Developments in cervical cancer screening related to the use of HPV testing might provide a viable alternative to the Pap test in women with developmental disabilities as it is suggested that "the high negative predictive value of high-risk HPV testing allows for accurate identification of a low-risk population in which the screening interval can be safely extended."[72]

Implications for policy and practice

Findings show that having a developmental disability leads to disparities in access to secondary prevention in Ontario beyond the effects of age, sex, income and location of residence. Disparities were also observed among those enrolled in a Family Health Team. The use of population-specific clinical guidelines and tools, such as the updated Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities,[16] is recommended. Successful implementation of such guidelines and accompanying clinical tools will require changes to policy and practice, including:

- Incentives to primary care providers for the provision of comprehensive annual health assessments for adults with developmental disabilities.
- Information campaigns aimed at adults with developmental disabilities and their families, as well as education and training of developmental disabilities support workers.
- Education and training of health care providers, including technicians, with regards to the importance of secondary prevention for adults with developmental disabilities, how to modify screening procedures and how to obtain informed consent.[64,73]
- Adapted cancer screening strategies reflecting the needs of and risks to adults with developmental disabilities (e.g., safe colonoscopy preparation protocol, one-on-one counselling for breast cancer, and human papillomavirus screening).

Data needs

Administrative data are insufficient to describe patient-physician interactions. The billing code does not always reflect what occurs in practice. To better use administrative data to examine and monitor the periodic health examination in adults with developmental disabilities, it is important to understand more about how physicians bill for this service. Electronic health records could be helpful in this regard.

As the life expectancy of adults with developmental disabilities continues to increase, there is a need to develop data sources which will allow for the study of health and health care access among seniors (those aged 65 years and older). Previous research has demonstrated that adults with developmental disabilities have poorer access to health care the more independently they live (alone vs. with family vs. in a group home).[7,74] Our data sources did not include a reliable indicator of living arrangement. Finally, some highly relevant indicators could not be examined due to lack of access to laboratory data (e.g., *H. pylori* testing).

Future research

This chapter provides a baseline regarding a select number of secondary prevention indicators in effect in Ontario in 2009/10. Continued monitoring is needed; this is particularly important where recommended care has changed (for example, the introduction of the Periodic Health Visit).

In order to adequately assess the impact of low cancer screening uptake among adults with developmental disabilities, studies of cancer-specific incidence, treatment and mortality are required.

Recommended actions listed above under *Implications for policy and practice* should be evaluated with a particular focus on untangling barriers to access.

The indicators in this chapter were assessed for one model of primary care, the Family Health Team. Future research should also include the additional models of primary care discussed in Chapter 3.

Conclusion

Adults with developmental disabilities in Ontario clearly experience disparities in secondary prevention. As such, they deserve recognition as a vulnerable population. As changes to primary care delivery and secondary prevention recommendations in the province continue to evolve, close monitoring of their impacts on adults with developmental disabilities combined with dedicated efforts to increase access are warranted.

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5 Chronic Disease Management

Inside

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MAIN MESSAGES

- Effective chronic disease management is especially relevant to adults with developmental disabilities because they experience higher rates of chronic diseases, such as diabetes, heart disease, osteoporosis and mental illnesses. They may also be less likely to initiate a visit with their family physician and to have the required skills and support to maintain self-care strategies that prevent disease complications.
- To examine how well chronic disease management is being provided for adults with developmental disabilities, four indicators of primary care management were selected. They were measures of diabetes care, mental health management, osteoporosis monitoring and preventable hospitalizations. The measures were compared to those for adults without developmental disabilities and the impacts of age, sex, neighborhood income and urban or rural residence were examined. Finally, regional differences and patterns for those receiving care through Family Health Teams were reported.
- Among persons with diabetes, rates of eye examinations over two years for adults with developmental disabilities compared favourably to those without developmental disabilities.
- Rates of follow-up with either a family physician or psychiatrist within 30 days after a psychiatric emergency department visit were similar among adults with and without developmental disabilities.
- The proportion of adults who received bone mineral density testing within one year of experiencing a low-trauma fracture was lower among those with developmental disabilities than among those without developmental disabilities.
- The rate of preventable hospitalizations for those with developmental disabilities was much higher across age groups and neighbourhood income. This suggests a problem providing adequate primary care for this population.
- More effective chronic disease management for adults with developmental disabilities can be achieved through the provision of individualized, coordinated plans that integrate social and medical supports; more formalized training in chronic disease management in both the health and social services sectors; raising awareness of health care professionals by emphasizing the specific needs of persons with developmental disabilities in chronic disease guidelines; and increasing the amount of information related to chronic disease management within developmental disabilities–specific health care guidelines.

Introduction

It is estimated that 80% of Ontarians over the age of 45 suffer from a chronic disease.[1] Chronic diseases include illnesses such as diabetes, arthritis, heart disease, osteoporosis and chronic depression. There is a high level of comorbidity among people who suffer from a chronic disease, likely due to the common risk factors associated with these illnesses (e.g., people with diabetes have higher blood pressure which is a risk factor for heart disease).[2] Among people living with a chronic disease in Ontario in 2003, 70% of those over the age of 45 reported having multiple chronic conditions.[1] The complications that result from these diseases can affect quality of life and place a large financial burden on the health care system.[1] The management of chronic diseases, also referred to as tertiary prevention, involves a combination of primary care, specialized care and self-directed patient care. Primary care providers play a large role in the management of chronic diseases by delivering ongoing treatment, conducting follow-up visits, providing referrals to specialists and teaching patients self-care strategies to prevent further complications of the disease.

The Ontario Ministry of Health and Long-Term Care has noted that the province's health care system is better equipped to handle acute health care problems, with an emphasis placed on diagnosis and symptom relief, rather than on addressing the seemingly less urgent concerns resulting from chronic diseases.[1] This results in medical practices that rely on patient-initiated visits, and visits that focus on the more urgent aspects of one's health, rather than on managing illness and preventing complications.[3]

The effectiveness of chronic disease management is especially relevant to adults with developmental disabilities as they experience higher rates of chronic diseases, mental health problems in particular (*see* Chapter 2). They also may be less likely to initiate a visit with their family physician or have the required skills and support to maintain self-care strategies in order to prevent disease complications. Due to their interdisciplinary nature and their focus on chronic disease management, Family Health Teams may be particularly well suited to address some of these concerns.[4]

TERTIARY PREVENTION involves managing chronic illness with the goal of preventing further complications while maximizing quality of life.[5]

This chapter presents information on four indicators of primary care that deal with the management of chronic diseases. The indicators include measures of diabetes care, mental health management, osteoporosis monitoring and preventable hospitalizations. These indicators were selected because they could be calculated using routinely collected administrative health data and because they address some of the diseases and conditions with high prevalence levels among adults with developmental disabilities (*see* Chapter 2). The four indicators were examined according to age, sex, urban or rural residence, neighbourhood income, level of morbidity, residence by Local Health Integration Network, and enrolment with a Family Health Team. There were two primary objectives: first, to describe how well chronic disease primary care is being provided for adults with developmental disabilities; and second, to contrast results of specific health indicators between this population and persons without developmental disabilities.

Background

Diabetes care: eye examinations

More than one million Ontarians live with diabetes, a number that is expected to approach two million by 2017.[6] Diabetes can lead to multiple health complications such as blindness, amputation, renal failure, and cardiovascular disease.[7] These comorbidities and complications mean that those with diabetes need to use health care services more frequently than the average Ontarian. Consequently, the management of diabetes is expensive. It is estimated that diabetes costs Ontarians $4.9 billion per year.[8] Groups such as immigrants, those with lower income and persons with disabilities are at higher risk for diabetes.[9]

RETINAL EYE EXAMINATION allows physicians to test for eye problems, such as diabetic retinopathy. Involves the dilation of the pupils by placing eye drops into the patient's eye. The physician then uses a special magnifying glass to examine the back of the eye for signs of damage.[10,11]

As reported in Chapter 2, the prevalence of diabetes among Ontarians with developmental disabilities is 10.4%, compared to 6.5% for persons without developmental disabilities. These findings are consistent with research conducted in the United States.[12] Some of the factors contributing to the high prevalence of diabetes among adults with developmental disabilities are similar to those for the general population. For example, high levels of obesity due to poor diet and sedentary lifestyle have been identified in both groups.[13,14] Persons with developmental disabilities are also prescribed medications, such as antipsychotics, at high rates (*see* Chapter 6), which contribute to a higher risk for developing diabetes.[15]

CANADIAN DIABETES ASSOCIATION CLINICAL PRACTICE GUIDELINES

People with diabetes should have a retinal eye exam once every one to two years.[16]

In effect during the period of study; updated in 2013.

In 2008, the Ontario government established the Ontario Diabetes Strategy in an effort to expand and enhance diabetes prevention, care and management province-wide.[17] This strategy has identified goals and is tracking progress on indicators related to the management of diabetes.[17,18] One indicator that can be studied using administrative health data across Ontario is eye examinations. The Canadian Diabetes Association's clinical practice guidelines recommend that people with diabetes have a retinal eye examination once every one to two years depending on the situation.[16] Although the updated Canadian Consensus Guidelines for Primary Care of Adults with Developmental Disabilities highlight the need to screen for diabetes in those with developmental disabilities,[19] no guidelines exist for managing diabetes in this population specifically.

As an indicator of chronic disease management, we determined the proportion of adults with and without developmental disabilities who had diabetes and underwent a routine eye examination between April 1, 2009 and March 31, 2011.

Mental health management: psychiatric emergency follow-up

Mental illness has an impact on almost everyone, either directly or indirectly. The many people who experience a mental health problem are directly affected, while the families and caregivers supporting them are affected indirectly.[20] According to the Mental Health Commission of Canada, more than 6.7 million people in Canada were living with mental illness in 2011,[21] which equates to approximately one in five Canadians.

As demonstrated in Chapter 2, close to half of adults with developmental disabilities have a coexisting mental illness[22] sometimes referred to in Ontario as "dual diagnosis." Research has found that those with developmental disabilities and coexisting mental illness are more likely to be frequent users of emergency department services[23] and have high rates of psychiatric re-hospitalization.[24] Emergency department visits can be traumatic for adults

Roger, a father: *"As parents, we went through a feeling of utter helplessness. The hospital system tried to do its best, but we were offered band-aid solutions (probably because they were hampered by budget restraints and limited space). Though the level of care was good during emergencies, there was a recurring mantra of 'patch her up and send her out until the next time.' We really hoped for a lasting solution outside of initial crisis intervention. We found doctors to be hard-pressed for time to provide a course of action for family caregivers beyond intervention, and they ultimately left it to us to find a solution on our own. We felt then as we feel now, that there needs to be a better process that connects hospitals, caregivers, family doctors and patients with a focus on long-term intervention, thereby reducing the need for emergency hospitalization."*

with developmental disabilities[25,26] and challenging for hospital staff.[27] This is partly due to problems with communication and obtaining an accurate patient history.

CONSENSUS GUIDELINES FOR PRIMARY HEALTH CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Develop crisis plans in consultation with patients at risk of crisis and their caregivers. Review this plan annually and after any crisis.[19]

In effect during the period of study; updated in 2011

Research has shown that, for adults with developmental disabilities, both access to primary care and the preparation of a crisis plan reduce the likelihood of psychiatric crises resulting in emergency visits.[28] In addition, the Behavioural and Mental Health Guidelines section of the 2006 Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities[19] emphasized that primary care providers need to develop crisis plans in consultation with at-risk patients and their caregivers. The recommendation stresses the need to review these crisis plans both periodically *and* after any psychiatric crisis.

Consequently, as an indicator of mental health management, we determined the proportion of adults with and without developmental disabilities who received a follow-up with a physician within 30 days of a psychiatric emergency department visit. This indicator was measured over the two-year period from April 1, 2009 to March 31, 2011.

Osteoporosis monitoring: fracture care

Osteoporosis is a skeletal disease in which bone mineral density is reduced, resulting in compromised bone strength and an increased risk of fracture.[29] In Canada approximately one in four women and one in eight men over the age of 50 have osteoporosis.[30]

An American study of adults with developmental disabilities reported that 19.0% of men and 14.5% of women had osteoporosis.[31] This study, however, examined the prevalence of osteoporosis among adults in all age ranges, making it difficult to compare prevalence estimates in the developmental disabilities population to those in the general population. It is nonetheless acknowledged that adults with developmental disabilities are at increased risk for osteoporosis due to the long-term use of certain medications (e.g., anticonvulsants), limited mobility and the presence of genetic syndromes such as Prader-Willi and Down.[19]

LOW-TRAUMA FRACTURE refers to fractures that occur from minor impact or force (e.g., occurring spontaneously or falling from standing height) that would not usually be strong enough to result in a broken bone.[29] A low-trauma fracture increases the risk of additional fractures, as well as the risk of hospitalization and mortality.[32] A low-trauma fracture is also referred to as a fragility fracture or an osteoporotic fracture.

Experiencing a low-trauma fracture is often the first sign that an individual has osteoporosis.[33] Low-trauma fractures resulting from osteoporosis can impact one's quality of life, affecting self-care, mobility and ambulation.[34] Individuals may experience chronic pain resulting from these fractures and in cases such as hip fractures there is an increased risk of mortality.[29] Economic analyses estimate the financial burden of osteoporosis in Canada to be $2.3 billion,[35] with the greatest direct costs associated with the treatment of fractures and fracture complications.[29]

CLINICAL PRACTICE GUIDELINES FOR THE DIAGNOSIS AND MANAGEMENT OF OSTEOPOROSIS

Bone mineral density testing is recommended for postmenopausal women and for men over the age of 50 with one of the other major risk factors for fracture. A prior fragility fracture occurring after the age of 40 is considered a major risk factor for osteoporosis.[29]

In effect during the period of study; updated in 2010

The risk of fracture and the costs of fracture-related care highlight the need to focus on the management of osteoporosis to prevent low-trauma fractures. The management of osteoporosis involves a wide variety of treatment options including monitoring bone mineral density, calcium and vitamin D supplementation, pharmacologic and physical therapy and lifestyle changes.[29,32] However, research suggests that many individuals are not receiving adequate care, including monitoring bone mineral density.[36]

Lou is a 47-year-old man with Down syndrome. At age 39, Lou started to fall frequently. He was diagnosed with left hip osteoarthritis and had a successful total hip replacement. Since his operation, he has regained some of his independence but continues to experience near-falls. Lou's family has been closely involved with his care and planning for the health problems he has experienced over the years.

Lou's dad, Alex, has this to say about Lou's recent health care: *"Once [he got] access, in most cases, Lou's experiences with health services have been excellent. The challenge is that you have to push, and look for health professionals who are sympathetic, especially for the bigger procedures. Hospitals are not set up to support people like Lou. We had to hire someone to stay with him overnight while he was hospitalized. We even had some problems getting Lou into a falls-prevention program. As Lou ages, we know he will be experiencing more health problems related to the aging process."*

Bone mineral density tests determine bone density by measuring the amount of absorption of X-rays at the proximal femur and lumbar spine. Tests of the hip and spine are considered a valid tool to diagnose osteoporosis and monitor ongoing fracture risk.[29,33]

The 2002 Clinical Practice Guidelines for the Diagnosis and Management of Osteoporosis in the general population recommended bone mineral density testing for postmenopausal women and men over the age of 50 who have experienced a prior low-trauma fracture.[29] These individuals are believed to be at high risk for subsequent fractures and should therefore be considered for treatment.[29] The Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities focus on the screening of men and women for osteoporosis but, due to a lack of research specifically on developmental disabilities, the Guidelines do not make additional clinical recommendations for the management and treatment of this disease or consider follow-up tests for low-trauma fractures.[19]

However, based on the guidelines for the general population, the use of bone mineral density testing

following a low-trauma fracture is both a reasonable indicator and one which can be measured using administrative health data.[29,33] Consequently, our indicator of osteoporosis management was determined by comparing the proportion of men and women aged 40 to 64 years with and without developmental disabilities who had a bone mineral density test within one year of experiencing a low-trauma or fragility fracture.

Preventable hospitalizations: hospitalizations for ambulatory care-sensitive conditions

As described in Chapter 3, 7.5% of adults with developmental disabilities and 4.4% of people without developmental disabilities were hospitalized in the period from April 1, 2009 to March 31, 2010. Some of these hospitalizations could have been prevented through better access to primary care and management of chronic disease. The rationale is that timely and effective primary care helps to reduce the risk of hospitalization by either delaying the progression of the illness or preventing complications.[37] This is especially true for certain chronic conditions like asthma, diabetes and congestive heart failure.

Researchers have created lists of conditions for which primary care plays a particularly important role in preventing hospitalizations. These conditions are called ambulatory care–sensitive conditions.[38] A list of these conditions has been developed and validated specifically for persons with developmental disabilities, and the list has been used to study the adequacy of primary care for this population in Manitoba and in the United Kingdom.[39,40] In Manitoba, persons with developmental disabilities had a rate of preventable hospitalizations six times higher than Manitobans without developmental disabilities.[39] Among persons with developmental disabilities living in the United Kingdom, 12.5% of admissions were for preventable hospitalizations.[40]

AMBULATORY CARE–SENSITIVE CONDITIONS are conditions like asthma and diabetes for which timely and effective primary care helps to reduce the risk of hospitalization by either delaying the progression of the illness or preventing complications.[37] A hospital admission for an ambulatory care-sensitive condition is considered a potentially preventable hospitalization.

Not all hospitalizations are preventable, and there are no guidelines indicating the appropriate rate of hospitalization for specific conditions. However, if a population subgroup or a particular region shows a greater than normal frequency of hospitalizations for these conditions, it is considered an indication that there is a problem with access to primary care in that subgroup or region.[41]

PREVENTABLE HOSPITALIZATIONS GUIDELINES
No guidelines address preventable hospitalizations. However, researchers commonly use rates of preventable hospitalizations in the general population as a benchmark for comparing with population sub-groups.

The Canadian Institute for Health Information has been reporting national rates of preventable hospitalizations for several years,[42] and Health Quality Ontario's *Quality Monitor* (published annually since 2006) reports this same indicator to determine if primary care is improving over time.[43]

As an indicator of access to and the quality of chronic disease management through primary care, rates of preventable hospitalization for adults with and without developmental disabilities were compared over a one-year period.

List of Exhibits

EXHIBIT 5.1 Proportion of adults with diabetes aged 30 to 64 years with or without developmental disabilities who had an eye examination, overall and by age group, in Ontario, 2009/10 to 2010/11

Findings

- Among adults with diabetes, the proportion who had an eye examination was higher for those with developmental disabilities in each age group except those aged 55 to 64 years.
- In those without developmental disabilities, the proportion who had an eye examination increased by approximately 10% with each age group. In those with developmental disabilities, the proportions were more constant across age groups.
- There was no evidence of an income gradient for this indicator for persons with or without developmental disabilities (data not shown).

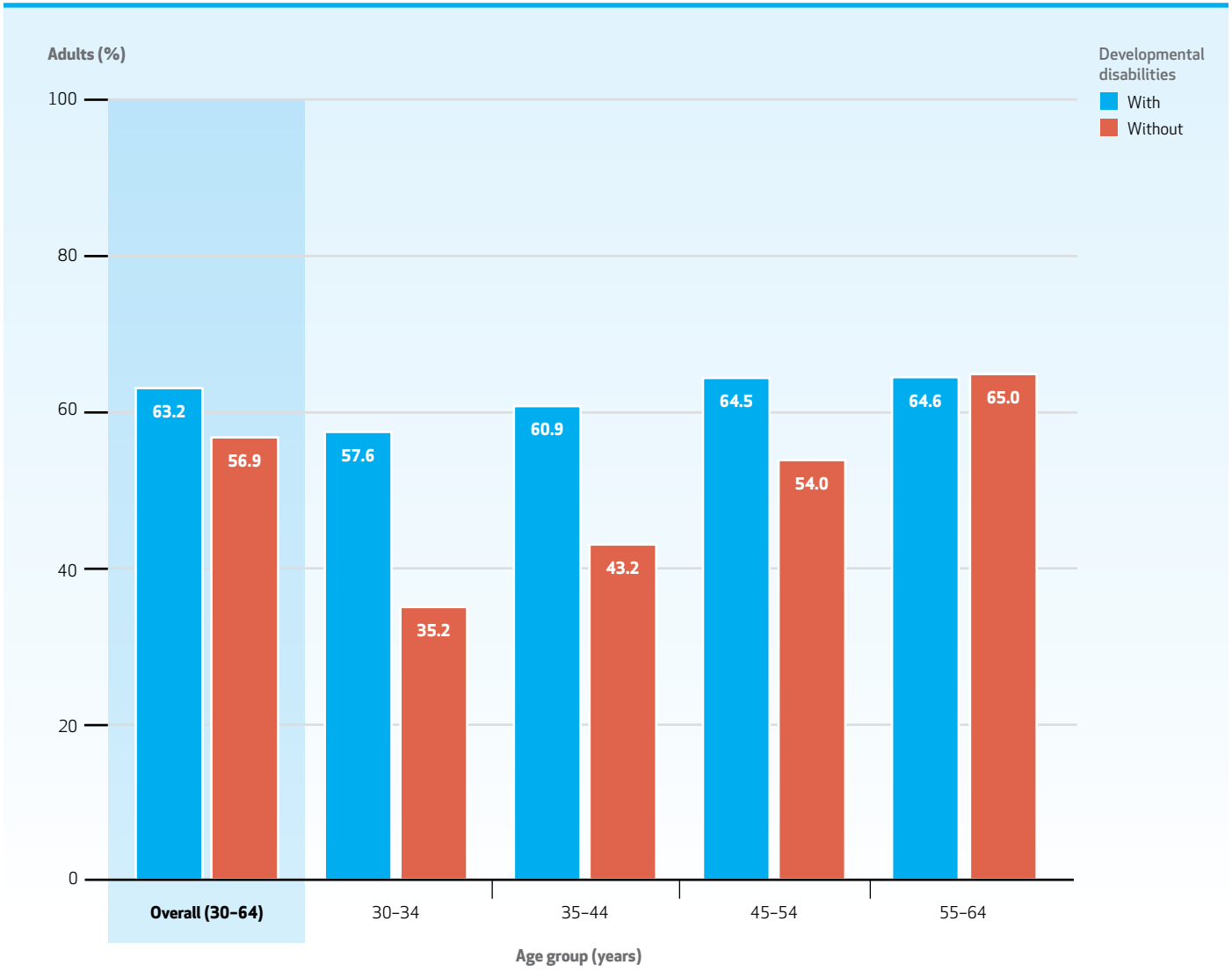


EXHIBIT 5.2 Proportion of adults aged 18 to 64 years with or without developmental disabilities who received follow-up within 30 days of a psychiatric emergency department visit, overall and by type of follow-up, in Ontario, 2009/10 to 2010/11

Findings

- Levels of follow-up after a psychiatric emergency department visit were similar for adults with and without developmental disabilities.
- Close to half of the follow-up visits in both groups occurred within the first week (data not shown).
- Adults with developmental disabilities were more likely than those without developmental disabilities to receive follow-up care from a psychiatrist alone or from both a psychiatrist and a family physician.
- Overall, men were less likely than women to receive follow-up care (respectively, 55.5% vs. 62.8% among those with developmental disabilities and 55.1% vs. 62.8% among those without) (data not shown).
- An income gradient was observed in both groups whereby those living in lower-income neighbourhoods were less likely to receive follow-up care than those in higher-income neighbourhoods (data not shown).

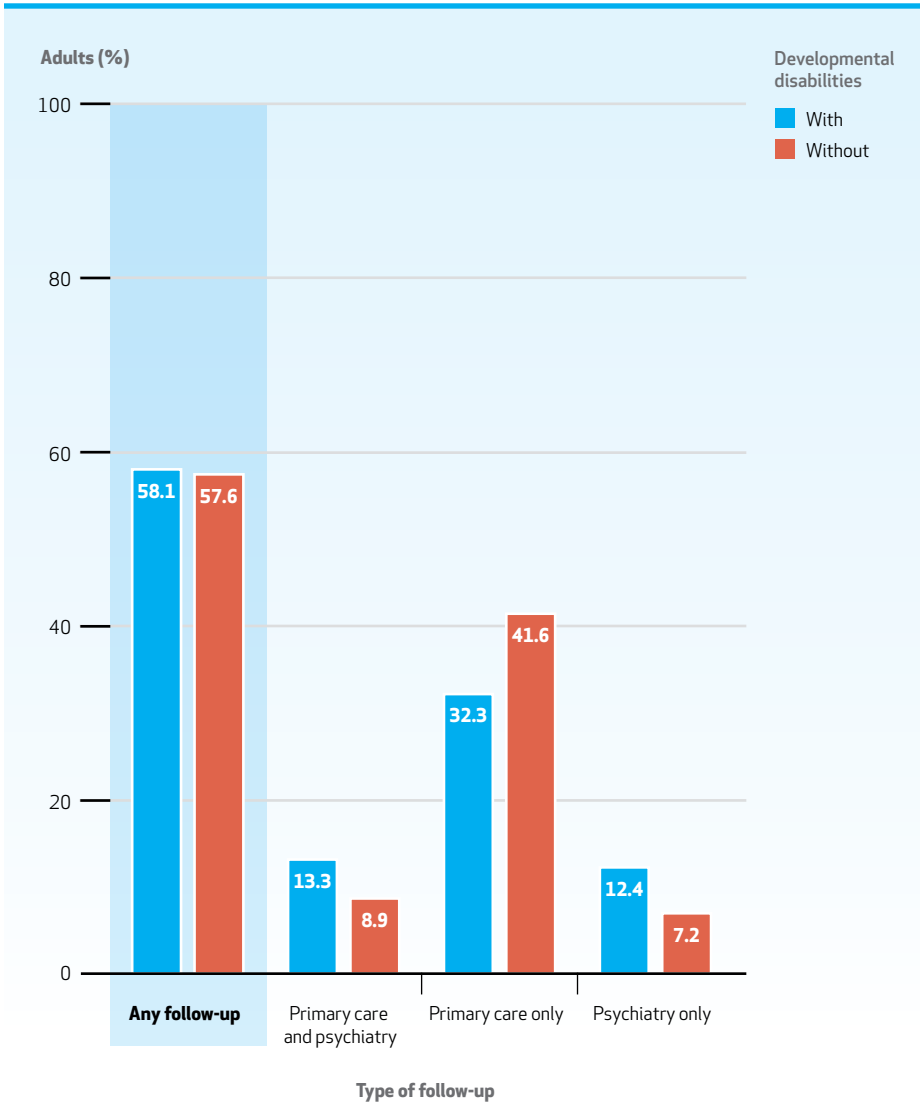


EXHIBIT 5.3 Rate per 10,000 population for adults aged 40 to 64 years with or without developmental disabilities who had a low-trauma fracture, overall and by age group, in Ontario, 2009/10

Finding

- For every age group, adults with developmental disabilities experienced low-trauma fractures at a much higher rate than adults without developmental disabilities.

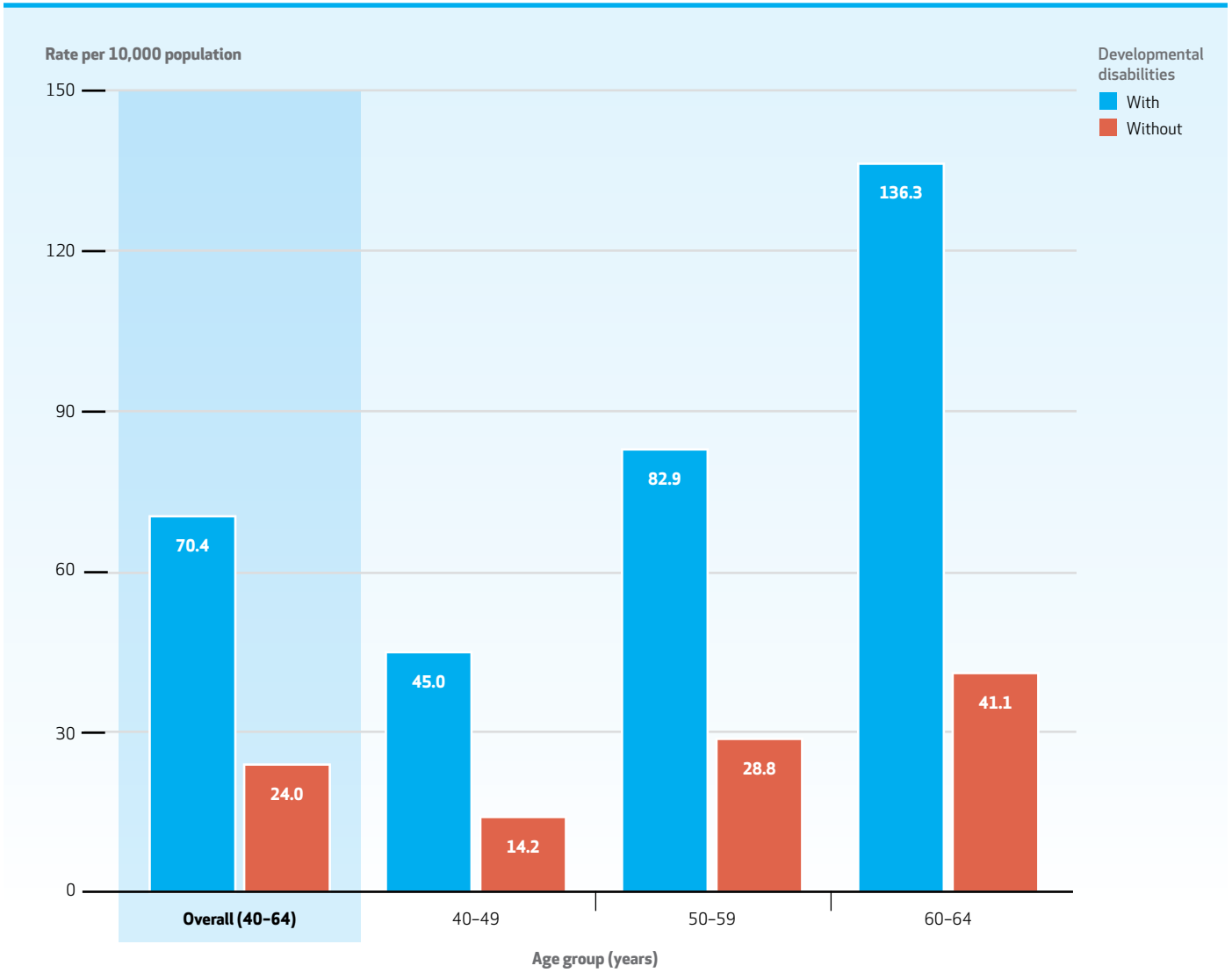


EXHIBIT 5.4 Proportion of adults aged 40 to 64 years with or without developmental disabilities who received a bone mineral density test within one year post-discharge after a low-trauma fracture, overall and by age group, in Ontario, 2009/10

Findings

- Combining results for all age groups, the proportion of adults with developmental disabilities who had a bone mineral density test following a low-trauma fracture was lower than among adults without developmental disabilities (16.2% vs. 21.5%).
- The disparity in testing between adults with and without developmental disabilities was most striking among those aged 50 to 59 years.
- The disparity in testing between adults with and without developmental disabilities remained regardless of the case definition for low-trauma fracture. When a broader definition of low-trauma fracture was applied, the proportion of persons with developmental disabilities who received bone mineral density testing was 14.2% compared to 19.5% among adults without developmental disabilities (data not shown).

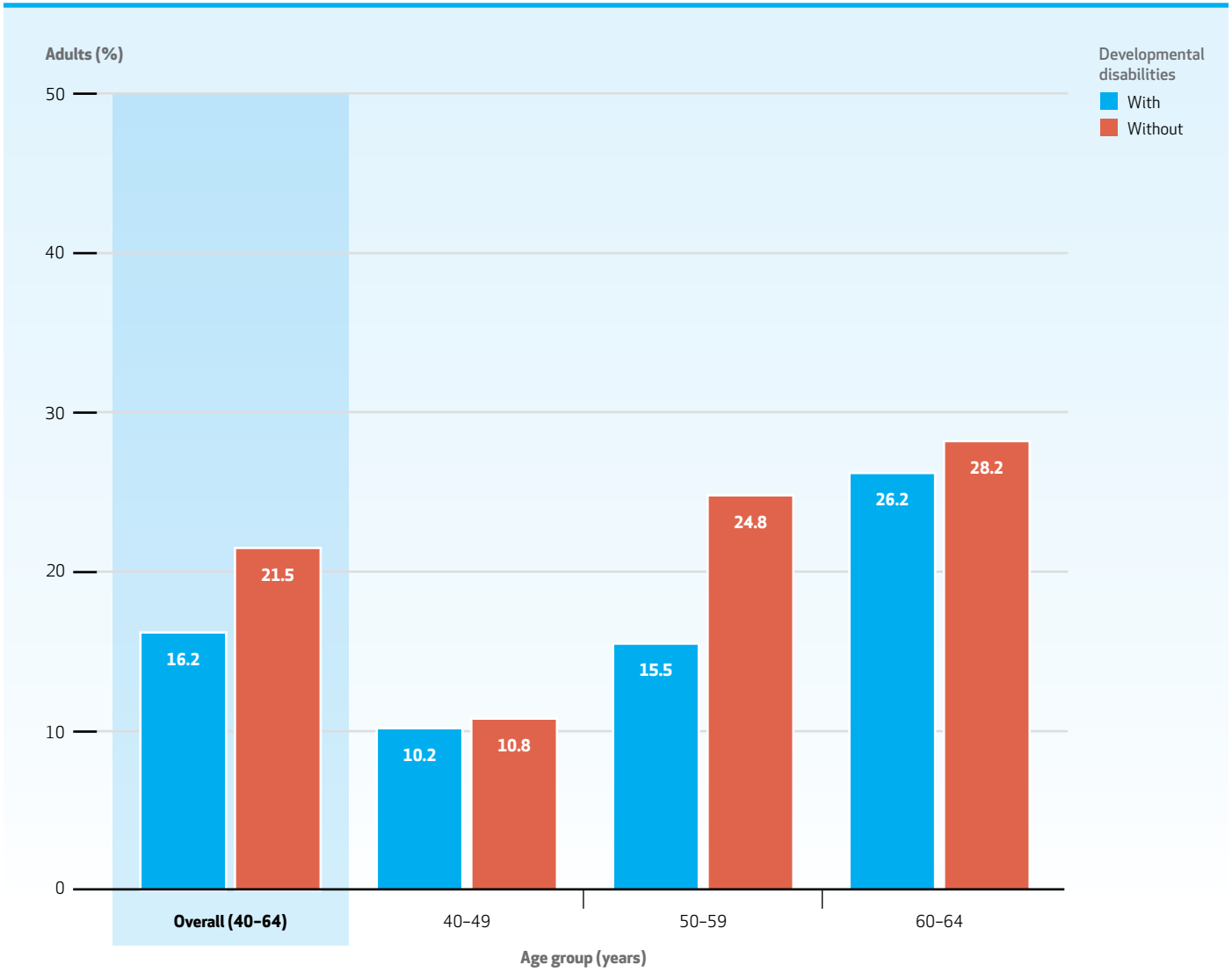


EXHIBIT 5.5 Rate per 100,000 population for adults aged 18 to 64 years with or without developmental disabilities who were hospitalized for an ambulatory care–sensitive condition, overall and by age group, in Ontario, 2009/10

Findings

- Across all age groups, there was a dramatically higher rate of hospitalization for ambulatory care–sensitive (ACS) conditions among persons with developmental disabilities compared to those without.
- The rate of hospitalization for ACS conditions among persons with developmental disabilities aged 25 to 34 years was almost 10 times higher than the rate for adults without developmental disabilities in that age group.
- Among persons in both populations, there was an increase in the rate of hospitalization for ACS conditions with each successive age group. However, the increase was more marked for adults with developmental disabilities.
- Persons with developmental disabilities were hospitalized for ACS conditions at rates higher than persons without developmental disabilities at every level of morbidity as measured by Resource Utilization Band (*see the* Technical Appendix *for an explanation of this measure*) (data not shown).

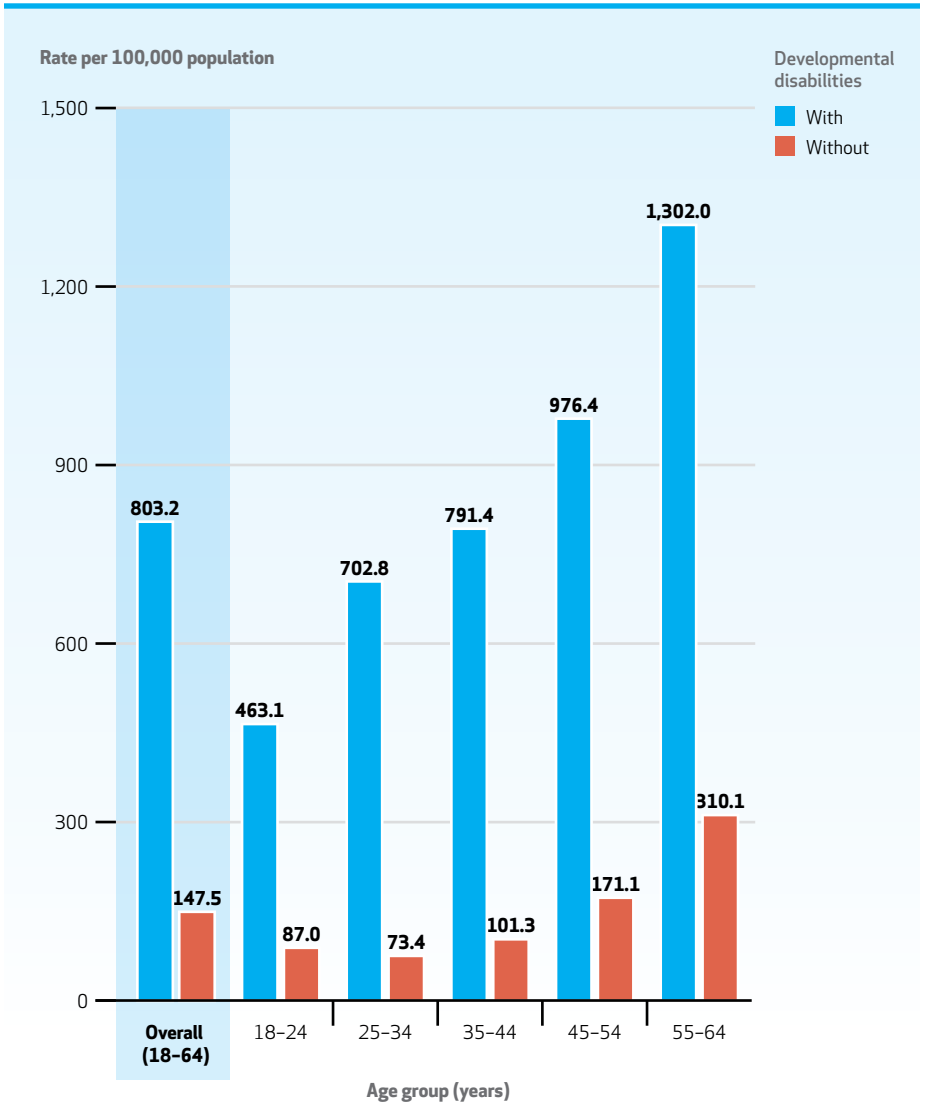
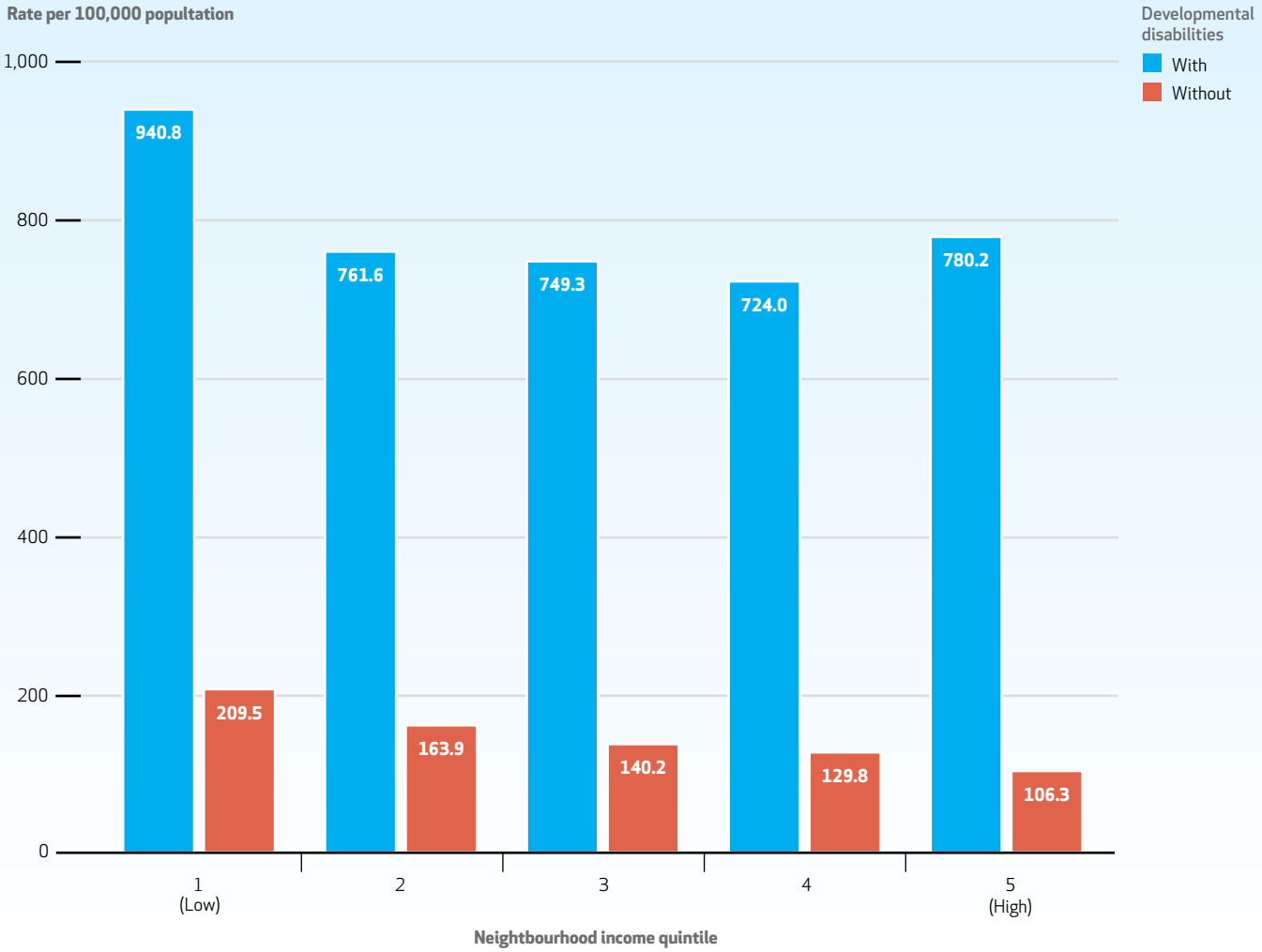


EXHIBIT 5.6 Rate per 100,000 population for adults aged 18 to 64 years with or without developmental disabilities who were hospitalized for an ambulatory care–sensitive condition, by neighbourhood income quintile, in Ontario, 2009/10

Findings

- Persons with developmental disabilities living in the lowest-income neighbourhoods (quintile 1) were hospitalized for ambulatory care–sensitive conditions more frequently than those in other neighbourhoods.
- Although an income gradient was apparent among persons without developmental disabilities, this pattern was less evident in those with developmental disabilities.



Note: Excludes individuals for whom a postal code was missing

EXHIBIT 5.7 Results for each indicator of chronic disease management, by Local Health Integration Network and in Ontario, 2009/10 to 2010/11

Findings

- Among adults with diabetes, those with developmental disabilities were more likely to have had an eye examination than those without developmental disabilities in all Local Health Integration Networks (LHINs) except the North West LHIN.
- Among adults with developmental disabilities and diabetes, the proportion seen for an eye examination varied from 55% to 71% across the LHINs.
- Rates of psychiatric emergency follow-up for adults with developmental disabilities ranged from 37% to 73% across LHINs. LHINs with larger urban populations had higher follow-up rates than northern LHINs.
- The majority of LHINs had similar rates of psychiatric emergency follow-up for adults with and without developmental disabilities.
- Across all LHINs, adults with developmental disabilities were hospitalized for ACS conditions at a rate higher than those without developmental disabilities.
- Among adults with and without developmental disabilities, the largest discrepancy in hospitalizations for ACS conditions tended to be in the more sparsely populated areas, such as the North West and North East LHINs.

	Indicator								
	Diabetes care: Eye examinations (%)			Psychiatric emergency follow-up with psychiatrist or family physician within 30 days (%)			Hospitalizations for ambulatory care-sensitive conditions* (rate per 100,000 population)		
	Developmental disabilities			Developmental disabilities			Developmental disabilities		
	With	Without	Difference	With	Without	Difference	With	Without	Difference
Ontario	63.2	56.9	6.3	58.1	57.6	0.5	803.2	147.5	-655.7
Local Health Integration Network									
1. Erie St. Clair	64.7	61.9	2.8	58.5	57.1	1.4	1,010.6	173.7	-836.9
2. South West	71.4	62.1	9.3	54.7	55.7	-1.0	945.4	174.7	-770.7
3. Waterloo Wellington	67.5	60.0	7.5	51.4	55.3	-3.9	704.0	116.4	-587.6
4. Hamilton Niagara Haldimand Brant	60.8	59.6	1.2	60.6	60.2	0.4	862.5	182.8	-679.7
5. Central West	55.7	53.8	1.9	68.0	65.4	2.6	473.7	135.8	-337.9
6. Mississauga Halton	62.6	55.2	7.4	70.3	66.2	4.1	458.6	110.6	-348.0
7. Toronto Central	54.7	52.0	2.7	73.1	63.0	10.1	765.2	136.7	-628.5
8. Central	60.4	52.5	7.9	67.6	64.7	2.9	770.7	107.0	-663.7
9. Central East	60.4	57.4	3.0	58.9	61.0	-2.1	626.6	121.0	-505.7
10. South East	66.1	61.0	5.1	52.2	54.5	-2.3	477.2	213.0	-264.2
11. Champlain	63.4	57.6	5.8	58.7	54.6	4.1	698.2	115.5	-582.7
12. North Simcoe Muskoka	66.1	56.4	9.7	57.4	55.8	1.6	647.5	208.7	-438.8
13. North East	68.9	65.4	3.4	41.5	45.7	-4.2	1,424.7	295.3	-1,129.4
14. North West	58.2	61.4	-3.2	37.1	36.9	0.2	1,422.3	291.6	-1,130.7

*For the one-year period from April 1, 2009 to March 31, 2010.

Notes:

1. For diabetes eye examinations and psychiatric emergency follow-up, a higher value represents a better outcome. For hospitalizations for ambulatory care-sensitive conditions, a higher value represents a worse outcome, and the 'difference' is expressed as a negative value to reflect this.
2. Results for bone mineral density testing folowing low-trauma fracture are not shown due to small cell size.

EXHIBIT 5.8 Results for each indicator of chronic disease management, overall and for patients seeing a Family Health Team physician, in Ontario, 2009/10 to 2010/11

Findings

- The gap in indicator results between those with and without developmental disabilities receiving care in Family Health Teams was similar to the gap found overall.
- For patients who were treated by Family Health Teams, the proportion receiving eye examinations and fracture care was higher for both adults with and without developmental disabilities when compared to the overall rate for Ontario.

	Indicator											
	Diabetes care: Eye examinations (%)			Psychiatric emergency follow-up with psychiatrist or family physician within 30 days (%)			Fracture care* (%)			Hospitalizations for ambulatory care-sensitive conditions* (rate per 100,000 population)		
	Developmental disabilities			Developmental disabilities			Developmental disabilities			Developmental disabilities		
	With	Without	Difference	With	Without	Difference	With	Without	Difference	With	Without	Difference
Family Health Team only	70.5	63.5	7.0	56.5	55.8	0.7	21.3	22.9	-1.6	963.0	182.8	-780.2
Overall (including Family Health Team)	63.2	56.9	6.3	58.9	57.6	1.3	16.2	21.5	-5.3	803.2	147.5	-655.7

*For the one-year period from April 1, 2009 to March 31, 2010.

Note: For diabetes eye examinations, psychiatric emergency follow-up and fracture care, a higher value represents a better outcome. For hospitalizations for ambulatory care-sensitive conditions, a higher value represents a worse outcome, and the 'difference' is expressed as a negative value to reflect this.

Discussion

Diabetes care: eye examinations

Diabetic retinopathy is a common complication among persons with diabetes mellitus, and vision loss due to this disease is an independent predictor of early death.[44] Screening through a routine eye examination is important for the early detection and treatment of this complication.[16] This is especially important for people with developmental disabilities, as they have higher rates of diabetes than the general population (*see* Chapter 2).

We found that the proportion of adults with developmental disabilities and diabetes who received an eye examination between April 2009 and March 2011 was higher than that of adults without developmental disabilities and diabetes (63.2% versus 56.9%). A U.S. study of persons with developmental disabilities and diabetes found that approximately 30% of adults aged 31 to 65 years received an eye examination over a one-year period.[12] The proportion from the U.S. study is lower than what we found in our research. Although the United States uses clinical practice guidelines similar to those used in Canada,[45] because of the difference in the time periods studied (two years versus one year), it is difficult to accurately compare the U.S. results with the findings from this study. It is good news that more than half of persons with developmental disabilities received an eye examination over the study period; however, neither persons with or without developmental disabilities are meeting the Ontario Diabetes Strategy's goal of retinal eye examinations for 80% of people with diabetes "at least every year."[18]

One limitation of our study is that the administrative health data we used did not permit us to specifically identify when a retinal eye examination (as opposed to a standard eye examination) was performed. As a proxy, claims submitted to the Ontario Health Insurance Program (OHIP) were used where a dilated retinal eye examination would have likely occurred. It is, however, possible that professionals performing eye examinations missed opportunities to conduct retinal examinations if they were unaware of a patient's diabetes status.

This eye examination indicator, used on an ongoing basis, would be a useful tool to monitor and evaluate how new health policies or public health interventions affect persons with developmental disabilities and diabetes. For example, it has recently been reported that adults with diabetes in Ontario are getting fewer government-funded eye examinations than they were in the past, despite continued OHIP funding for this procedure among persons with diabetes.[46] This is believed to be an unintended consequence of delisting eye examinations from OHIP for healthy adults younger than 65 years. It is unknown if there was a similar effect among adults with developmental disabilities and diabetes who remained entitled to routine eye examinations due to their diabetes diagnosis or, for many, as a result of their coverage through the Ontario Disability Support Program. Future research could be conducted to assess how policy changes such as the aforementioned affect health service access for persons with developmental disabilities and diabetes.

Mental health management: psychiatric emergency follow-up

Research demonstrates that timely follow-up for psychiatric emergencies is critical for everyone, but particularly for those with developmental disabilities.[28] In recognition of the importance of this practice in persons with developmental disabilities, the authors of the updated Canadian Consensus Guidelines for Primary Care of Adults with Developmental Disabilities[47] strengthened the original guidelines related to crisis follow-up.[19] The updated guidelines state: "If the patient is at risk of recurrent behavioural crises, involve key stakeholders, including local emergency department staff, to develop a proactive, integrated emergency response plan."

This report's findings are the first published data on rates of follow-up care among persons with developmental disabilities who present to the emergency department with a psychiatric problem. These results indicate that rates were comparable between those with and without developmental disabilities by sex, age group and neighbourhood income. In this way, gaps in follow-up care were no worse in those with developmental disabilities than in those without. Nevertheless, the fact that 42% of adults with developmental disabilities had no

follow-up psychiatric or primary care within one month of their mental health emergency is problematic. Repeat visits are more common in those with developmental disabilities,[23] and there is evidence that primary care contact and crisis plans reduce the likelihood of mental health-related emergency visits in the developmental disabilities population.[28] Emergency departments may not recognize the importance of emphasizing the need for follow-up care, and adults with developmental disabilities may not have the skill set to initiate this on their own. More effort is required to increase the proportion of adults with developmental disabilities who receive timely follow-up and therefore achieve the recommendation from the updated Canadian Consensus Guidelines for Primary Care of Adults with Developmental Disabilities.[47]

It is positive that some persons with developmental disabilities paid visits to both primary care providers and psychiatrists. Mental health issues are more complicated when there is an underlying developmental disability, and these individuals can benefit from specialist attention. Along the same lines, having multiple health professionals involved in both regular care and crisis follow-up care is recommended for adults with developmental disabilities.[19,47] However, even among Family Health Teams with the capacity to do so, 41% of their adult patients with developmental disabilities received no physician follow-up care within the 30 days following a mental health emergency. For many mental health emergencies, debriefing and future crisis planning would benefit from the contributions of a broader mental health team involving professionals beyond primary care. Emphasis should be placed on how to facilitate the type of debriefing and planning recommended in the updated guidelines.[47]

Osteoporosis monitoring: fracture care

Low-trauma fractures can negatively impact quality of life and contribute significant financial costs to the health care system.[34,35] Bone mineral density should be tested to screen those at high risk, to make the initial diagnosis of osteoporosis after a low-trauma fracture and to monitor response to therapy.[29,32] Early diagnosis and treatment may be particularly relevant for those with developmental disabilities given the higher rates of fractures within this population.[31,48,49] We discovered that persons with developmental disabilities (compared to those without) experienced low-trauma fractures at a much higher rate. We also found that the proportion of individuals with developmental disabilities who received a bone mineral density test following a low-trauma fracture was lower than among those without developmental disabilities. Thus, adults with developmental disabilities are in double jeopardy as they are both more likely to have fractures and more likely to have poor follow-up. This highlights the importance of ensuring that adults with developmental disabilities receive adequate osteoporosis-related care.

Currently in Ontario, some falls prevention programs restrict participation to include only those older than 65 years.[50] This works as a barrier to persons with developmental disabilities who, according to our results, need access to these services at a younger age.

Although recent guidelines addressing the primary care of adults with developmental disabilities stress the importance of screening and the use of calcium and vitamin D supplementation,[47] there are no recommendations specifically addressing the monitoring of bone mineral density. Our results suggest the need to add the *management* of osteoporosis-related injuries to the current focus on screening for this disease.

It may also be beneficial to include adults with developmental disabilities as a group for special consideration under the clinical practice guidelines for osteoporosis. While the updated guidelines highlight the need to monitor individuals who are taking certain classes of medications over extended periods of time (e.g., steroid hormones),[32] there is no mention of groups who are vulnerable due to developmental disabilities or of the additional risk factors that may come with having a developmental disability (e.g., long-term use of anticonvulsants, limited mobility). The consideration of osteoporosis management in the Canadian Consensus Guidelines for Primary Care of Adults with Developmental Disabilities and the inclusion of those with developmental disabilities as a group needing special consideration in the osteoporosis guidelines may improve the level of fracture care for this group.

Preventable hospitalizations: hospitalizations for ambulatory care–sensitive conditions

Hospitalizations for ambulatory care–sensitive (ACS) conditions are recognized as an indirect measure of access to and quality of primary care.[38] Our findings show large discrepancies in hospitalizations for ACS conditions between Ontarians with and without developmental disabilities. Among Ontarians aged 25 to 34 years, the rate of preventable hospitalizations for adults with developmental disabilities was almost 10 times higher than the rate for adults without developmental disabilities. Similar large discrepancies between these two groups have been reported in other research. In Manitoba, rates of hospitalization for ACS conditions were consistently higher among persons with developmental disabilities.[39] The largest discrepancy was in adults aged 30 to 39 years where the rate of preventable hospitalization was 13 times higher among persons with developmental disabilities.

A limitation of our study is that we did not control for variables that could explain the large discrepancy in rates of hospitalization for ACS conditions between adults with and without developmental disabilities. However, researchers from other jurisdictions who controlled for variables such as rural or urban living and chronic disease prevalence found that these had only a small effect for both the general population[41] and for persons with developmental disabilities.[39]

The multiple physical and mental health conditions included in lists of ACS conditions deem the preventable hospitalizations indicator particularly useful; it provides a broad perspective on how well the primary care system is functioning and can be used to identify an overreliance on hospitalization for certain populations or regions.[41] Decreasing the number of unnecessary hospitalizations is a priority of the provincial government.[43] A Health Quality Ontario report provides suggestions to improve chronic disease management for the general population in Ontario in an effort to decrease preventable hospitalizations.[43] Our findings suggest that more can be done to decrease reliance on hospital admissions for the management of chronic conditions among persons with developmental disabilities.

Implications for policy and practice

The life expectancy of persons with developmental disabilities has been increasing[51,52] and like the rest of the population, they are experiencing more age-related health conditions.[53,54] As seen in Chapter 2, the prevalence of chronic conditions is higher among Ontarians with developmental disabilities than in those without developmental disabilities. In this chapter, we reported on indicators related to diabetes care, mental health management, osteoporosis monitoring and preventable hospitalizations. We now examine potential policy and practice options that may help improve the health outcomes of adults with developmental disabilities who require chronic disease management.

Ontario's Framework for Preventing and Managing Chronic Disease describes practical strategies that can be applied to persons with developmental disabilities who are experiencing a chronic disease.[1] It states that successful chronic disease management requires regular and ongoing contact that often needs to be initiated by the health care provider. Patient and physician reminders and the use of outreach workers have been shown to be effective mechanisms.[1] Periodic, planned visits between patients and health care providers that focus specifically on the chronic condition have been shown to improve health outcomes by slowing disease progression and preventing complications.[1] The Framework also discusses how disease management should involve multifaceted interventions providing integrated social and medical support.[1,55] This is especially true among persons with developmental disabilities since they have problems communicating their symptoms and rely heavily on their families and social support services to help them navigate the health care system.

In keeping with the Framework, the government of Ontario has recently encouraged the creation of Community Health Links (CHLs) to improve coordination of care for patients with high-needs such as seniors and persons with complex conditions.[56] The program will "encourage greater collaboration and co-ordination between a patient's different health care providers as well as the development of personalized care plans."[56] A CHL could include professionals and agencies such as "family doctors, specialists, hospitals, home care, long-term care and community support agencies."[56]

Alex, Lou's father (not pictured): *"Lou's serious eye problems, which are typical of individuals with Down syndrome, also affected his mobility, and it took too long to have this corrected with a double cornea transplant. Busy doctors are often reluctant to take the time needed to deal properly with people with mental challenges who have poor communication skills.*

The quality of care in our residential agencies has improved dramatically since the institutions have closed, and the employees are competent and caring. However, they are encountering high turnover and inevitably lack of timely training. This has a negative impact and is particularly critical in dealing with health issues."

The actions proposed by the CHL initiative are consistent, potentially useful strategies to improve the health services provided for Ontarians with developmental disabilities. For example, a CHL will facilitate the creation of an individualized coordinated plan which health care providers will help to ensure is being followed. As we have reported in this chapter, the development and regular review of a plan is a guideline-supported priority for Ontarians with developmental disabilities and mental health issues.[19,47] We recommend that such individualized plans be applied to all persons with developmental disabilities living with a chronic disease regardless of whether their illness is mental or physical in nature.

Chronic disease management guidelines developed for the general population should more clearly identify persons with developmental disabilities as a vulnerable population at high risk for developing conditions such as mental illness and diabetes (among others). This may increase awareness among health care professionals of the chronic health problems that affect persons with developmental disabilities. In addition, health care guidelines that address the needs of persons with developmental disabilities should place more emphasis on the management of chronic diseases in addition to prevention, screening and diagnosis.

Lack of training in developmental disabilities among health and social services providers has been previously reported as a deficiency that contributes to poor care and merits attention.[57] More specifically, there is a need for more formalized training in both the health and social services sectors in order to address chronic disease management in persons with developmental disabilities. Chapter 7 reviews some Ontario Government initiatives addressing this issue. Ideally, training of health professionals would stress the role of the family and social services providers in the management of ongoing health issues in adults with developmental disabilities and would include direct contact with persons with developmental disabilities in a health care context.[58] Training for social services providers should cover topics such as the major chronic diseases faced by persons with developmental disabilities; methods to help persons with developmental disabilities interact with health professionals; and ways to advocate for access to comprehensive health services.

The overall goal of our proposed actions would be to avoid the complications of disease, avoid preventable emergency department visits and hospitalizations, and thus improve the quality of life of persons with developmental disabilities.

Data needs

There are important measures of chronic disease status and its management that could not be reported on because the information is not available in administrative health databases.

For example, the retinal eye examination is only one of three key tests that the Ontario Diabetes Strategy considers most important to monitor for the management of diabetes. HbA1C (a blood test measuring sugar levels) and LDL-C (a blood test measuring "bad" cholesterol concentrations) are the other recommended tests that could not be reported on in our work. For a more thorough understanding of how well diabetes and other chronic conditions are being managed, data from hospital and community-based laboratories need to be collected, including descriptions of which tests were performed and the results.[59]

One potentially useful source of this type of information is the electronic medical record (EMR). Currently at ICES, data from EMRs are available for more than 300,000 patients, providing information for primary care indicators related to diabetes and ischemic heart disease.[60] (This data is held in accordance with ICES policies and procedures for maintaining patient privacy and confidentiality and in compliance with provincial legislation governing the use of health information.) It would be useful to review data from the EMRs of persons with developmental disabilities.

Future research

Our findings will generate research questions that deal with the four indicators described in this chapter and with broader issues.

As described earlier, Canadian-based information on the key blood tests used to monitor diabetes would be useful in planning better health services for persons with developmental disabilities.

Researchers should consider exploring follow-up care in persons with developmental disabilities whose emergency visits result in psychiatric hospitalization. Is their follow-up care better than what is provided to those who are not admitted?

The large disparities in rates of preventable hospitalizations between persons with and without developmental disabilities warrant research to develop interventions that have an impact on admissions. For example, developing effective interventions that address the high rate of fractures related to osteoporosis could lead to decreased need for hospitalizations in this population.

Our indicators were assessed for one model of primary care, the Family Health Team. Future studies should also include the additional models of primary care discussed in Chapter 3.

This chapter included crude results for indicators related to chronic diseases. Future researchers should investigate these indicators in more detail and include analyses to control for possible confounders. More research is also needed with regard to the social determinants of health and how they influence health outcomes in this population.[61] Indicators that measure health issues that are specifically important to persons with developmental disabilities should be developed. Community health centres, which care for disadvantaged populations, may provide a model of primary care that is well suited to persons with developmental disabilities living with chronic disease; however, the influence of community health centres on health outcomes for persons with developmental disabilities has not been studied.

Conclusion

These results demonstrate that it is feasible to adopt health indicators used for the general population to measure aspects of chronic disease management in persons with developmental disabilities. Ongoing monitoring of these indicators would be useful in identifying problems or improvements in the provision of care for this population.

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6 Medication Use

Inside

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MAIN MESSAGES

- Persons with developmental disabilities are at higher risk for physical and mental health problems and are frequently dispensed multiple medications to treat health conditions. Underlying abnormalities of the central nervous system or comorbidities, such as epilepsy or metabolic disorders, may cause them to react differently to medications than the general population. Without appropriate medication dispensing practices and ongoing monitoring, their health can be jeopardized.

- We explored medication use among adults with developmental disabilities in Ontario, with particular attention to those being dispensed multiple medications. The impact of age, sex, neighborhood income, urban or rural residence, and regional differences is presented.

- Nearly one in two adults with developmental disabilities were dispensed multiple medications at one time, with one in five receiving five or more medications concurrently. Older persons with developmental disabilities, women and those with high levels of morbidity were more likely to be dispensed multiple medications. Regular follow-up visits with the same family physician did not take place for 32% of persons dispensed five or more medications at once.

- The most commonly prescribed medications were for mental health or behavioural issues, with antipsychotic medications being prescribed most frequently. Approximately one in five adults prescribed antipsychotics were dispensed two antipsychotics concurrently, putting them at risk for adverse reactions, including death.

- Multisectoral and team-based initiatives are needed to improve the quality and coordination of the complex supports used by adults with developmental disabilities. Education for these adults and their caregivers on the appropriate use of medications and on side-effect monitoring is important. Regular follow-up with the same physician for medication monitoring and the adoption of clinical guidelines on medication use in persons with developmental disabilities are recommended.

Introduction

Persons with developmental disabilities are at higher risk of physical and mental health problems compared to those without developmental disabilities. For example, and as highlighted in Chapter 2, 10.4% of Ontarians with developmental disabilities have diabetes compared to 6.5% of those without, and 17.5% of adults with developmental disabilities have asthma compared to 12.2% of those without. Almost half of Ontarians with developmental disabilities have a comorbid psychiatric diagnosis. Ontarians with developmental disabilities also tend to have higher levels of morbidity (i.e., poorer health) than those without developmental disabilities.

The use of medication may be required to treat physical or mental health conditions or to alleviate their symptoms. In the context of chronic physical and mental health comorbidities, the use of multiple medications may be clinically advised.[1] However, the concurrent use of multiple medications may be harmful or dangerous because of medication nonadherence, adverse reactions and medication interactions.[1-6]

The use of multiple medications may also put individuals at greater risk of hospitalization[7] and mortality.[8]

Furthermore, persons with developmental disabilities might react differently to medications than the general population because of underlying abnormalities of the central nervous system or

comorbidities, such as epilepsy or metabolic disorders.[9,10] Some persons with developmental disabilities may also have difficulty reporting side effects of or discomfort resulting from medications.[11-13]

Certain medication combinations are particularly dangerous and should be avoided. However, previous research has demonstrated that they may be prescribed among persons with developmental disabilities.[14-19] For example, the use of multiple psychotropic drugs, particularly multiple anti-psychotics, may increase the risk of cardiac problems and death.[20]

For these reasons, medication use in persons with developmental disabilities, although sometimes indicated, should be carefully monitored.

In this chapter, we explore medication use among adults with developmental disabilities living in Ontario, and pay particular attention to those being dispensed multiple medications. We also report on the proportion of persons with developmental disabilities dispensed multiple antipsychotics. And, among those using multiple medications, we examine the proportion receiving regular follow-up with the same family physician.

MEDICATION In this chapter, medication refers to all drug products covered by the Ontario Drug Benefit Program. Over-the-counter medications, supplements and vitamins are not included.

DISPENSED MEDICATION This chapter examines medications dispensed, rather than prescribed or administered. This means that we do not know when medications were prescribed but not filled or whether medications were actually taken by the individual.

MEDICATIONS DISPENSED CONCURRENTLY Medications were included in the count when they were dispensed for a treatment period that included October 1, 2009. The prescriptions were not necessarily filled on that date.

PSYCHOTROPIC MEDICATIONS have an effect on the central nervous system and are prescribed for the treatment of emotional or behavioural problems (e.g., depression, anxiety), or seizures.[21]

ANTIPSYCHOTIC MEDICATIONS are psychotropic medications used to treat symptoms of psychosis (e.g., schizophrenia), but are sometimes prescribed for emotional or behavioural problems.

ANTICONVULSANTS are psychotropic medications used to treat seizures, or emotional or behavioural problems (e.g., mood disorder).

MEDICATION CLASS groups all drug products that have a similar chemical structure and are used to treat similar problems. For example, antibiotics are a medication class used to treat infections caused by a bacterium.

INTRACLASS POLYPHARMACY is the concurrent use of multiple drug products from the same class (for example, the use of two antibiotics).

INTERCLASS POLYPHARMACY is the concurrent use of multiple drug products from different classes (for example, the use of an antibiotic plus an analgesic).

Background

Medication use

Previous research from the United States, the United Kingdom, Australia and Canada has suggested that many persons with developmental disabilities use multiple medications, with proportions ranging from 11% to 60% depending on the characteristics of the study sample.[5,14-19,22-26]

CONSENSUS GUIDELINES FOR PRIMARY HEALTH CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES

Multiple medications prescribed because of comorbid conditions can result in risk of harm that can be alleviated through vigilance.[27]

In effect during the period of study; updated in 2011.

In this chapter, we examine medications dispensed to a subset of 52,404 adults with developmental disabilities who were identified as eligible to have medications paid for under the Ontario Drug Benefit Program because they received income support from the Ontario Disability Support Program.

Comparisons with adults without developmental disabilities could not be made as only some of them were eligible for the Ontario Drug Benefit Program.

We describe medication use on a given date (chosen as October 1, 2009), and the medication classes most commonly dispensed to adults with developmental disabilities. We then examine factors associated with multiple concurrent medications by dividing our sample into three groups: (1) those dispensed no medications concurrently (none or one medication); (2) those dispensed two to four medications concurrently; and (3) those dispensed five or more medications concurrently.

Use of multiple antipsychotics

Concurrent use of multiple medications, especially from the same class, increases the risk of adverse reactions. The use of multiple antipsychotics is indicated only under exceptional circumstances because of the high risk of cardiac problems and death.[20] Therefore, the use of multiple antipsychotic medications concurrently should be avoided.[20,28,29]

INTERNATIONAL CONSENSUS HANDBOOK: PSYCHOTROPIC MEDICATIONS AND DEVELOPMENTAL DISABILITIES

Keep psychotropic medication regimens as simple as possible. Intraclass polypharmacy (the use of two psychotropic medications from the same class) is rarely justified, and interclass polypharmacy (the use of two or more psychotropic medications from different classes at the same time) should be minimized.[28]

When a prescribed psychotropic drug has failed to alleviate symptoms, it is generally withdrawn gradually while another drug product is introduced. For this reason, use of multiple antipsychotics on a given day might be justified. However, this usage should not persist over time.

To correct for potential overestimates, we describe multiple antipsychotic use in adults with developmental disabilities as follows:

- the proportion who were dispensed two or more antipsychotics concurrently;
- the proportion who were dispensed two or more antipsychotics continuously for a three-month period and a six-month period.

Francine: *"My brother had been on numerous medications for almost 10 years. He became very quiet, slowed down and sluggish. He also gained a lot of weight and didn't have the energy he used to have. Over those 10 years, we began to feel that this was just who he was and forgot about his old energetic self who was always on the go. However, he began to get upset with this sluggish self and slowly became more aggressive and began lashing out, always telling us he didn't feel well or wasn't happy. It was a long and painful process, but we eventually realized that he was likely overmedicated. Once this issue was cleared up, we saw a re-emergence of his old self. With the right balance of medication, he could be happy and energetic and also have his psychiatric issues under control."*

Follow-up with the same physician

When an individual is prescribed multiple medications, regular follow-up with the same physician is recommended.

CONSENSUS GUIDELINES FOR PRIMARY HEALTH CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES
The same health care provider should review all medications, ideally every three months.[27]

In effect during the period of study; updated in 2011.

We define our indicator as the proportion of adults with developmental disabilities dispensed multiple concurrent medications who received regular follow-up with the same family physician.

Beth's 21-year-old daughter has been on a number of psychotropic medications from a very young age. Since she started taking medication, Beth's daughter has received care from multiple service providers.

When asked about her experience with prescribing health care providers, Beth had this to say: *"We didn't have somebody following us regularly. It was just a consultation here and there. It was very much left to the parent to decide when to increase dosages and when to reduce them and when to cut out a medication, and I don't have the training or the experience and there was no back-up help for that."*

List of Exhibits

EXHIBIT 6.1 Proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program, by number of medications dispensed concurrently, in Ontario, October 1, 2009

Findings

- Of adults with developmental disabilities receiving income support from the Ontario Disability Support Program, 60.5% (n=31,722) were dispensed medications covered by the Ontario Drug Benefit Program (range: one to 41 medications; mean: 4.1; median: 3.0) on October 1, 2009.
- Among adults with developmental disabilities, 52.5% (n=27,475) were not dispensed any concurrent medications, 26.0% (13,647) were dispensed two to four medications concurrently, and 21.5% (11,282) were dispensed five or more medications concurrently.

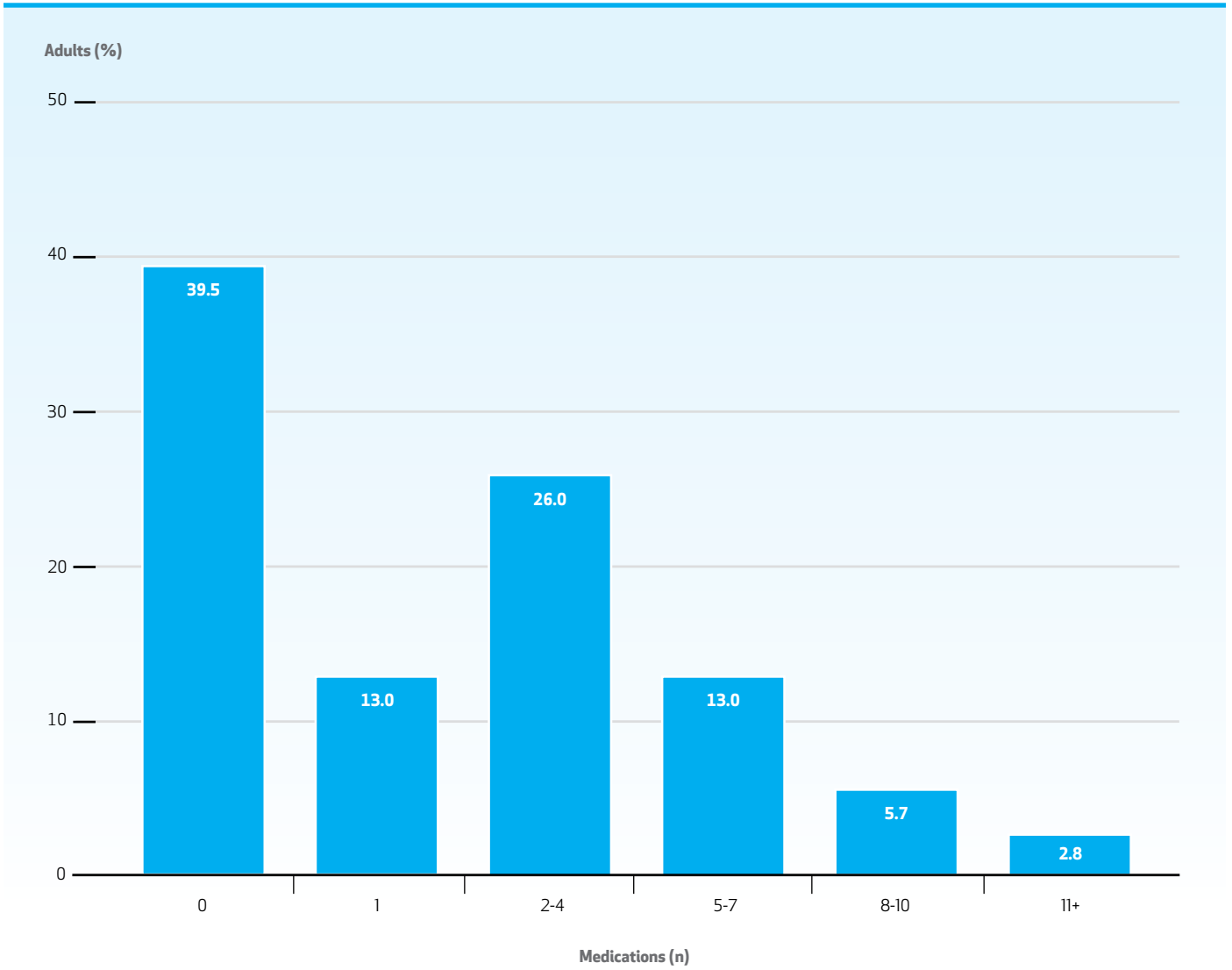
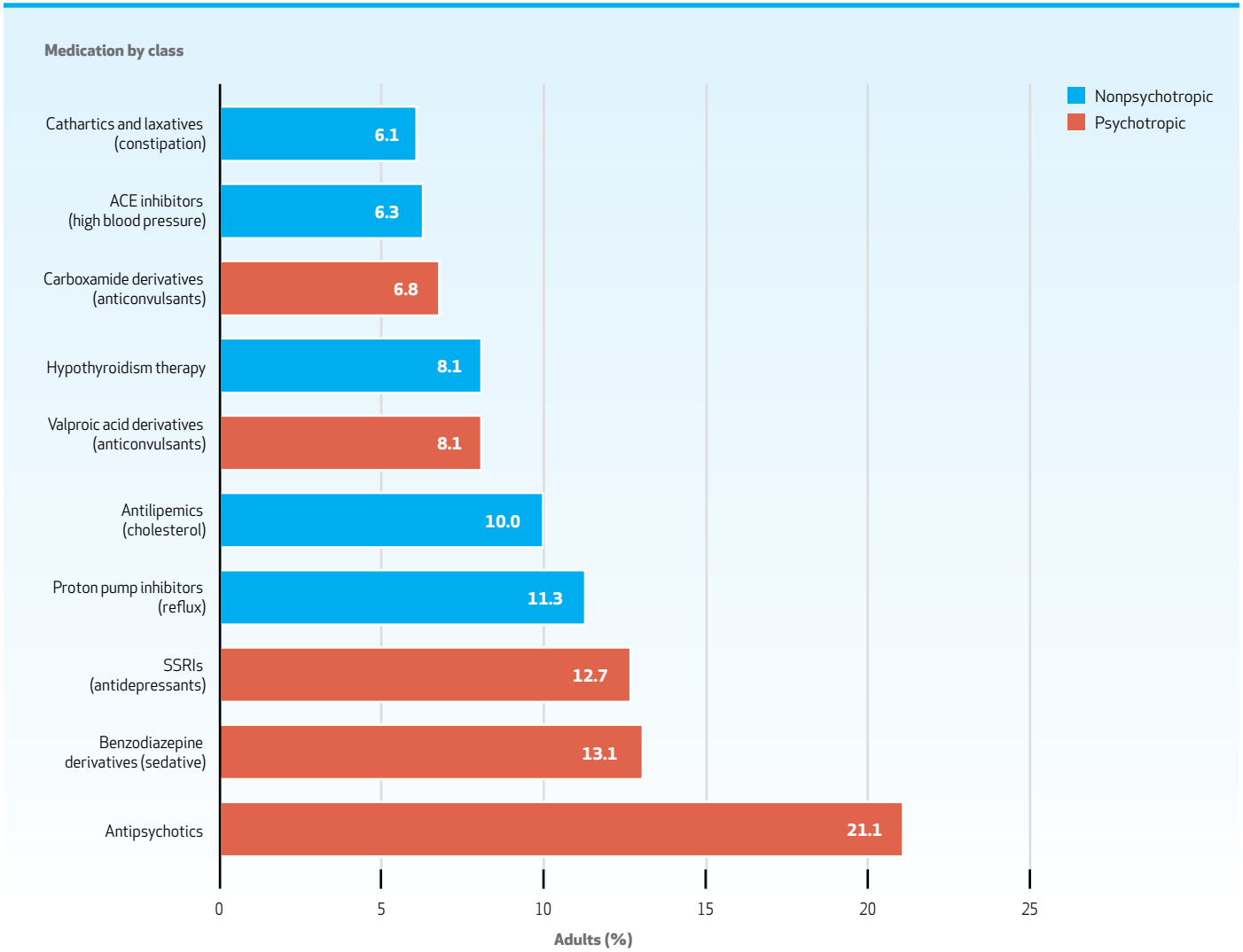


EXHIBIT 6.2 Proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program, by the 10 most commonly dispensed medication classes, in Ontario, October 1, 2009

Findings

- Antipsychotics were the most commonly dispensed class of medication (dispensed to 21.1% of adults with developmental disabilities). The antipsychotics risperidone, olanzapine and quetiapine fumarate were among the five most frequently dispensed drug products (data not shown).
- Five of the 10 most frequently dispensed medication classes were psychotropic medications (i.e., antipsychotics, sedatives, antidepressants and anticonvulsants).
- The remaining five most commonly dispensed medication classes are indicated for the treatment of gastric acid reflux, cholesterol, hypothyroidism, high blood pressure and constipation.



Note: The categories displayed are not mutually exclusive. Some individuals were dispensed medications from multiple classes.

EXHIBIT 6.3 Proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program, by number of medications dispensed overall and by age group, in Ontario, October 1, 2009

Findings

- The number of medications dispensed concurrently to adults with developmental disabilities increased with age.
- Among adults with developmental disabilities who were dispensed five or more medications, the proportion aged 55 to 64 years was seven times higher than the proportion aged 18 to 24 years.
- Among persons with developmental disabilities who were dispensed multiple medications (data not shown):
  - The proportion of women was higher than the proportion of men (52.3% vs. 44.0%).
  - No gradient was observed by neighborhood income quintile; 47.7% lived in the lowest income neighborhoods and 47.9% in the wealthiest neighborhoods.
  - Rurality had no impact; 47.7% lived in rural areas and 47.5% in urban areas.

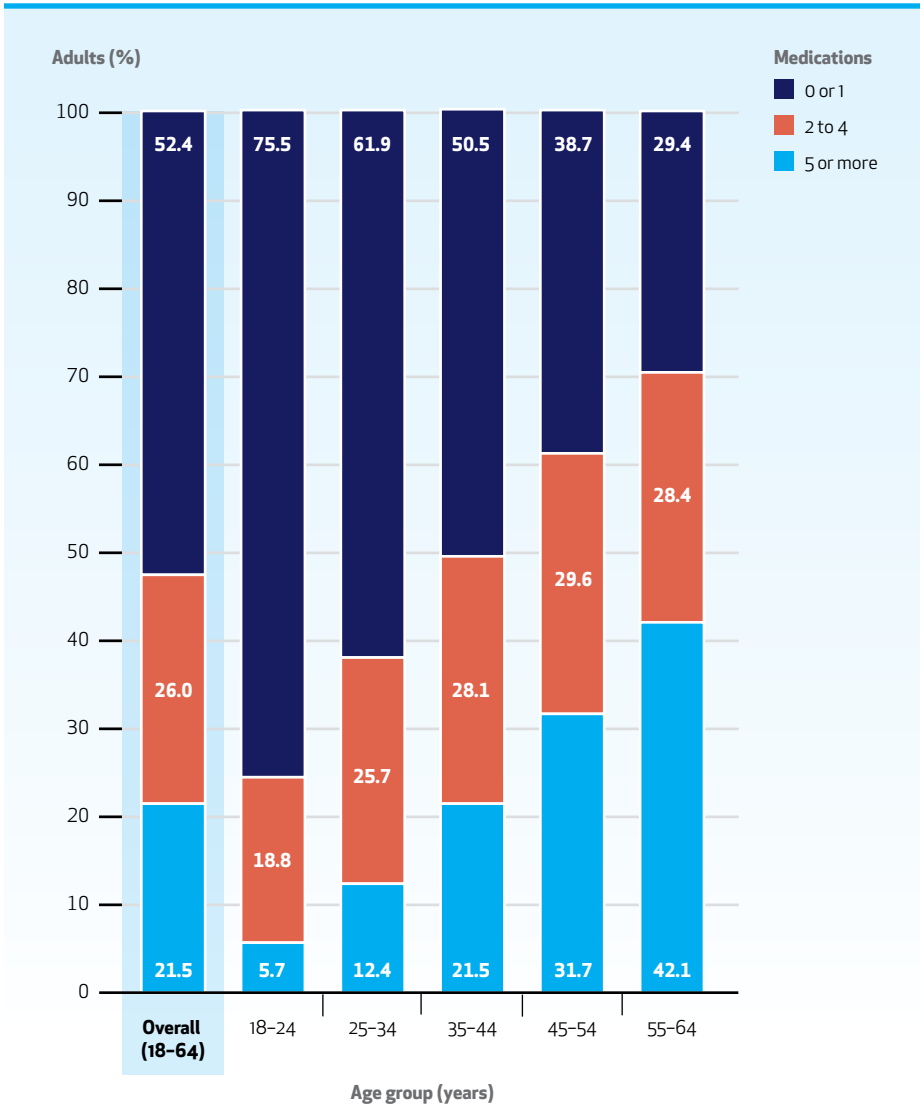
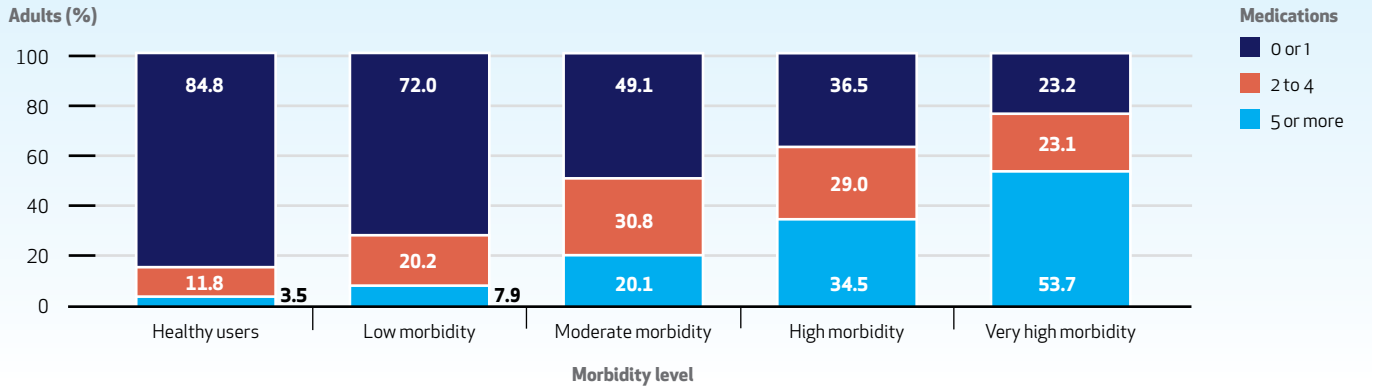


EXHIBIT 6.4 Proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program, by number of medications dispensed and morbidity level, in Ontario, October 1, 2009

Finding

- The proportion of adults with developmental disabilities who were dispensed multiple medications was higher among those with very high morbidity levels (76.8%) compared to those with low morbidity levels (28.1%).



Note: Medication use for people with missing comorbidity values is not shown.

EXHIBIT 6.5 Proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program, by number of medications dispensed and presence of a comorbid psychiatric diagnosis, in Ontario, October 1, 2009

Finding

- Adults with developmental disabilities and a comorbid psychiatric diagnosis were dispensed multiple medications in greater proportion than those with no psychiatric diagnosis (59.2% versus 35.6%).

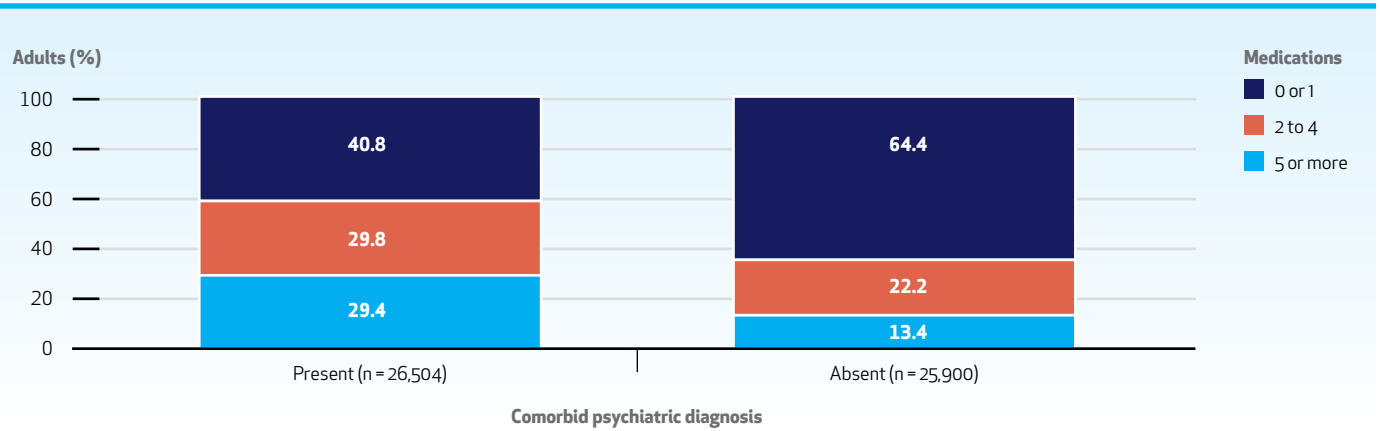
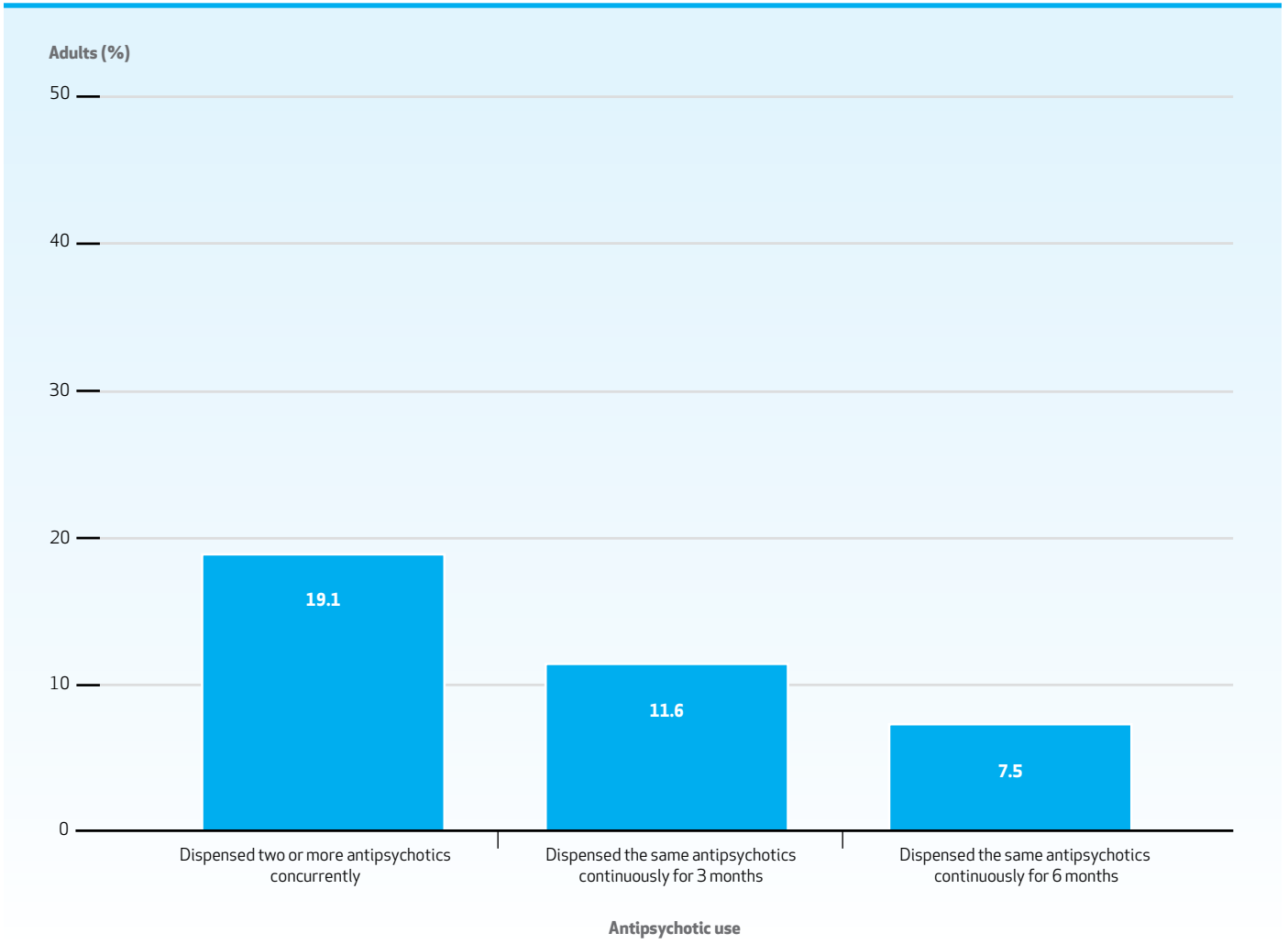


EXHIBIT 6.6 Proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program and were dispensed antipsychotics, by concurrent and continuous use of two or more antipsychotics for three or six months, in Ontario, from October 1, 2009

Findings

- As shown in Exhibit 6.2, antipsychotics were dispensed to 21.1% of adults with developmental disabilities.
- Among adults aged 18 to 64 years with developmental disabilities who were dispensed antipsychotics, 19.1% were dispensed two or more antipsychotics concurrently.
- Among adults aged 18 to 64 years with developmental disabilities who were dispensed antipsychotics, 11.6% were dispensed two or more antipsychotics continuously for three months; and 7.5% were dispensed two or more antipsychotics continuously for six months.

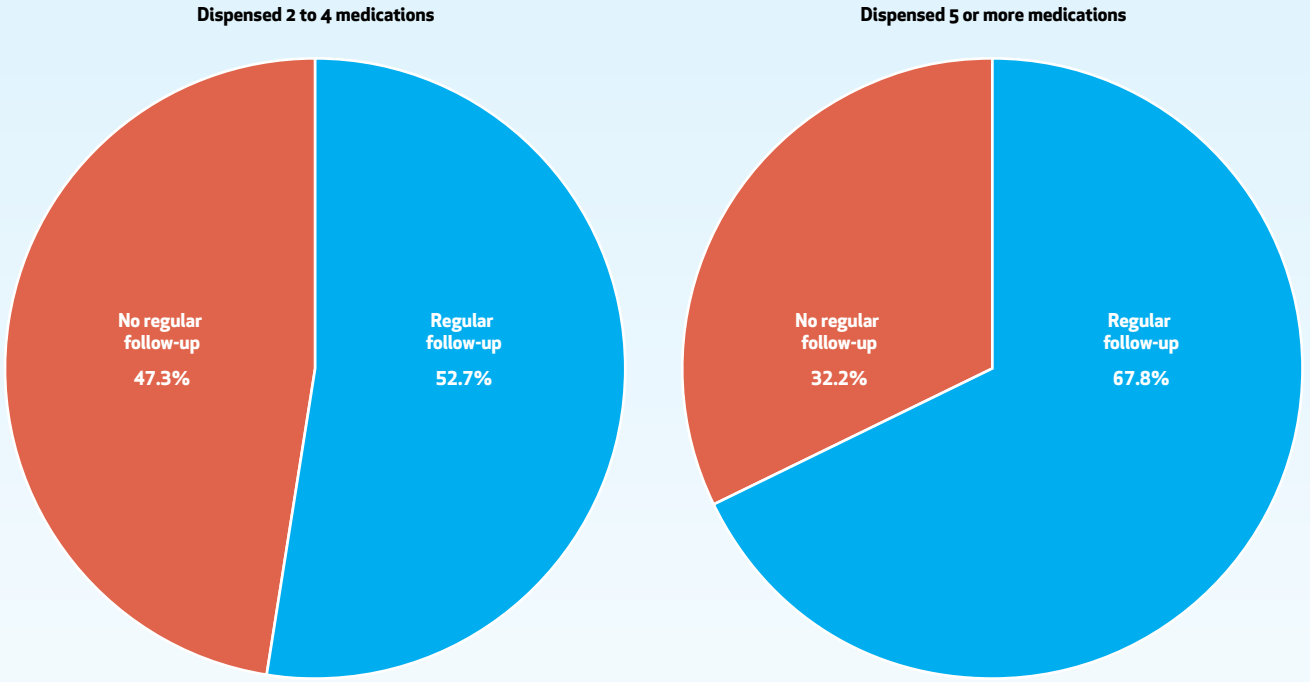


Note: Displayed categories are not mutually exclusive. People dispensed multiple antipsychotics continuously for a six-month period were also part of the group dispensed multiple antipsychotics for a three-month period. Both groups are included in the first bar representing those dispensed multiple antipsychotics on October 1, 2009.

EXHIBIT 6.7 Proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program and were dispensed multiple medications concurrently, by regularity of follow-up with the same family physician, in Ontario, October 1, 2009

Findings

- Among adults with developmental disabilities, 52.7% who were dispensed two to four medications and 67.8% who were dispensed five or more medications visited the same family physician for regular follow-up.
- Among adults with developmental disabilities dispensed five or more medications, 32.2% did not have regular follow-up visits with the same family physician.



Note: Regular follow-up is defined as three or more visits in the year following October 1, 2009

EXHIBIT 6.8 Number and proportion of adults aged 18 to 64 years with developmental disabilities who were eligible for the Ontario Drug Benefit Program, by number of medications dispensed, by Local Health Integration Network and in Ontario, October 1, 2009

Findings

- There was some variation across the Local Health Integration Networks (LHINs) in the proportions of adults with developmental disabilities categorized by the number of dispensed medications.
- The proportion of adults with developmental disabilities who were dispensed none or one medication ranged from 48.8% in the Hamilton Niagara Haldimand Brant LHIN to 60.3% in the North West LHIN.
- The proportion of adults with developmental disabilities who were dispensed five or more medications concurrently ranged from 16.4% in the Central West LHIN to 24.9% in the Hamilton Niagara Haldimand Brant LHIN.

	Adults (n)	Adults by number of medications dispensed (%)		
		0 or 1	2 to 4	5 or more
Ontario	52,404	52.4	26.0	21.5
Local Health Integration Network				
1. Erie St. Clair	3,481	50.7	25.1	24.2
2. South West	5,213	51.6	26.7	21.7
3. Waterloo Wellington	2,496	53.0	27.4	19.6
4. Hamilton Niagara Haldimand Brant	6,954	48.8	26.3	24.9
5. Central West	1,690	58.8	24.7	16.4
6. Mississauga Halton	2,115	56.4	26.8	16.8
7. Toronto Central	3,245	53.0	27.2	19.7
8. Central	3,736	52.6	26.9	20.4
9. Central East	5,180	54.6	25.6	19.8
10. South East	3,903	50.3	26.3	23.4
11. Champlain	5,694	50.2	26.3	23.5
12. North Simcoe Muskoka	2,293	50.3	28.0	21.7
13. North East	4,544	53.3	24.8	21.9
14. North West	1,574	60.3	22.4	17.3

Note: 553 persons could not be assigned to a specific LHIN.

Discussion

We examined claims to the Ontario Drug Benefits Program for adults with developmental disabilities aged 18 to 64 years who were receiving income support from the Ontario Disability Support Program (N=52,404).

Medication use

In total, 60.5% of adults with developmental disabilities receiving disability support were dispensed medications, and 21.5% were dispensed five or more with a treatment period overlapping October 1, 2009. Of particular concern are the 1,452 individuals (almost 3%) who were dispensed 11 or more medications on October 1, 2009. Some individuals were dispensed up to 41 medications on that day. Older persons with developmental disabilities, women and those with high levels of morbidity were more likely to be dispensed multiple medications.

Clinical variables (i.e., comorbid diagnosis of a mental health problem, comorbidities associated with aging) could justify concurrent use of medications in some individuals. However, it is not clear why women with developmental disabilities would be prescribed multiple medications in greater proportion than men. This pattern has not been previously reported in research in developmental disabilities; however, these studies have relied mostly on clinical samples. Our finding does mirror what has been reported in the general population.[30,31]

The proportion of adults with developmental disabilities dispensed multiple medications is greater in older age groups. Because the population with developmental disabilities is aging and their life expectancy improving,[32] the proportion of individuals using multiple medications is anticipated to increase.

Use of psychotropic medications

The most commonly dispensed medications among adults with developmental disabilities were psychotropic medications, that is, medications used to treat emotional and behavioural problems (e.g., anxiety, depression or schizophrenia) or seizures. More than 20% of the adults studied were dispensed antipsychotics, and of these, 11.6% (n=1,282) were dispensed two or more antipsychotics continuously for at least three months. These rates are lower than those found in a Florida study using a comparable method.[19] Nonetheless, the fact that more than 1,200 individuals receiving Ontario Disability Support Program benefits were dispensed two antipsychotics concurrently—a potentially dangerous and ineffective treatment—from October 1, 2009 to December 31, 2009 must not be ignored.

Other harmful medication combinations that have been reported as being prescribed to individuals with developmental disabilities in Florida include the use of two or more anticonvulsants (18.7% of persons with a developmental disability) and the use of valproic acid derivatives (an anticonvulsant) with another psychotropic medication (20.2%).[19] The proportion of adults with developmental disabilities in Ontario who were dispensed harmful medication combinations other than the use of concurrent antipsychotics is not reported in this Atlas and would require further study.

In 2011, Sullivan et al. proposed additional guidelines for the prescription of psychotropic medications in adults with developmental disabilities (*not in effect at the date of data collection; see* next page).[29] They emphasized that nonpharmacological treatments should be considered first to manage

Andrew, a patient: *"When the doctor writes a prescription, it would be better to have it in terms that people with disabilities can understand, because we can't always expect our parents to be there to help."*

problem behaviours. When psychotropic medications are prescribed, their use should be monitored and reduced or stopped in the absence of a diagnosed psychiatric problem. Furthermore, antipsychotics should not be used as a routine treatment.

UPDATED CANADIAN CONSENSUS GUIDELINES FOR THE PRIMARY CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES

- Antipsychotic medications should no longer be regarded as an acceptable routine treatment of problem behaviours in adults with developmental disabilities.
- Regularly audit the use of prescribed psychotropic medication, including those used as needed. Plan for a functional analysis (typically performed by a behavioural therapist or psychologist) and interdisciplinary understanding of problem behaviours.
- Review with care providers psychological, behavioural and other nonmedication interventions to manage problem behaviours.
- Consider reducing and stopping, at least on a trial basis, medications not prescribed for a specific psychiatric diagnosis.[29]

In effect since 2011.

Regular follow-up with a family physician

Regular follow-up with the same health care provider is recommended when multiple medications are prescribed.[27,29] However, in this analysis, almost one-third of those dispensed five or more medications did not have regular follow-up with the same family physician.

The updated Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities provide more detailed recommendations to physicians when a patient with a developmental disability is prescribed multiple medications.[29] Guidelines include the review of indication, effectiveness and side effects of medications every three months. The guidelines also recommend that patients with developmental disabilities and their caregivers understand how to appropriately use medications.

UPDATED CANADIAN CONSENSUS GUIDELINES FOR THE PRIMARY CARE OF ADULTS WITH DEVELOPMENTAL DISABILITIES

- Multiple or long-term use of some medications by adults with developmental disabilities can cause harm that is preventable.
- Review the date of initiation, indication, dosages and effectiveness of all medications regularly (e.g., three months).
- Determine patient adherence capacity and recommend dosettes, blister-packs and other aids, if necessary.
- Watch for both typical and atypical signs of adverse effects. Regularly monitor potentially toxic medications or interactions of medications (e.g., liver function tests or serum medication levels) at the recommended interval for each medication.
- Ensure that patient and staff or caregivers are educated about appropriate use of medications, including over-the-counter, alternative and as-needed medications.[29]

In effect since 2011.

Implications for policy and practice

Findings suggest that a large proportion of adults with developmental disabilities use multiple medications, and some are dispensed potentially dangerous combinations of medications that can contribute to higher morbidity and even premature death. Therefore, adoption of clinical guidelines on medication use in persons with developmental disabilities must be strongly encouraged. These include the regular review of prescribed medications. Nonpharmacological interventions, specifically behavioural and psychological supports, are also beneficial for managing behaviour and mental health problems. Data examined in this chapter do not allow us to comment on access to nonpharmacological interventions. However, previous research has demonstrated that access to specialized mental health services is limited for persons with developmental disabilities.[33]

Efforts should also be made to educate adults with developmental disabilities on appropriate use of medications, as well as on the monitoring of side effects. As persons with developmental disabilities may have limitations impeding communication with health care providers, caregivers play a significant role when observing and reporting symptoms and effects of medications, or understanding the prescription. However, as many adults with developmental disabilities live by themselves and do not have 24-hour support, it is important that these individuals be supported with regards to adherence to treatment without limiting their independence. Support can be provided by health care providers through recommending the use of dosettes or blister-packs, and prescriptions can be explained in a way that adults with developmental disabilities can understand.

Collaboration between patients with developmental disabilities, their caregivers, health care providers and developmental disability services is advisable. The Community Networks of Specialized Care appear to be a major player in this regard as they aim to bring together professionals across sectors involved in the care of individuals with developmental disabilities and behaviour problems. The Community Health Links are another multisectoral and team-based initiative that could help improve the quality and coordination of the complex supports needed by adults with developmental disabilities.

Medication reconciliation should be part of a coordinated plan. It is a formal process facilitating the communication between health care providers, patients and caregivers to ensure that all information on current medications and medication history is recorded. It allows for a systematic and comprehensive review of all medications used by an individual, and informs health care providers of the most appropriate prescribing decisions for the patient.

A team-based approach and medication reconciliation are critical for individuals who are dispensed potentially harmful medication combinations.

Data needs

This is the first attempt to study medication use in the Ontario population with developmental disabilities. Linking data from the Ontario Disability Support Program with administrative health data held at ICES offers a unique opportunity to study medication use in adults with developmental disabilities up to the age of 64. However, information is not available for medications dispensed to individuals not covered by the Ontario Drug Benefit Program (approximately 14,000 individuals from our original cohort) nor is it available for those younger than 18 years. Individuals aged 65 years and older with and without developmental disabilities have medication coverage through the Ontario Drug Benefit Program; therefore, comparisons are possible between the two populations in this age group.

These findings are population-based and extend beyond psychotropic drugs, whereas most of the published studies on medication use in adults with developmental disabilities use clinical samples and only count psychotropic medications. This makes comparisons difficult.

Administrative data do not provide information on the reasons for prescribing a specific medication. It is therefore impossible to comment on the appropriateness and clinical indication of the prescriptions. For example, we do not know whether psychotropic medications are prescribed for a diagnosed psychiatric disorder, or for unspecified challenging behaviours. It is also important to note

Colleen is the parent of a 21-year-old woman with a diagnosis of autism spectrum disorder and obsessive compulsive disorder. In the past, her daughter has struggled with behaviour issues, particularly aggression. As a result, Colleen has tried a variety of different psychotropic medications alongside behaviour management interventions.

When asked what advice she would give to prescribing health care providers, Colleen had this to say: *"You almost need two doctors—a family physician and a more specialized psychiatrist or psychologist with experience in ASD. And that is hard. It was all based on my information, me providing notes to the family physician. If you or your child don't verbalize well or write well, how do you get it across to your doctor? Especially if English isn't your first language. It's tricky."*

that anticonvulsants may be prescribed to treat seizures or as a mood stabilizer.

These findings did not explore dosages. This would provide additional information on the appropriateness of the treatment. In addition, persons with developmental disabilities may be prescribed medications "as needed" (*pro re nata*, or PRN). In this chapter, medications are counted as dispensed but might not have been taken by the individual or taken only in exceptional circumstances.

Future research

Variables not considered in this chapter deserve further attention to better understand medication use in adults with developmental disabilities. Impact of coordination and continuity of care should be explored. Specifically, it would be relevant to examine medication use patterns across primary care patient enrolment models (*see* Chapter 3).

Additional research should also investigate disparities between men and women with developmental disabilities in their prescription profiles. This chapter did not explore how medication use varies by residential setting among adults with developmental disabilities, although research in the United Kingdom, Australia and Canada has suggested that the use of multiple medications is more frequent in congregate settings.[15,16,26] Similar findings have been reported for persons with dementia.[34]

This chapter examined one potentially harmful medication combination: two or more antipsychotics. It would also be beneficial to provide similar information on other nonrecommended combinations being dispensed to adults with developmental disabilities, such as the use of two anticonvulsants.[19]

Conclusion

A large proportion of adults with developmental disabilities are dispensed medications, and multiple medication use is reported for nearly half of them. Psychotropic medications, especially antipsychotics, are dispensed most frequently. Persons with developmental disabilities are also at risk of being prescribed multiple antipsychotics. These findings are concerning because of the dangerous reactions associated with the use of these medications in combination, including cardiac problems and death.

When being dispensed multiple medications, adults with developmental disabilities tend to see their family physician regularly, as recommended for this population. However, almost a third of those dispensed five or more medications did not have regular follow-up with the same family physician. All adults with developmental disabilities and their caregivers should be supported in using medications appropriately and in monitoring side effects.

Efforts should be made to facilitate the adoption of clinical guidelines regarding prescribing practices in adults with developmental disabilities. Team-based coordinated care and medication reconciliation are advisable to support health care providers in making the best possible prescribing decisions. For adults with behaviour problems, nonpharmacological interventions must be an integral part of an effective treatment plan.

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7 Excellent Care for All Adults with Developmental Disabilities: Conclusion

Inside

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MAIN MESSAGES

- This Atlas offers a snapshot of the health status and health care patterns of 66,484 adults with developmental disabilities in Ontario. Overall, our findings reveal many gaps in care that need to be addressed in order for Ontario to provide *excellent care for all* adults with developmental disabilities.

- The Atlas findings suggest that we need to further reduce health care inequities experienced by adults with developmental disabilities, building on efforts such as the updated Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities, primary care reform in Ontario, and the newly created Community Health Links. While primary care providers are pivotal to achieving needed changes, the broader health care context as well as the infrastructure that supports primary care provision also need to be considered. In this final chapter, we propose changes in three related areas: (1) improving quality of primary care based on best evidence and care standards; (2) modifying broader health care system structures and processes; and (3) strengthening partnerships with adults with developmental disabilities, their families and their paid caregivers.

- Ontario needs enhanced data sources to continue its monitoring of the health and health care of citizens with developmental disabilities across the lifespan. Improved data sharing and coordination among all individuals in the patients' circle of care will ensure that adults with developmental disabilities receive more appropriate and better quality care.

- In future research, the H-CARDD program will expand its focus to study the broader health system, particularly the health care of vulnerable subpopulations and the impact of efforts to improve the health care of these individuals across Ontario.

Introduction

This Atlas offers a snapshot of the health status and health care patterns of 66,484 adults with developmental disabilities in Ontario, the largest such population ever studied. This cohort is unique because it includes individuals typically missed when using data from only one sector. Chapter 2 established that adults with developmental disabilities live in poorer neighbourhoods than adults without developmental disabilities and have higher rates of physical and mental health problems. Chapter 3 demonstrated that the majority of adults with developmental disabilities access primary care and use it frequently, but use emergency services more often than adults without developmental disabilities and are more likely to be hospitalized. Uptake of secondary prevention, particularly cancer screening, occurs at a lower level in adults with developmental disabilities than in those without, as noted in Chapter 4. Certain types of chronic disease management, according to Chapter 5, are comparable to or better among those with developmental disabilities than among those without, and some are worse. However, rates of preventable hospitalizations are considerably higher among adults with developmental disabilities than among those without. Finally, Chapter 6 indicates that many adults with developmental disabilities are receiving multiple medications, and some use medication combinations that can be harmful. When not well monitored, the use of multiple medications can lead

to additional health complications. Overall, our findings reveal many gaps in care that need to be addressed in order for Ontario to provide *excellent care for all* adults with developmental disabilities.

Putting It All Together

Throughout the Atlas, we present current initiatives that could be leveraged to improve primary care for adults with developmental disabilities. These include the creation and dissemination of the updated Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities[1] (hereafter referred to as the Canadian Consensus Guidelines) with accompanying clinical tools and related training, the introduction of enrolment models and inter-professional Family Health Teams through primary care reform, and the launching of Community Health Links.[2] The Atlas findings suggest that we need to build on these efforts and on relevant initiatives from other parts of the world (e.g., the United Kingdom's Learning Disabilities Observatory: Improving Health and Lives[3]) to further reduce the health care inequities experienced by adults with developmental disabilities. While primary care providers are pivotal to achieving the needed changes, the broader health care context and the infrastructure that supports primary care provision also need to be considered. In this final chapter, we propose changes in three related areas:

1. Improving quality of primary care based on best evidence and care standards
2. Modifying broader health care system structures and processes
3. Strengthening partnerships with adults with developmental disabilities, their families and their paid caregivers

1. Improving quality of primary care based on best evidence and care standards

The *Excellent Care For All Act* states that quality and its continuous improvement is a critical goal across the health care system and that it should be supported by the best evidence and care standards.[4] The Canadian Consensus Guidelines were first distributed to all family physicians in Canada in 2006.[5] Findings from this Atlas suggest that mere guideline dissemination is not enough to achieve meaningful uptake.[6] Further steps would include fostering greater awareness of the 2006 and updated 2011 Canadian Consensus Guidelines among primary care providers and the development of competencies with respect to providing care for persons with developmental disabilities. Our work in this Atlas suggests that developing competencies will require emphasizing a balanced, comprehensive approach to care, that such care be delivered through interprofessional teams, and that relevant guidelines and supporting tools be embedded into daily practice.

A BALANCED COMPREHENSIVE APPROACH TO CARE

Comprehensive primary care for adults with developmental disabilities requires a balanced emphasis on the prevention and management of chronic diseases. Both the 2006 and 2011 Canadian Consensus Guidelines take a preventive approach.[1,5] Considering the high rates of physical and mental health problems co-occurring with developmental disabilities (*see* Chapter 2), further guidelines and tools for the management of chronic diseases and multiple conditions in adults with developmental disabilities would complement the Canadian Consensus Guidelines and help to reduce emergency visits and preventable hospitalizations.

AN INTERPROFESSIONAL TEAM APPROACH TO CARE

Provincial policies and the Canadian Consensus Guidelines recognize the importance of continuity in primary care, particularly for more vulnerable individuals.[1,5,7,8] As mentioned in Chapter 3, the relationship with the primary care provider is critical for good care and disease prevention. However, adults with developmental disabilities have complex care needs (as reported in Chapter 2) that are likely not met by a single health professional. As articulated in the Chronic Disease Prevention and Management Framework and in the Canadian Consensus Guidelines, adults with developmental disabilities require an interprofessional team of health care providers who can work together.[9] For this mix of health professionals to be successful, they need to have clearly articulated roles and responsibilities and an agreed upon way to share information with each other. In Ontario, Family Health Teams foster an interprofessional team approach (*see* Chapter 3). Two current examples of Ontario curricula that address how a team should work together to support patients with developmental disabilities are Perspectives[10] and the Developmental Disabilities Primary Care Initiative training course. Learning from other jurisdictions, such as the United Kingdom and the Netherlands, where specialized training in developmental disabilities exists for nurses and physicians, the development of competencies appears to be key to implementing change.[11-15] In addition to primary care providers, key allied health professionals to target for training would include pharmacists, social workers, psychologists, and behaviour, physical and occupational therapists.

EMBEDDING GUIDELINES AND TOOLS INTO DAILY PRACTICE

The utilization of evidence-based practice guidelines and clinical tools is crucial to improving care. The challenge is to support professionals in embedding these into their daily practice.[9] Reminders and prompts within the electronic health record would be useful in that regard. For example, when multiple medications are prescribed, providers could be reminded of the potential drug interactions, as is done with other populations.[9] Electronic prompts could also remind health care providers to book longer appointments for persons with developmental disabilities, as well as provide helpful information to prepare patients and caregivers for tests and procedures or to obtain informed consent.

The starting point for many of these suggestions might be to flag the presence of a developmental disability in a person's health record and include links to relevant guidelines and tools for the care of adults with developmental disabilities. Certain teams across the province are attempting to embed the clinical tools created through the Developmental Disabilities Primary Care Initiative into their team structures and processes,[16] and related efforts are starting in other jurisdictions as well.[17] Successful implementation strategies need to be identified from such demonstration projects and shared more broadly, a next step for the H-CARDD program.

2. Modifying broader health care system structures and processes

Ontarians with developmental disabilities and their caregivers need an integrated and innovative health care system that is easy to navigate and is responsive to their unique health issues. Because of the high rates of comorbid physical and mental health problems in the population with developmental disabilities, a responsive health care system requires coordination between its different sectors, as well as the development of an infrastructure allowing providers to spend more time with their patients with developmental disabilities.

CARE PLANS

For collaborative care models to be successful, there need to be structures in place to allow service providers from different sectors to work together. Care plans are critical for this type of collaborative care. The crisis plan is one type of care plan recommended in the Canadian Consensus Guidelines,[1,5] with evidence supporting its use. Mechanisms should be put in place to develop these care plans across sectors and to keep them available to and updated among different providers. Other types of care plans could also be developed, related to specific physical and/or mental health concerns, as suggested in Chapter 5. The processes developed through the Community Health Links initiative[2] (*see* Collaboration and coordination, *below*) on the creation and communication of care plans for the most complex cases will be very relevant to the

population with developmental disabilities who have higher rates of chronic disease and would benefit from having unified plans of care.

COLLABORATION AND COORDINATION

Among the mechanisms that would support sharing and updating care plans, information systems (such as the electronic medical record) would assist with the timely transfer of information between providers and thus avoid fragmentation. Community Health Links, a program introduced in 2012, is one promising initiative in this regard.[2] This program, currently in the demonstration stage, was created for patients with high needs to "encourage greater collaboration and coordination between a patient's different health care providers as well as the development of personalized care plans." (*See* Chapters 3, 5 *and* 6 *for more on CHLs.*) This type of initiative would likely be relevant to all adults with developmental disabilities regardless of the complexity of their health condition.

Furthermore, Ontarians with developmental disabilities receive supports from multiple ministries: the ministries of Health and Long-Term Care and of Community and Social Services being the primary support providers in adulthood, and the ministries of Children and Youth Services and of Education in childhood. Coordination therefore requires that these different sectors share information about the individuals they jointly support. In addition to policy and planning partnerships, government representatives and support providers should develop agreements and protocols to safely and confidentially share relevant

clinical information across agencies, organizations and ministries. The development of a province-wide developmental disabilities clinical registry is one option to explore.

FINANCIAL STRUCTURES

In order to provide excellent care to all adults with developmental disabilities, modifications to their routine care are necessary. One barrier reported by adults with developmental disabilities, their caregivers and health care providers is that primary care providers do not have sufficient time to provide the care required.[18-20] Payment models could consider developmental disabilities as part of a list of chronic conditions requiring special care. Financial incentives for specific procedures related to chronic diseases are also very relevant here. As mentioned in Chapter 4, incentives for performing the comprehensive health assessment for adults with developmental disabilities have been very successful in increasing examination rates and in identifying early stages of disease in jurisdictions where they has been implemented (e.g., Australia).[21-23]

3. Strengthening partnerships with adults with developmental disabilities, their families and their paid caregivers

The success of the *Excellent Care For All Act* relies on organizing the care around the person receiving the care.[4] Similarly, improving the care of adults with developmental disabilities requires empowering them and their caregivers to be active partners in their health care. Ideally, engagement about how to be partners in health care should begin prior to adulthood. It can be a focus at home and even taught as part of the health curriculum at school. A first and crucial step toward empowerment is to provide information on the health services and health management that is accessible to persons with cognitive and communicative limitations. In other jurisdictions, health care providers in partnership with individuals with developmental disabilities and their caregivers have identified, developed and evaluated information and empowerment tools. Examples include the "Diabetes to the Point" web-based tool in Australia that explains what diabetes is and how best to manage it.[24] The "Books Beyond Words" series in the United Kingdom was developed to facilitate discussions about health care issues through illustrations of health care scenarios

accompanied by questions for health care providers or caregivers to guide discussion.[25] Similar work has begun in Ontario through the Developmental Disabilities Primary Care Initiative; in 2013, the initiative introduced caregiver tools and resources, including monitoring sheets for medication, sleep and menstrual cycles.[26] Additionally, the DD CARES project is introducing tools into the emergency department to help patients share relevant information at intake (the About Me booklet), and then communicate the outcome of their visit to their primary care providers (the My Exit Interview summary form).[27] These projects need to be pursued further in Ontario, and their impact evaluated.

This Atlas is not the first to emphasize the importance of partnerships between health care providers and recipients. The Chronic Disease Prevention and Management Framework also prioritizes partnerships between health care providers and patients.[9] However, because that strategy emphasizes "patient self-management," the role of caregivers is given limited attention. In supporting patients with developmental disabilities, the role of the caregiver (whether a family member or paid staff) needs explicit mention because it is often pivotal to empowering patients to be involved in their health care.

Conclusion

The health care inequities among persons with developmental disabilities that are described in this Atlas have also been documented in parts of Europe[28] and in the United Kingdom,[29] the United States[30] and Australia.[31] This has led some jurisdictions to invest in developing strategic plans for the care of their citizens with developmental disabilities.[32] These plans typically include an evaluation component allowing them to monitor activities and outcomes. Moving forward, Ontario needs enhanced data sources to continue its monitoring of the health and health care of citizens with developmental disabilities across the lifespan. Improved data sharing and coordination between all individuals in the patients' circle of care will ensure that adults with developmental disabilities receive more appropriate and better quality care. Moving forward, H-CARDD will expand its primary care focus to study the broader health care system. It will explore the health of and health care provision for vulnerable subpopulations, such as those with psychiatric disorders (i.e., a dual diagnosis), youth transitioning into adulthood, women and the elderly, and it will evaluate the impact of implementation efforts to improve health care across Ontario.

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Glossary

Anticonvulsant medications
Psychotropic medications used to treat seizures or emotional or behavioural problems, such as mood disorders.

Antipsychotic medications
Psychotropic medications used to treat symptoms of psychosis (e.g., schizophrenia) but sometimes prescribed for other emotional or behavioural problems.

Ambulatory care–sensitive (ACS) conditions
Chronic conditions, like asthma and diabetes, for which timely and effective primary care helps to reduce the risk of hospitalization by either delaying the progression of the illness or preventing complications.[1] A hospital admission for an ACS condition is considered a potentially preventable hospitalization.

Bone mineral density test (BMDT)
Determines bone density by the amount of absorption of X-rays at the proximal femur and lumbar spine. BMDTs of the hip and spine are considered valid tools used to diagnose osteoporosis and monitor ongoing fracture risk.[2,3]

Capitation
A method of payment whereby a physician is paid a set amount of money for each patient enrolled with the practice, whether the patient visits or not.

Colonoscopy
An endoscopic technique for colorectal cancer screening. During a colonoscopy, the lining of the rectum and colon are examined for polyps using a lighted flexible tube connected to a video screen. Polyps may be removed during colonoscopy. Colonoscopy typically follows a positive result for a fecal occult blood test (FOBT) and is conducted in persons with a family history of colorectal cancer.[4]

Comorbidity
The core concept of comorbidity is that at a given time, an individual has been diagnosed with more than one distinct condition.[5]

Drug interaction
The result when the effects of one drug are affected by the administration of a second drug.[6]

Dual diagnosis
The Ontario ministries of Health and Long-Term Care and of Community and Social Services define adults with a dual diagnosis as "persons 18 years of age and older with both a developmental disability and mental health needs."[7]

Fecal occult blood test (FOBT)
A screening test used to detect hidden (occult) blood in one's stool, as blood vessels on the surface of polyps or tumours in the colon may release trace amounts of blood into the stool. Using this test, adenomatous polyps may be identified before they become cancerous. A colonoscopy typically follows a positive FOBT.[8]

Interclass polypharmacy
The concurrent use of multiple drug products from different classes (e.g., the use of an antibiotic plus an analgesic).

Intraclass polypharmacy
The concurrent use of multiple drug products from the same class (e.g., the use of two antibiotics).

Low-trauma fracture
Refers to fractures that occur from minor impact or force (e.g., occurring spontaneously or by falling from standing height) that would not usually be strong enough to result in a broken bone. A low-trauma fracture increases the risk of additional fractures, as well as the risk of hospitalization, institutionalization and mortality. May also be referred to as a fragility fracture or an osteoporotic fracture.[9]

Mammography
Using a low-dose X-ray to produce images of the internal structure of the breast. This imaging may show abnormal areas of density, mass or calcification that may indicate the presence of cancer.[10]

Medication class
A group of all drug products used to treat similar problems and that have a similar chemical structure. For example, antibiotics are a medication class used to treat infections caused by bacteria.

Medication reconciliation
A formal process facilitating the communication between health care provider, patient and caregiver to ensure that all medication information and history are recorded. It allows for a systematic and comprehensive review of all medications used by an individual and informs health care providers on the most appropriate prescribing decisions for the patient.[11]

Morbidity
A 'diseased state.'[12] Measures of morbidity show how close or far away a person is from a state of well-being or good health. In health care, high morbidity levels can signal a need for immediate or intensive treatment or a need for a combination of different kinds of care that are coordinated with each other.

Papanicolaou test
Also called the Pap test or Pap smear, this screening test is used to detect pre-malignant and malignant lesions early so that they can be treated. In taking a Pap smear, a speculum is used to open the vaginal canal to allow for the collection of cells from the outer opening of the cervix. This test is conducted by family physicians or other health care providers during women's regular physical examinations.[13]

Periodic health examination
The periodic health examination, also known as the annual health exam, is an opportunity for primary care providers to ensure preventive care and early disease detection are regularly undertaken. It may include an examination of the whole body, discussion of health behaviours, immunization updates and screening tests. It is a time to discuss health issues not addressed during regular appointments directed to specific, new symptoms or concerns of the patient, or to follow-up and manage chronic diseases.
The periodic health examination was replaced in Ontario effective January 1, 2013 by the periodic health visit.[14]

Periodic health visit
An annual visit to primary care providers that does not necessarily include a complete medical history, physical examination or routine laboratory tests. *The periodic health visit replaced the periodic health examination in Ontario as of January 1, 2013.*[14]

Primary care
Several attributes differentiate primary care from specialty care. Primary care includes having the first point of contact within the health care system, having continuity of care, providing comprehensive care and coordinating care across the health care sector.[15] Currently family physicians are the main providers of primary care in Canada.[16] However, nurse practitioners are increasingly providing primary care to some populations.[17,18]

Primary prevention
The aim of primary prevention is to avoid the occurrence of disease in the first place.[19]

Psychotropic medications
Drugs that have an effect on the central nervous system and are prescribed for the treatment of emotional or behavioural problems (such as depression and anxiety) or seizures.[20]

Retinal eye examination
Conducted by physicians to test for eye problems, such as diabetic retinopathy. Involves the dilation of the pupil by placing eye drops into the patient's eye, after which the physician uses a special magnifying glass to examine the back of the eye and assess for damage.[21,22]

Secondary prevention
Involves the early detection of disease while it is asymptomatic and before it progresses. Secondary prevention is part of a comprehensive approach to preventive health care that has been promoted in primary care.

Sigmoidoscopy
An endoscopic technique for colorectal cancer screening. Flexible sigmoidoscopy differs from colonoscopy in that it examines only the rectum and distal portion of the colon but similarly uses a lighted, flexible tube connected to a video screen to identify polyps. Tissue sampling and polyp removal may also be conducted using flexible sigmoidoscopy. A feature of this technique is that it may be conducted as an outpatient procedure without the patient being sedated. A referral for colonoscopy may follow sigmoidoscopy.[23]

Tertiary prevention
Involves managing chronic illness with the goal of preventing further complications while maximizing quality of life.[19]

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Technical **Appendix**

Inside

H-CARDD Cohort Derivation: An Overview

The H-CARDD cohort is the result of linking two types of data: administrative health data and disability income support data. To link these data, we first had to compare them on the information they contained. Important characteristics of the health data were that they covered the entire age range and, because they were sourced from various parts of the health care system, they used recorded diagnostic information in different ways (e.g., ICD-8, ICD-9, ICD-10, DSM-IV) and varying degrees of specificity (e.g., OHIP billing only provides the first three digits of a diagnostic code). Two important characteristics of the disability income support data: they only covered individuals aged 18 to 64 years and they used the first three digits of the ICD-9 diagnostic codes. Our second step was to make the health data more compatible with the disability income support data. Consequently, only the health data for individuals aged 18 to 64 years were included. We also created a list of the health data diagnoses that seemed most consistent with legislative definition of developmental disabilities described in Chapter 1, and that are used to inform estimates of developmental disabilities within the Ontario Disability Support Program. The process of selecting the final list of diagnostic codes was iterative, informed by research conducted in other jurisdictions and discussions with our policy partners, as discussed in Chapter 1.

Finally, using a method called probabilistic linkage, the administrative health data and the disability income data were linked. Because the two types of data do not have a common identifier, information such as name and birthdate were used to determine which records were derived from the same individual. The actual linkage used statistical methods to identify the best matches, as well as a case-by-case examination of those records that were particularly complex. The linkage was conducted in a highly controlled, anonymized manner that was closely monitored and compliant with Ontario's privacy legislation. The final linked data did not include any information that would allow individuals to be identified.

Using administrative health data

Linked, anonymized administrative health data held at the Institute for Clinical Evaluative Sciences (ICES) were used for the analyses. Five administrative health databases were consulted for this analysis, along with a registry of persons eligible to receive provincial health insurance benefits (the Registered Persons Database, or RPDB) and data from the Canadian census. Together, the five administrative health data sets capture the vast majority of the formal medical services for which all legal residents of Ontario are eligible to receive health insurance coverage. Both the Ontario Mental Health Reporting System (OMHRS) and the Canadian Institute of Health Information's Discharge Abstract Database (DAD) capture inpatient discharges for all acute care psychiatric and nonpsychiatric hospital beds. The Same Day Surgery (SDS) and National Ambulatory Care Reporting System (NACRS) databases, also held by the Canadian Institute for Health Information, record ambulatory care visits for inpatient surgery or to the emergency department. The Ontario Health Insurance Plan (OHIP) contains all claims submitted to the province by fee-for-service physicians.

To identify individuals with developmental disabilities, we looked back to the beginning of each database (that is, its inception date) for diagnostic codes related to developmental disabilities. Some of the databases contained more than one field where diagnostic information could be coded, and for those, we examined every field. The list of codes we used was developed by reviewing codes from previously published studies and reports and comparing them with the codes used by the Ministry of Community and Social Services to capture developmental disabilities. This comparison was needed because different diagnostic codes are used in the administrative health data and because the definition of developmental disabilities varies across jurisdictions. (*See* Exhibit A.1 *below for codes for each health data set; see* Exhibit A.2 *for relevant ICD-9 and ICD-10 codes for developmental disabilities.*)

An individual was included in the administrative health data-derived cohort if he or she was between 18 and 64 years of age and had one of the following:

- One or more hospital visits (as recorded in the DAD, SDS and OMHRS databases) with a developmental disabilities code; or

- One or more emergency department visits (according to NACRS) with a developmental disabilities diagnostic code; or
- Two or more physician visits (according to the OHIP database) with a developmental disabilities code.

Individuals who had only a single physician visit and no other contact associated with developmental disabilities were excluded. (Reasons for choosing this definition are described in greater detail by Lin et al.[1])

EXHIBIT A.1 Diagnostic codes used to identify individuals with developmental disabilities in the administrative health data

Database	Year of inception	Diagnoses	Criteria
Discharge Abstract Database	1988	Discharges with any diagnosis listed in Exhibit A.2	• In any diagnostic field • For all facilities submitting to DAD, SDS and NACRS • From inception of database to March 31, 2010
Same Day Surgery Database	1991		
National Ambulatory Care Reporting System	2002		
Ontario Mental Health Reporting System	2005	Q3 = 1 or Q2aa, Q2ab or Q2ac (i.e., Axis I) in 299 to 299.80 or Q2b (i.e., Axis II) in 317 to 319.99 or I11a–I11f = any diagnosis of Qxxx as listed in Exhibit A.2	• For all facilities submitting to OMHRS • From inception of database to March 31, 2010
Ontario Health Insurance Plan	1991	299, 319	• For all providers submitting to OHIP • From June 1991 to March 31, 2010

EXHIBIT A.2 Developmental disabilities and related codes included in the International Classification of Diseases, 9th and 10th editions

Code	Label
ICD-9	
299–299.99	Pervasive developmental disorders (e.g., autism)
317–317.99	Mental retardation
318–318.99	Mental retardation
319–319.99	Mental retardation
758.0–758.39	Chromosomal anomalies for which a developmental disability is typically present
758.5	Other conditions due to autosomal anomalies
758.8, 758.89	Other conditions due to chromosome anomalies (do not include 758.81)
758.9	Conditions due to anomaly of unspecified chromosome
759.5	Tuberous sclerosis
759.81	Other and unspecified congenital anomalies: Prader-Willi syndrome
759.821	Other and unspecified congenital anomalies: de Lange syndrome (include only if 6 digits exist; i.e., do not include 759.82)
759.827	Other and unspecified congenital anomalies: Seckel syndrome (include only if 6 digits exist)
759.828	Other and unspecified congenital anomalies: Smith-Lemli-Opitz syndrome (include only if 6 digits exist)
759.83	Other and unspecified congenital anomalies: Fragile X syndrome
759.874	Other and unspecified congenital anomalies: Beckwith-Wiedemann syndrome (include only if 6 digits exist)
759.875	Other and unspecified congenital anomalies: Zellweger syndrome (include only if 6 digits exist)
759.89	Other and unspecified congenital anomalies: other (e.g.,Menkes disease, Laurence-Moon-Biedl syndrome, Rubinstein-Taybi syndrome)
760.71	Fetal alcohol syndrome
760.77	Fetal hydantoin syndrome
ICD-10	
F700	Mild mental retardation with the statement of no, or minimal, impairment of behaviour
F701	Mild mental retardation, significant impairment of behaviour requiring attention or treatment
F708	Mild mental retardation, other impairments of behaviour
F709	Mild mental retardation without mention of impairment of behaviour
F710	Moderate mental retardation with the statement of no, or minimal, impairment of behaviour
F711	Moderate mental retardation, significant impairment of behaviour requiring attention or treatment
F718	Moderate mental retardation, other impairments of behaviour
F719	Moderate mental retardation without mention of impairment of behaviour
F720	Severe mental retardation with the statement of no, or minimal, impairment of behaviour
F721	Severe mental retardation, significant impairment of behaviour requiring attention or treatment
F728	Severe mental retardation, other impairments of behaviour
F729	Severe mental retardation without mention of impairment of behaviour
F730	Profound mental retardation with the statement of no, or minimal, impairment of behaviour
F731	Profound mental retardation, significant impairment of behaviour requiring attention or treatment
F738	Profound mental retardation, other impairments of behaviour
F739	Profound mental retardation without mention of impairment of behaviour
F780	Other mental retardation with the statement of no, or minimal, impairment of behaviour
F781	Other mental retardation, significant impairment of behaviour requiring attention or treatment
F788	Other mental retardation, other impairments of behaviour
F789	Other mental retardation without mention of impairment of behaviour
F790	Unspecified mental retardation with the statement of no, or minimal, impairment of behaviour
F791	Unspecified mental retardation, significant impairment of behaviour requiring attention or treatment
F798	Unspecified mental retardation, other impairments of behaviour
F799	Unspecified mental retardation without mention of impairment of behaviour
F840	Childhood autism
F841	Atypical autism
F843	Other childhood disintegrative disorder
F844	Overactive disorder associated with mental retardation and stereotyped movements
F845	Asperger's syndrome
F848	Other pervasive developmental disorders
F849	Pervasive developmental disorder, unspecified
Q851	Tuberous sclerosis
Q860	Fetal alcohol syndrome
Q861	Fetal hydantoin syndrome
Q871	Aarskog, Prader-Willi, deLange, Seckel, etc.
Q8723	Rubinstein-Taybi syndrome (include only if all 5 digits)
Q8731	Sotos syndrome (include only if all 5 digits)
Q878	Other
Q900–Q939 except Q926	All Down syndrome types, cri du chat, etc., except extra marker chromosomes
Q971	Female with more than three X chromosomes
Q992	Fragile X syndrome
Q998	Other specified chromosome abnormalities

Using social services data

A data sharing agreement between the Institute for Clinical Evaluative Sciences and the Ontario Ministry of Community and Social Services was signed in 2011. This agreement paved the way for social services data—particularly from the Service Delivery Model Technology database, which includes information on recipients of Ontario Disability Support Program (ODSP) benefits—to be linked to administrative health data to create the H-CARDD cohort. ODSP data for the period from April 1, 2009 to March 31, 2010 was shared, and the records were probabilistically linked to the Registered Persons Database, which contains demographic details on all individuals eligible for Ontario Health Insurance Plan benefits. In total, 94% of the records were linked. Two fields in the ODSP database record diagnostic information; if either field included a developmental disability diagnostic code (*see* Exhibit A.3), the individual was eligible for inclusion in the H-CARDD cohort.

EXHIBIT A.3 ICD-9 codes used to identify individuals with developmental disabilities in the ODSP database

ICD-9 Code	Description
299	Pervasive developmental disorders
759	Other and unspecified congenital anomalies
760	Fetus or newborn affected by maternal conditions that may be unrelated to present pregnancy
317	Mild mental retardation
318	Other specified mental retardation
319	Unspecified mental retardation
758	Chromosomal anomalies

Creating the H-CARDD Cohort

Individuals who met the definition of having a developmental disability in either the administrative health data or the social services data were identified. Of these, individuals included in the H-CARDD cohort were:

- alive on March 31, 2010,
- eligible for OHIP benefits through March 31, 2010,
- coded as either male or female in one of the two databases, and
- aged 18 to 64 years as of April 1, 2009.

Individuals who did not meet all of these criteria were excluded.

The Comparison Cohort

After the H-CARDD cohort was identified, a 20% random sample was drawn from the remaining Ontario population to serve as a comparison cohort. A random sample was used rather than the entire population as it significantly reduced computer processing time while still providing a meaningful comparison group. This method has been used in scientific studies that have analyzed the OHIP database.[2]

Stratification Variables

Neighbourhood income

Neighbourhood income quintiles were derived by linking 2006 census data to the patients' residential postal code data. Statistics Canada has adjusted income for household size and community size such that each community would be expected to have 20% of its population in each income quintile. Quintiles are defined within smaller geographic areas called Census Metropolitan Areas (CMAs) or census agglomerations (CAs), rather than for the entire province, to better reflect the relative nature of this measure, to minimize the effect on household welfare of large differences in housing costs, and to ensure that each CMA or CA would have an approximately equal percentage of the population in each income quintile.

Patient enrolment model status

See description of primary care patient enrolment models in Chapter 3.

Resource Utilization Band

In this Atlas, we used the Johns Hopkins Adjusted Clinical Groups (ACGs) Case-Mix System to measure morbidity. This system, which is commonly used in health services research, uses diagnostic information obtained from administrative databases to describe and predict the use of health care resources by individuals based on their health records. This information is used to categorize individuals in case-mix groups (the ACGs) that are then put into broader groups called Resource Utilization Bands (RUBs). The ACG software automatically assigns six RUB classes: 0 (No or Only Invalid Diagnosis); 1 (Healthy Users); 2 (Low); 3 (Moderate); 4 (High); 5 (Very High). Using the RUBs, patients were categorized according to their morbidity levels and corresponding expected use of health care resources.

Rural or urban place of residence

An individual's place of residence was designated rural or urban as flagged in Statistics Canada census files. The flag is based on community size according to the 2006 census population in each census metropolitan area (CMA) or census agglomeration (CA). The census defines five community-size categories, one of which is "community size 5," also known as "rural and small town Canada." This category includes locations not included in a CMA or CA that have an urban population of less than about 10,000 or are a rural area. All records with a valid Forward Sortation Area are assigned to a CMA or CA and therefore to a community-size category. Statistics Canada recommends that rural and small town Canada be defined as community size 5.[3]

Indicators

PREVALENCE, DEMOGRAPHIC AND DISEASE PROFILES

Prevalence estimates

Definition: The total number of cases of developmental disabilities identified at a certain point in time, per 100 people in the total population.

Numerator: Persons aged 18 to 64 years identified as having developmental disabilities (i.e., included in the H-CARDD cohort).

Denominator: Statistics Canada intercensal population estimates of individuals aged 18 to 64 years in Ontario.

Age-sex standardization: Computed only for Local Health Information Networks (LHINs) using 1991 census age and sex distributions.

Data sources: Registered Persons Database (RPDB), Ontario Health Insurance Program (OHIP) database, Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS), Ontario Mental Health Reporting System (OMHRS), Ontario Disability Support Program (ODSP) database, Statistics Canada population estimates.

Measurement time frame: April 1, 2009 to March 31, 2010.

Stratification variables: Age, sex, neighbourhood income, rurality, Local Health Integration Network, Resource Utilization Band.

Notes:

1. Prevalence rates were age-standardized for Local Health Information Networks (LHINs) using the 1991 Canada population. This means that the prevalence rate for each LHIN reflects what would have occurred if the age distribution in the LHIN were the same as for Canada in 1991 (a commonly used census year for standardization). This allows for prevalence rates among LHINs to be directly compared as though they all had the same age structure.

2. A map was generated to demonstrate the location of prevalent cases by Forward Sortation Area (FSA). The dots on the map, which represent groups of five individuals, were placed semi-randomly within a given FSA to protect individual anonymity.

Proportion with chronic disease

Definition: The proportion of individuals with developmental disabilities who had at least one of the following chronic disease diagnoses as of April 1, 2009: diabetes, hypertension, chronic obstructive pulmonary disease, asthma, congestive heart failure and/or psychiatric conditions.

Numerator: Individuals in the H-CARDD cohort diagnosed with diabetes, hypertension, chronic obstructive pulmonary disease, asthma, congestive heart failure and/or psychiatric conditions as of April 1, 2009.

Denominator: Persons identified as having developmental disabilities (i.e., the H-CARDD cohort).

Data sources: Registered Persons Database (RPDB), Ontario Health Insurance Program (OHIP) database, Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS), Ontario Mental Health Reporting System (OMHRS), Ontario Disability Support Program (ODSP) database, Statistics Canada population estimates; Ontario Diabetes Database (ODD), and ICES-derived databases for congestive heart failure, hypertension, chronic obstructive pulmonary disease and asthma.

Measurement time frame: Diabetes: April 1, 1991 to March 31, 2009; hypertension: April 1, 1988 to March 31, 2009; chronic obstructive pulmonary disease: April 1, 1988 to March 31, 2009; asthma: April 1, 1993 to March 31, 2009; congestive heart failure: April 1, 1991 to March 31, 2009; and psychiatric condition: April 1, 2007 to March 31, 2009.

Stratification variables: Not applicable.

Notes:

1. The chronic disease registries used included: Ontario Diabetes Database (ODD), ICES-derived databases for congestive heart failure, hypertension, chronic obstructive pulmonary disease and asthma. For each registry, only diagnoses that were recorded prior to April 1, 2009 were considered.

2. Definitions for the chronic diseases assessed in this Atlas:

    a) Diabetes: two OHIP 250 diagnostic codes, or one OHIP fee code Q040, K029, K030, K045, K046, or one CIHI (DAD or SDS) admission (ICD-9: 250; ICD-10: E10, E11, E13, E14) in two years.

    b) Congestive heart failure (CHF): restricted to individuals aged 40 years or older at diagnosis. One hospital admission (DAD or OMHRS) with CHF, or OHIP claim/NACRS record with CHF followed within two years by a second OHIP/NACRS or hospital admission. ICD-9/OHIP: 428; ICD-10: I500, I501, I509.

    c) Chronic obstructive pulmonary disease (COPD): restricted to individuals aged 35 years or older at diagnosis. One CIHI discharge (DAD or SDS) or OHIP billing for COPD. ICD-9/OHIP code: 491, 492, 496; ICD-10 code: J41, J42, J43, J44.

    d) Asthma: one CIHI discharge (DAD or SDS) or two OHIP claims of asthma within two years. ICD-9/OHIP: 493; ICD-10: J45, J46.

    e) Hypertension: one CIHI discharge (DAD or SDS) or one OHIP claim followed by a second OHIP claim or a CIHI discharge within two years. ICD-9/OHIP: 401, 402, 403, 404, 405; ICD-10: I10, I11, I12, I13, I15.

    f) Mental health: OHIP visit, OMHRS admission, CIHI discharge (DAD or SDS), or NACRS emergency department visit between April 1, 2007 and March 31, 2009 with a mental health code. ICD-9/OHIP: 290–298, 300–316; ICD-10: F00–F69, F99.

HEALTH SERVICES UTILIZATION

Proportion who visited family physicians and specialists; Average number of visits to family physicians and specialists

Definition:

1. The proportion of adults aged 18 to 64 years who visited a physician for a home or office-based consultation, examination or procedure during the measurement time frame.

2. The average number of visits among adults aged 18 to 64 years who visited a physician for a home or office-based consultation, examination or procedure during the measurement time frame.

Numerator:

1. The number of adults in each cohort subset (e.g., age, sex or neighbourhood income quintile groups) who visited a physician for a home or office-based consultation, examination or procedure.

2. The total number of visits made by adults in each cohort subset (e.g., age, sex or neighbourhood income quintile groups) to a physician for a home or office-based consultation, examination or procedure.

Denominator:

1. The number of adults aged 18 to 64 years in Ontario in each cohort subset.

2. The number of adults aged 18 to 64 years in Ontario in each cohort subset who made at least one visit to a physician for a home or office-based consultation, examination or procedure.

Data source: Registered Persons Database, Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: April 1, 2009 to March 31, 2010.

Stratification variables: Age, sex, neighbourhood income, physician type (primary care; specialty care per the categories provided below).

Notes:

1. Fee codes in the OHIP database for care provided in inpatient or long-term care settings, as well as laboratory testing and radiological examinations, were excluded.

2. Physician type was derived from OHIP specification codes and was categorized according to the following rubric. The proportion of individuals with visits was calculated for both family physicians and for specialists, by category:

   a) Family physicians: 00 – Family practice/ General practice.

   b) Specialists: 19 – Psychiatry; 18 – Neurology; 41 – Gastroenterology; 47 – Respiratory disease.

   c) Surgical specialists: 03 – General surgery; 04 – Neurosurgery; 06 – Orthopaedic surgery; 08 – Plastic surgery; 09 – Cardiothoracic surgery; 17 – Vascular surgery; 49 – Dental surgery; 50 – Oral surgery; 64 – Thoracic surgery.

   d) Other nonsurgical specialists: 02 – Dermatology; 05 – Community medicine; 07 – Geriatrics; 13 – Internal medicine; 15 – Endocrinology; 34 – Therapeutic radiology; 44 – Medical oncology; 46 – Infectious disease; 48 – Rheumatology; 60 – Cardiology; 61 – Hematology.

For general internal medicine specialists and geriatricians, it was not possible to distinguish between primary care and specialty consultative visits using fee codes. Therefore, office visits to these specialists were based on consultation fee code claims that included an A or K prefix. Nursing home visits, inpatient visits, laboratory tests, surgical procedures and radiological examinations were excluded.

All codes that could be identified as Location = Home, Office or LTC (long-term care) were selected, and the specialty of the physician who billed that code was examined.

Proportion who visited an emergency department; Average number of emergency department visits

Definition:

1. The proportion of adults aged 18 to 64 years who had an unplanned emergency department visit in Ontario during the measurement time frame.

2. The average number of emergency department visits among adults aged 18 to 64 years who visited an emergency department in Ontario during the measurement time frame.

Numerator:

1. The number of adults aged 18 to 64 years in each cohort who had an unplanned emergency department visit.

2. Total number of unplanned emergency department visits made by adults aged 18 to 64 years in each cohort.

Denominator:

1. The number of adults aged 18 to 64 years in each cohort in Ontario.

2. Total number of adults aged 18 to 64 years in each cohort who made at least one unplanned emergency department visit in Ontario.

Data source: National Ambulatory Care Reporting System.

Measurement time frame: April 1, 2009 to March 31, 2010.

Stratification variables: Age, sex, neighbourhood income.

Proportion who were hospitalized; Average number of hospitalizations

Definition:

1. The proportion of adults aged 18 to 64 years who had an inpatient hospitalization in Ontario during the measurement time frame.

2. The average number of hospitalizations among adults aged 18 to 64 years who were hospitalized in Ontario during the measurement time frame.

Numerator:

1. The number of adults aged 18 to 64 years in each cohort who were hospitalized.

2. The total number of hospitalizations among adults aged 18 to 64 years in each cohort.

Denominator:

1. Number of persons aged 18 to 64 years in each cohort in Ontario.

2. Total number of adults aged 18 to 64 years in each cohort who were hospitalized at least once in Ontario.

Data source: Discharge Abstract Database.

Measurement time frame: Records with an admission date between April 1, 2009 and March 31, 2010.

Stratification variables: Age, sex, neighbourhood income.

Usual Provider Continuity (UPC) Index

Definition: The proportion of the total number of office-based primary care visits to family physicians that were to the usual provider over a two-year time frame, expressed as a value between 0 and 1 and categorized as follows: High – 0.80 or higher; Moderate – 0.50 to 0.80; Low – 0.0 to 0.50; Less than 3 visits – Fewer than three visits to any physician over two years.

Numerator: The number of visits to the usual provider over a two-year time frame.

Denominator: Total number of visits.

Data source: Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: April 1, 2009 to March 31, 2011.

Stratification variables: Age, sex, neighbourhood income.

Notes:

1. Individuals who did not have at least three visits over the two-year time frame were excluded from the calculation of the UPC index.

2. Visits were restricted to those made to a general practitioner/family physician (OHIP specialty code = 00) for primary care in the office, home or long-term care facility, or specialist visits with a referring general practitioner/family physician. Emergency department and inpatient visits were excluded from this calculation.

3. Visits to a specialist are attributed to the general practitioner/family physician who referred the patient and are also included in the calculation.

4. The physician who provided the greatest proportion of care is specified as the usual provider.

Proportion enrolled in primary care patient enrolment models

Definition: The percentage of adults aged 18 to 64 years who were rostered to or seeing a physician belonging to a primary care patient enrolment model on April 1, 2009.

Numerator: The number of adults aged 18 to 64 years who were either rostered to a physician belonging to a primary care patient enrolment model on the index date, or who saw a physician belonging to a model according to the virtual roster algorithm (*see* Note *below*).

Denominator: The total number of adults aged 18 to 64 years who had a valid health card number during the measurement time frame.

Data source: Client Agency Program Enrolment (CAPE) tables, Corporate Provider Database (CPDB), Ontario Health Insurance Program (OHIP) database.

Measurement time frame: April 1, 2009.

Stratification variable: Practice model type (refer to Chapter 3 for model types).

Note: For those patients who are not part of a roster in the CAPE tables, all OHIP records over a two-year period from a collection of core PC codes (A001, A002, A003, A007, A261, A268, A903, E075, G212, G271, G372, G373, G365, G538, G539, G590, G591, K005, K013, K017, K267, K269, P004) are pulled. The standard price file is applied to those billings and from this, the physician with the highest billing for each patient. The patient is then virtually rostered with that physician and his/her group, if one exists.

SECONDARY PREVENTION

Periodic health examination

Definition: The proportion of adults aged 18 to 64 years on April 1, 2009 who received at least one comprehensive physical examination in Ontario during the measurement time frame.

Numerator: The number of adults aged 18 to 64 years in each cohort who received at least one comprehensive physical examination.

Denominator: The number of adults in each cohort aged 18 to 64 years on April 1, 2009.

Data sources: Registered Persons Database (RPDB), Ontario Health Insurance Plan (OHIP) database, Client Agency Program Enrolment (CAPE) tables, Corporate Provider Database (CPDB).

Measurement time frame: April 1, 2009 to March 31, 2011.

Stratification variables: Age (as of April 1, 2009), sex, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model (particularly, enrolment in a Family Health Team on April 1, 2009).

Notes:
A comprehensive physical examination captured by OHIP billing code A003 (General assessment) with diagnostic code 917 (Annual health examination adolescent/adult well vision care).

1. Assessment of patient enrolment model status was limited to identifying whether or not each individual in the two cohorts was enrolled in a Family Health Team on April 1, 2009. This analysis was done by consulting the CAPE tables and the CPDB.

2. Individuals with a missing or invalid health insurance number, date of birth, sex or postal code were excluded from this analysis.

Colorectal cancer screening

Definition: The proportion of adults aged 50 to 64 years who had at least one colorectal cancer screening test, including fecal occult blood test (FOBT), flexible sigmoidoscopy or colonoscopy, during the measurement time frame.

Numerator: The number of adults aged 50 to 64 years in each cohort who had at least one colorectal cancer screening test (FOBT, flexible sigmoidoscopy, colonoscopy).

Denominator: The number of adults in each cohort aged 50 to 64 years on March 31, 2010 who resided in Ontario on April 1, 2009.

Data sources: Registered Persons Database (RPDB), Ontario Cancer Registry (OCR), Client Agency Program Enrolment (CAPE) tables, Corporate Provider Database (CPDB).

Measurement time frame: For individuals aged 50 to 64 years on March 31, 2010 who resided in Ontario on April 1, 2009, records were searched for at least one colorectal cancer screening test between April 1, 2000 and March 31, 2010.

Stratification variables: Age, sex, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model status.

Notes:
1. The outcome was defined as 'up-to-date' with colorectal tests (yes/no) and was captured by assessing whether or not at least one of the following tests was conducted, according to the OHIP database: FOBT (L181 Lab Med – Biochem – Occult Blood; G004 Lab Med in Office – Occult Blood; L179 ColonCancerCheck Fecal Occult Blood Testing) between April 1, 2008 and March 31, 2010; flexible sigmoidoscopy (Z580) between April 1, 2005 and March 31, 2010; colonoscopy (Z555 +/- other E codes) between April 1, 2000 and March 31, 2010.

2. The following individuals were excluded from the analysis:

   a) Individuals with a missing or invalid health insurance number, date of birth, sex or postal code.

   b) Individuals with a diagnosis of colorectal cancer in the OCR prior to January 1, 2010. A diagnosis of colorectal cancer was coded as follows: ICD-9: 153 (excluding 153.5), 154.0 or 154.1; or ICD-O-3: C18 (excluding C18.1), C19, C20 or C26.

   c) Individuals with a total colectomy claim in OHIP prior to April 1, 2009 (billing codes S169, S170, S172).

   d) Individuals with OHIP fee code Q142A (colorectal exclusion) recorded between April 1, 2008 and March 31, 2010.

3. Multiple records with the same health insurance number, procedure date and type of procedure were counted as a single record.

4. The analyses were limited to adults aged 50 to 64 years, as Cancer Care Ontario recommendations stipulate that individuals aged 50 to 74 years should undergo FOBT every two years.[4]

Cervical cancer screening

Definition: The proportion of women aged 18 to 64 years who had at least one Pap test during the measurement time frame.

Numerator: The number of women aged 18 to 64 years in each cohort who had at least one Pap test.

Denominator: The number of women aged 18 to 64 years on April 1, 2009 in each cohort.

Data sources: Ontario Health Insurance Plan (OHIP) database, Registered Persons Database (RPDB), Ontario Cancer Registry (OCR), Client Agency Program Enrolment (CAPE) tables, Corporate Provider Database (CPDB).

Measurement time frame: For women aged 18 to 64 years on April 1, 2009 who resided in Ontario on April 1, 2009, records were searched for at least one Pap test between April 1, 2009 and March 31, 2012.

Stratification variables: Age, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model status.

Notes:

1. A Pap test was defined as the presence of:
   a) Fee code G365 or G394 with fee suffix 'A,' or
   b) E430 for Pap test billing, or
   c) L812, L713 (laboratory code).
2. The following were excluded from the analysis:
   a) Individuals with a missing or invalid health insurance number, date of birth, sex or postal code.
   b) Individuals with a previous diagnosis of cervical, endometrial or ovarian cancer in the OCR prior to January 1, 2010 indicated by ICD-9 diagnostic codes 179, 180.0, 180.1, 180.8, 180.9, 182.0, 182.1, 182.8, 183.0, 183.2 to 183.5, 183.8, 183.9.
   c) Individuals with hysterectomy prior to March 31, 2010 in the OHIP database indicated by OHIP fee codes S710, S727, S757, S758, S759, S762, S763, S765, S766, S767, S810, S816.

Breast cancer screening

Definition: The proportion of screening-eligible women (*see* Note 2 *below*) aged 50 to 64 years who had at least one mammogram during the measurement time frame.

Numerator: The number of women aged 50 to 64 years in each cohort who at least one mammogram.

Denominator: The number of screening-eligible women aged 50 to 64 years on April 1, 2009 in each cohort.

Data sources: Ontario Breast Screening Program (OBSP), Ontario Health Insurance Plan (OHIP) database, Ontario Cancer Registry (OCR), Registered Persons Database (RPDB), Discharge Abstract Database (DAD), Same Day Surgery (SDS) Database.

Measurement time frame: For women aged 50 to 64 years on April 1, 2009 who resided in Ontario on April 1, 2009, records were searched for at least one mammogram between April 1, 2009 and March 31, 2011.

Stratification variables: Age, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model status.

Notes:

1. A mammogram was defined as the presence during the study period of either:
   a) OBSP variable "mamdone" = Y, or
   b) OHIP fee code X185.
2. The following were excluded from the analysis:
   a) Individuals with a missing or invalid health insurance number, date of birth, sex or postal code.
   b) Women who ever had a diagnosis of breast cancer prior to January 1, 2011 (ICD-9 code 174.x in the OCR).
3. The analyses were limited to women aged 50 to 64 years, as Cancer Care Ontario recommendations stipulate that women aged 50 to 74 years should undergo a mammogram every two years.[5]

CHRONIC DISEASE MANAGEMENT

Diabetes eye examinations

Definition: The proportion of adults aged 30 to 64 years with diabetes mellitus who underwent an eye examination within two years of diagnosis.

Numerator: The number of adults aged 30 to 64 years in each cohort who had diabetes mellitus diagnosed as of April 1, 2009 and who underwent an eye examination within two years of diagnosis.

Denominator: The number of adults aged 30 to 64 years in each cohort who had diabetes mellitus diagnosed as of April 1, 2009.

Data sources: Ontario Diabetes Database (ODD), Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: For individuals aged 30 to 64 years on April 1, 2009 who resided in Ontario on April 1, 2009 and had a diagnosis of diabetes mellitus as of that date, records were searched for at least one eye examination between April 1, 2009 and March 31, 2011.

Stratification variables: Age, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model status.

Notes:

1. Billing to OHIP under any of the following fee codes counted as an eye examination:
   a) A110, A111, A112, A114, A115 when treating physician specialty = 00 or 23.
   b) A233, A234, A235, A236, A237, A238, A239, A240, A252, A253, A254 when physician specialty = 23.
   c) C233, C234, C235, C236 when physician specialty = 23.
   d) K065, K066 when physician specialty = 23.
   e) V401, V402, V404, V405, V406, V407, V408, V409, V450, V451 when physician specialty = 56.
2. The following were excluded from the analysis:
   a) Individuals younger than 30 years or older than 64 years on April 1, 2009.
   b) Individuals who were not found to have a diagnosis of diabetes mellitus on April 1, 2009 according to the ODD.
   c) Individuals with a missing or invalid health insurance number, date of birth, sex or postal code.

3. The analyses were limited to adults aged 30 to 64 years, as individuals 30 years of age and older are more likely to have been newly diagnosed with type 2 diabetes; as such, screening is recommended for this group.

Psychiatric emergency follow-up

Definition: The proportion of adults aged 18 to 64 years who had general physician or psychiatric follow-up within 45 days after their index unplanned psychiatric visit (not resulting in hospital admission) to an emergency department in Ontario.

Numerator: The number of adults aged 18 to 64 years in each cohort who visited the office of a family physician or psychiatrist at least once or had at least one planned psychiatric emergency department visit within 45 days after an unplanned psychiatric emergency department visit.

Denominator: The number of adults aged 18 to 64 years in each cohort who had an unplanned psychiatric visit to an emergency department in Ontario which did not result in hospitalization.

Data sources: Registered Persons Database (RPDB),Ontario Health Insurance Plan (OHIP) database, National Ambulatory Care Reporting System (NACRS).

Measurement time frame: For adults aged 18 to 64 years on April 1, 2009 who resided in Ontario on April 1, 2009 and had an emergency department visit between April 1, 2009 and September 30, 2010, records were searched for at least one primary care physician or psychiatrist visit or a planned emergency department visit within 45 days of the initial (index) ED visit.

Stratification variables: Age, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model status.

Notes:

1. Only index emergency department visits were considered for this indicator. For individuals with only one emergency department visit for psychiatric reasons, the index visit was that visit. For individuals with more than one visit for psychiatric reasons, the index visit was the first visit that occurred during the measurement time frame. An index emergency department visit was defined as an unplanned psychiatric emergency department visit (F code).

2. A follow-up visit was defined as a visit within 45 days after the index emergency department visit of either:

   a) An office visit to either a family physician or a psychiatrist (office visit with accompanying specialty code 00 – GP/FG or 19 – Psychiatry) or

   b) A planned emergency department visit.

3. The following were excluded from the analysis:

   a) Individuals with a missing or invalid health insurance number, date of birth, sex or postal code.

   b) Individuals younger than 18 years on April 1, 2009.

Fracture care

Definition: The proportion of adults aged 40 to 64 years who received a bone mineral density test within one year post-discharge after a low-trauma fracture.

Numerator: The number of adults aged 40 to 64 years in each cohort who underwent a bone mineral density test within one year post-discharge after a low-trauma fracture.

Denominator: The number of adults aged 40 to 64 years in each cohort who had a low-trauma fracture for which they visited an emergency department and/or were hospitalized.

Data sources: Registered Persons Database (RPDB), Ontario Health Insurance Plan (OHIP) database, Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS).

Measurement time frame: For adults aged 40 to 64 years on April 1, 2009 who resided in Ontario on April 1, 2009 and had a low-trauma fracture between April 1, 2009 and March 31, 2010, records were searched for at least one bone mineral density test within one year post-discharge.

Stratification variables: Age, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model status.

Notes:

1. The following codes were used to identify low-trauma fracture (the presence of both S and W codes was necessary): ICD-10: S220, S221, S320,S321, S323, S324, S325, S327, S328, S422, S52x, S720, S721, S722; External cause of injury codes: W00–W10, W18, W19. If a person was seen more than once in the emergency department and/or hospital within 13 weeks (91 days) for the same type of fracture, it was assumed that these were all due to the same fracture.

2. Occurrence of a bone mineral density test was indicated if a person had at least one of the following tests over the two-year time frame: OHIP radiology codes X145, X146, X149, X152, X153, X155.

3. The following were excluded from the analysis:

    a) Individuals with a missing or invalid health insurance number, date of birth, sex or postal code.

    b) Individuals younger than 40 years or older than 64 years on April 1, 2009.

    c) Individuals who had a bone mineral density test in the year prior to the date of fracture.

    d) Individuals who died in the follow-up period.

    e) A fracture for which the diagnostic code starts with a 'V' (motor vehicle accident).

    f) Any diagnosis of cancer in the fiscal year of fracture or the prior two years.

    g) The analyses were limited to adults aged 40 to 64 years as our findings indicate that high rates of low-trauma fractures among persons with developmental disabilities begin at a younger age compared to persons without developmental disabilities.

Preventable hospitalization

Definition: The proportion of adults aged 18 to 64 years who were hospitalized for an ambulatory care–sensitive (ACS) condition within a one-year period, expressed as a rate per 100,000 population.

Numerator: The number of adults aged 18 to 64 years in each cohort who were hospitalized for an ACS condition.

Denominator: The number of adults in each cohort aged 18 to 64 years.

Data sources: Registered Persons Database (RPDB), Discharge Abstract Database (DAD).

Measurement time frame: For adults aged 18 to 64 years on April 1, 2009 who resided in Ontario on April 1, 2009, records were searched for hospitalizations for an ACS condition between April 1, 2009 and March 31, 2010.

Stratification variables: Age, neighbourhood income, rurality, Local Health Integration Network, patient enrolment model status.

Notes:

1. Repeat hospitalizations for the same person were counted as a single hospitalization.

2. An ambulatory care–sensitive condition was defined to include the most responsible diagnostic codes listed in Exhibit A.4. The following diagnosis categories are presented to broadly classify ACS conditions into composite conditions and are not intended to be used for producing rates outside of the ACS conditions context.

3. Cases resulting in death before discharge were excluded.

EXHIBIT A.4 ICD-9 and ICD-10 codes used to identify ambulatory care-sensitive conditions for the analysis of preventable hospitalization

Generic Diagnosis	ICD-9 Code[6]	ICD-10 Code	Comment
Asthma	493	J45	
Angina pectoris	413	I20	Exclude cases with surgical procedure
Anxiety, dissociative and somatoform disorders	300	F40–F42	
Congestive heart failure	428	I50	Exclude cases with surgical procedure
Constipation	564.0	K59.0	Exclude cases with surgical procedure
Dental conditions	521, 522, 523, 525, 528	K02–K06, K08, K09.8, K09.9, K12, K13	
Diabetes mellitus	250	E10, E14	
Epilepsy	345	G40, G41	
Gastroesophageal reflux	530.81	K21	
Gastrointestinal ulcer	531, 532, 533, 534	K25–K27	
Immunization-preventable infection	032, 033, 037, 055, 072	A36, A37, A35, B05, B26	
Malignant hypertension	401.0, 402.0, 403.0, 404.0	I10.0, I10.1, I11	
Otitis media	382	H66	
Schizophrenic disorders	295	F20	

MEDICATION USE

Medication use was assessed for the subset of the H-CARDD cohort that received income support from the Ontario Disability Support Program (ODSP) and was subsequently also eligible for prescription drug coverage from the Ontario Drug Benefit (ODB) Program. Of the total H-CARDD cohort (n=66,484), 52,404 individuals were eligible for ODB income support. These included:

- All individuals receiving disability income support (ODSP) because of a developmental disability (n=42,144); and
- All individuals deemed eligible for ODSP for a reason other than a developmental disability but identified as having a developmental disability in the administrative health data (n=10,260).

Information is not available for medications dispensed to individuals not covered by the ODB Program (approximately 14,000 individuals from the total H-CARDD cohort).

Dispensed medications

Definition: The proportion of adults aged 18 to 64 years with developmental disabilities who received ODSP payments and fell into one of three groups: (1) those dispensed no concurrent medications (0 or 1 medication); (2) those dispensed 2 to 4 medications concurrently; and (3) those dispensed 5 or more medications concurrently. Cut-offs were determined based on the distribution of the study population, with groups (2) and (3) being of equal proportions.

Data sources: Ontario Drug Benefit (ODB) Program database, Ontario Health Insurance Plan (OHIP) database

Measurement time frame: Claims to the ODB Program for which the prescription period overlapped with October 1, 2009 were examined. For example, medications dispensed on September 15, 2009 were included if the therapy period included October 1, 2009 or beyond. However, medications dispensed on the same date with a therapy period of one week (i.e., finishing before October 1, 2009) were not included. It is possible that medications dispensed with a therapy course overlapping October 1, 2009 and replaced by another drug product before the end of treatment were counted. For example, a physician prescribes drug A on September 15, 2009 for a four-week period. The medication is dispensed, but after a week of treatment and no improvement in symptoms, the physician switches to drug B for a three-week period. In this example, both drugs A and B would be counted in this study. October 1, 2009 was chosen as the census date because it was the midpoint in the fiscal year April 1, 2009 to March 31, 2010.

Stratification variables: None

Notes:

1. All medications examined in this analysis are covered by the ODB Program, which includes most of the 3,800 prescription drug products. It does not include over-the-counter medications, supplements or vitamins.

2. Medication use was operationally measured as medications dispensed, rather than prescribed or administered. This means that we do not know when medications were prescribed but not filled, or if the medications dispensed were actually taken by the individual.

Follow-up with the same family physician

Definition: The proportion of adults aged 18 to 64 years with developmental disabilities who were dispensed multiple concurrent medications and had at least three visits with the same family physician in the year following October 1, 2009.

Data sources: Ontario Drug Benefit (ODB) Program database, Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: The index date was October 1, 2009. OHIP billing records were scanned on at least three unique dates with the same physician, for any reason, for the period October 1, 2009 to September 30, 2010.

Stratification variables: None.

Note: All physician visits, regardless of their fee code, were included in the algorithm. There is no fee code specific to a review of medications.

Use of multiple antipsychotics

Definition: The proportion of adults aged 18 to 64 years with developmental disabilities dispensed at least one antipsychotic; the subset who were dispensed two or more antipsychotics concurrently; the subset who were dispensed two or more antipsychotics concurrently and continuously for a three-month period; and the subset who were dispensed two or more antipsychotics concurrently and continuously for a six-month period.

Data sources: Ontario Drug Benefit (ODB) Program database, Ontario Health Insurance Plan (OHIP) database.

Measurement time frame: The census date was set at October 1, 2009. Drugs were considered dispensed continuously for a three- or six-month period when: (a) they were dispensed on the census date or with a therapy course overlapping the census date; and (b) they were dispensed continuously from October 1, 2009 to December 31, 2009 (three-month therapy course) or March 31, 2010 (six-month therapy course), with continuous use defined as prescriptions refilled within a period of 1.5 times the duration of the previous prescription (for example, a seven-day prescription refilled within 10.5 days [7 x 1.5]).

Stratification variables: None

Note: Whether antipsychotics dispensed on the census date were dispensed continuously for three or six months was examined. It is possible that the following individuals were excluded from the analysis: those for whom one of the antipsychotics dispensed on the census date was replaced by another one, or those for whom a new antipsychotic was introduced over the three- or six-month period. The introduction of a new antipsychotic might be necessary when changing prescribed antipsychotics and thus would not inform on inappropriate practices.

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