Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario

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The views expressed in this report do not necessarily represent the position of the Centre for Addiction and Mental Health or the University of Ontario Institute of Technology.

About the Organizations Involved in This Report

H-CARDD

Health Care Access Research and Developmental Disabilities (H-CARDD) is a research program that aims to enhance the overall health and well-being of individuals with developmental disabilities through improved health care policy and services. H-CARDD research is conducted by dedicated teams of scientists, policy-makers, health care providers, people with disabilities and families working collaboratively.

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.

ICES

ICES is an independent, not-for-profit organization that produces knowledge to enhance the effectiveness of health care for Ontarians. Internationally recognized for its innovative use of population-based health data and information, ICES evidence supports health policy development and guides changes to the organization and delivery of health care services.

UOIT

The University of Ontario Institute of Technology (UOIT) is located in Oshawa, Ontario. UOIT welcomed its first class of students in September 2003 and currently has over 10,000 undergraduate and graduate students. The Faculty of Health Sciences is one of the university's seven faculties. Its mission is to integrate advanced technologies, learning methodologies and research in an interprofessional environment to inspire students who are committed to health, inquiry and social responsibility.

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List of Exhibits

Executive Summary

Issue

Building on previous work by the Health Care Access Research and Developmental Disabilities (H-CARDD) Program, which showed that Ontario adults with developmental disabilities have poorer physical and mental health and use more health care services than other adults, this report takes an integrated, cross-sectoral approach to further study this heterogeneous and vulnerable population.

We followed a cohort of 64,699 Ontario residents with developmental disabilities who were between 19 and 65 years of age in 2010 for a six-year period between April 2010 and March 2016 and compared this group to adults without developmental disabilities for five health and health care outcomes. We examined the five outcomes by age, sex and the wealth or poverty of the neighbourhood where people lived, as well as by the type of developmental disability they had.

This work was done collaboratively by a group of scientists, clinicians, advocates and policy-makers. Our findings have relevance in Ontario and other jurisdictions where there is interest in improving the health care and health status of individuals with developmental disabilities.

Study goals

- To describe how adults with developmental disabilities differ from other adults with regard to five important health and health care outcomes: 30-day repeat emergency department visits, 30-day repeat hospitalizations, alternate level of care, long-term care and premature mortality.
- To describe these five outcomes for three subgroups of individuals with developmental disabilities: adults with Down syndrome, adults with autism and adults with developmental disabilities and a mental health and/or addictions diagnosis.
- To synthesize patterns across all findings and develop outcome-specific and overarching recommendations that can enhance policy, practice and intersectoral planning.

Key findings

Compared to adults without developmental disabilities, adults with developmental disabilities consistently fared worse across all five outcomes. This pattern held true regardless of age, sex, the wealth or poverty of the neighbourhood where they lived or the kind of developmental disability they had.

Among adults with developmental disabilities, the pattern of poor outcomes differed depending on the type of developmental disability.

30-Day repeat emergency department visits

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to have at least one 30-day repeat emergency department visit in the six-year study period (34.5% vs. 19.6%). This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.
- Among adults with developmental disabilities, those with a mental health and/or addictions diagnosis had a particularly high rate of repeat emergency department visits (42.8%).

Recommendations to reduce 30-day repeat emergency department visits:

- Develop and update cross-sector crisis, safety or care plans for all individuals with developmental disabilities following their initial emergency department visit and assess the impact of these plans on preventing repeat visits.
- Include adults with developmental disabilities and partners from the developmental disabilities sector in the current Ontario quality review processes for patients with repeat emergency department visits.

30-Day repeat hospitalizations

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to be readmitted to hospital within 30 days of their initial discharge in the six-year study period (7.4% vs. 2.3%). This pattern was observed for all age groups and both sexes and

held regardless of the wealth or poverty of the neighbourhood where they lived.

- Among those with developmental disabilities, persons with a mental health and/or addictions diagnosis had a particularly high rate of repeat hospitalizations (11.0%).

Recommendations to reduce 30-day repeat hospitalizations:

- Because patients with developmental disabilities are at high risk for readmission, flag them upon admission, link that flag to specific actions and provide them with enhanced cross-sector supports to transition out of hospital.
- Address the unique needs of patients with developmental disabilities in broader health care system initiatives to reduce rehospitalizations, such as patient-oriented discharge summaries.

Alternate level of care

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to have at least one alternate level of care day in hospital in the six-year study period (4.6% vs. 0.7%). (Alternate level of care is defined as care administered to patients who remain in hospital but are ready for discharge.) This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. Among the age groups, the adults with the highest rate of alternate level of care were those with developmental disabilities who were 50 to 65 years old (9.7%).
- Among adults with developmental disabilities, those with a mental health and/or addictions diagnosis had a particularly high rate of alternate level of care days (6.1%).

Recommendations to reduce alternate level of care:

- Proactively begin discharge planning upon admission with the person with a developmental disability, his or her caregivers and his or her health and social service partners.
- Incorporate recognition of developmental disabilities into the broader system of alternate level of care solutions and tailor accordingly.

Long-term care

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to spend at least one day in long-term care in the six-year study period (3.5% vs. 0.2%). This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. Among age groups, adults with the highest rate of long-term care use were those with developmental disabilities who were 50 to 65 years old (9.6%).
- Among those with developmental disabilities, adults with Down syndrome had a particularly high rate of long-term care use (8.2%).

Recommendations to address long-term care issues:

- Because the health of people with developmental disabilities declines at an earlier age, planning should begin early to ensure that supports are in place to allow them to age at home appropriately and to delay entry to long-term care.
- Within long-term care settings, supports tailored to the needs of those with developmental disabilities should be available, including the provision of staff with enhanced knowledge and training about developmental disabilities.

Premature mortality

- Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to experience premature mortality in the six-year study period (6.1% vs. 1.6%). (Premature mortality is defined as death before age 75.).This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. Among the age groups, the adults with the highest rate of early death were those with developmental disabilities who were 50 to 65 years old (14.6%).
- Among those with developmental disabilities, adults with Down syndrome had a particularly high rate of premature mortality (12.3%).

Recommendations to address premature mortality:

- Conduct developmental disability mortality reviews, as is being done in other countries, to identify contributors to premature deaths with a focus on preventable causes.
- Design and monitor interventions based on these reviews.

Cross-outcome implications and guiding principles

Adults with developmental disabilities were consistently disadvantaged for every outcome examined in this report. This reinforces other research demonstrating that these adults are a complex and highly vulnerable population and supports the recommendation that they require multifaceted solutions that address a range of health care outcomes. In addition, these solutions need to be tailored to the needs of specific developmental disability subgroups in order to increase their impact and relevance.

Many of the recommendations for the five outcomes overlap, pointing to the need to take a broader system perspective when considering interventions. Otherwise, as has been shown in other jurisdictions, solutions risk being implemented in an uncoordinated and siloed fashion. We recommend that four system-wide guiding principles be kept in mind when considering and implementing solutions. It should be noted that these principles are consistent with the 2006 *United Nations Convention on the Rights of Persons with Disabilities*, the *Ontario Human Rights Code* and the 2005 *Accessibility for Ontarians with Disabilities Act*.

1. Follow the rule of *Nothing about us without us*. People with disabilities and their families and supporters should be fully and meaningfully involved in the development of policies, programs and services that affect their lives.
2. A range of proactive supports and health care services should be provided in the community that are appropriate for and accommodate the specific needs of people with developmental disabilities.
3. Appropriate supports and health care services should be available and accessible in emergency department, hospital and long-term care settings.
4. When adults with developmental disabilities transition between different health care services or between health care and community settings, these transitions should be planned, well-coordinated and seamless.

Recommending how these guiding principles should be operationalized and by whom is beyond the scope of this report and should be determined by collaborative decision-making among all stakeholders. Our experience and the literature suggest that implementing these principles will be difficult unless the following key ingredients are present:

- A fully integrated, province-wide infrastructure that provides routine and timely information to
  - Providers regarding which patients have a developmental disability (by flagging or documenting in a health record), what their needs are and what gaps in care and support need to be addressed; and
  - Administrators, planners and policy-makers so they can monitor and evaluate the performance of existing supports and services. In addition, new initiatives should be subjected to small but well-designed and time-sensitive evaluations.
- Education for all stakeholders about their respective roles and responsibilities in creating and maintaining good health for people with developmental disabilities; and
- Availability of individuals with specialized expertise in developmental disability health care, when required.

1. Background

Introduction

Since 2010, a group of scientists, clinicians, policy-makers, administrators and advocates have been working together to better understand and address health care disparities experienced by Ontario adults with developmental disabilities (DD), through the Health Care Access Research and Developmental Disabilities Program, or H-CARDD.[1] H-CARDD's vision is for Ontarians with DD to live healthy lives in their home communities and to access the health care they need. To achieve this vision, H-CARDD has two aims: to discover information that will help develop policies and practices that support Ontarians with DD and then to move that knowledge into action. This report is part of the information or knowledge discovery aim.

We know from our previous H-CARDD research that adults with DD are a vulnerable population with complex health needs. The *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* reported that adults with DD are more likely than other adults to live in lower income neighbourhoods and have higher rates of chronic illness.[2] They use and re-use more health care, including outpatient, emergency and inpatient hospital services. They struggle to access preventive care and chronic disease management. They also have high rates of medication use.

At the same time, we know that adults with DD are a heterogeneous group. There are many different causes of DD, and the health care issues encountered by individuals with these disabilities can differ depending on their age, sex and diagnosis. Between 2013 and 2016, several projects from the H-CARDD Program were conducted to better understand the health needs and health service use profiles of subgroups including transition-aged youth, women, older adults and those with a mental health and/or addictions diagnosis. These projects highlighted the fact that it was important to look at age, sex and diagnoses associated with DD to understand how health care was or was not being used. However, much of this previous work was done by studying subgroups or specific health care outcomes separately. To ensure that the needs of the entire DD population are met, an integrated approach to studying their health care use and planning services is required.

This report is the product of a three-year project that, in consultation with an advisory committee of health care planners, policy-makers from multiple government ministries, community service providers and advocates, took a unified approach

What are developmental disabilities?

Under Ontario's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, 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." (Also see Ontario Regulation 276/10 of the Act at http://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." Conditions such as intellectual disability, autism, Down syndrome and fetal alcohol syndrome would all fit under this umbrella term.

Developmental disabilities can be genetic in origin (e.g., fragile X syndrome or Williams syndrome) or can be caused by illness or injury prenatally (e.g., maternal rubella or maternal alcohol consumption) or in early childhood (e.g., meningitis); in some cases, their 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.

to the examination of health care use patterns across subgroups and across different outcomes. The goal of this unified approach is to ensure that people with DD are considered as a whole and in this manner, bridge existing information, policy and planning silos.

This report has three goals:

1. To describe how adults with DD differ from adults without DD with regard to five important health and health care outcomes: 30-day repeat emergency department visits, 30-day repeat hospitalizations, alternate level of care, long-term care and premature mortality. These findings are provided for all of Ontario and by region (**Section 3**).
2. To describe these five outcomes for three subgroups of individuals with DD: adults with Down syndrome, adults with autism and adults with DD-and-MHA (that is, with a mental health and/or addictions diagnosis in addition to DD) (**Section 4**).
3. To synthesize patterns across all findings, and develop outcome-specific and overarching recommendations that can enhance policy, practice and intersectoral planning (**Section 5**).

The report is designed so that it can be easily used as a reference document. Each finding is described using a series of text bullets that provide more detail about the graph on the opposite page.

Data sources

Ontario adults with DD were identified using a definition that reflected the province's *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (see page 6). This definition was applied to information obtained by linking two data sources: administrative health data and data from the Ontario Disability Support Program (ODSP). The research literature has suggested that combining data sources increases the likelihood of detecting individuals with DD,[3] and we found that this was indeed the case. By relying on only one data source, we would have missed more than a third of the adults with DD in Ontario.[4] The data linkage resulted in a group of 66,484 Ontario residents who were between the ages of 18 and 64 in 2009/10 and who had a DD diagnosis in the administrative data sources used. This group currently provides the most comprehensive portrait of adults with DD in Ontario.

We also define three subgroups with DD, which are not mutually exclusive. One subgroup consists of adults with Down syndrome. Individuals in this subgroup received a diagnosis of Down syndrome in either the administrative health or ODSP data. Identification in this way is consistent with research from other jurisdictions that have used administrative data to study health patterns in Down syndrome.[5,6] A second subgroup is adults with autism. The algorithm for this subgroup builds upon previous H-CARDD work looking at autism in young adults.[7] The third subgroup, adults with DD-and-MHA, also builds upon prior H-CARDD work and includes those adults with DD who had a mental health and/or addictions diagnosis recorded in their health data in the two years prior to the study period.[8] (For more details on the databases used and the DD and subgroups definitions, see **Appendix A**.)

Sociodemographic and clinical profiles

The 2013 *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* reported sociodemographic, clinical and service use profiles for Ontario adults with DD based primarily on 2009/10 data.[2] For this report, we followed that cohort from 2010/11 with the result that the original size changed from 66,484 to 64,699 adults because of factors such as death, a change in Ontario Health Insurance Plan eligibility or moving out of province and are referred to in this report as adults with DD. Because this decrease is slight (less than 3%), the sociodemographic, clinical and health service utilization profiles reported in the Atlas are essentially unchanged between 2009/10 and 2010/11 and consequently are not reported here.

A WORD ABOUT LANGUAGE

In this report, 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 that do not include significant cognitive limitations. In the past, the term *mental retardation* was commonly used in medical settings.This term is now considered pejorative and has been removed from legislation in Ontario and in the United States, as well as from medical jargon. It has been replaced with *intellectual disability* in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and with *disorder of intellectual development* in the International Classification of Diseases (ICD-11).

There is an ongoing debate about the use of 'person-first' or 'identify-first' language. In this report, we use the 'person-first' language throughout; that is, we refer to adults with developmental disabilities as opposed to developmentally disabled adults or the developmentally disabled.

Health and health care outcomes

We report on five important health and health care outcomes for both the entire group of adults with DD and the three subgroups. While these outcomes may be necessary in some circumstances because of individual needs, they have been flagged in the literature as potentially preventable. Additional detail is also provided by age, sex and neighbourhood income level because knowing who is at greater risk for the occurrence of these outcomes may guide efforts toward improvement. These outcomes and why they are important for adults with DD are described in more detail in **Section 2**.

Analysis

In our analyses, we provide descriptive and outcome information for adults with DD by following them for a six-year period from April 1, 2010, to March 31, 2016 (the year after the cohort was created to the most recent year for which data were available). We also present similar information for the one-year period from April 1, 2015, to March 31, 2016.

For context, we provide the same descriptive and outcome information for several comparison groups. For each of the five outcomes, adults with DD are compared to a 20% random sample of the Ontario population without DD (labeled Without DD). The subgroup of adults with Down syndrome is compared to other adults with DD who do not have Down syndrome (labeled DD-without-Down-syndrome). Similarly, adults with autism are compared to other adults with DD who do not have autism (labeled DD-without-autism). The subgroup of adults with DD-and-MHA are compared with the remaining adults with DD (labeled DD-only) and to the subgroup of individuals in the 20% sample who had a mental health and/or addictions diagnosis (labeled MHA-only). This provides more information on how similar or different adults with DD-and-MHA are from those with DD-only or MHA-only.

Meaningfulness: understanding and interpreting results

This report makes a number of comparisons (for example, between those with and without DD or between those with and without autism) in order to help the reader understand and interpret the results.

How do we know when a difference is meaningful? The answer is not simple. A number of methods are used to judge if a difference is important or can be ignored; none are perfect. Some of these methods and their downsides (as they pertain to our study) include the following:

Statistical significance. In the scientific literature, this is most commonly determined using such indicators as p-values or confidence intervals of 95% or 99%. The downside: When the groups being compared are large in number (as is the case for this report), almost every comparison will be statistically significant and therefore tell us nothing about importance. For example, in a large sample, the difference between 2.0% and 2.2% could be statistically significant but perhaps not meaningful in the real world. Finally, statistical significance is designed for testing hypotheses, which is not being done in this report. Therefore, we do not report on statistical significance.

Clinical or practical significance. This method focuses on whether a difference makes a real-world impact. There are many ways to define impact. For example, a small difference in percentage points may amount to a large difference when translated into dollars spent or individuals affected. This method is appealing because it seems to connect directly to making real-world decisions. The downside: There is no consistent way to determine practical significance for the five outcomes examined in this report. For example, is a difference of one percentage point important in the premature death rate of those with DD compared to those without? Therefore, we are not using this method.

Absolute difference. Sometimes a threshold method is used; for example, if the difference between the two percentage points is 5% or greater. The downside: The percentages for several of our results are very small (for example, 1.0 vs. 0.5%). Using a common threshold of 5% would imply that all of these results can be ignored. For outcomes that are rare but important, this method could be problematic.

Difference ratio. This method compares two percentages in terms of how many times higher one is than the other. This has the advantage of highlighting the magnitude of differences (for example, adults with DD are five times as likely to have a particular outcome compared to adults without). The downside: This method on its own can lead to exaggerated and possibly inappropriately alarming results if the percentages are small; for example, the rate for a particular outcome is 20 times higher for adults with DD compared to those without (based on a difference between 3.5% and 0.2%). A more thoughtful approach would be to look at both the absolute difference between the groups (which may be small) and the difference ratio to highlight that an event may be rare but that it also occurs more frequently in one group than another.

Eyeball method. This approach interprets results based on the visual impact of a graph (for example, which bar is the highest?). This can be useful when there are really striking differences. The downside: This method can be misleading if something other than actual numbers is being graphed. For example, Group A may have a premature death rate of 50% compared to a 10% rate for Group B, resulting in a bar for Group A that is five times higher than the bar for Group B. However, if Group A consists of two people while Group B consists of 1,000 people, this translates into an actual difference of one person versus 100 people who have died.

Pattern approach. This approach compares patterns across findings. For example, in this report, we have found that for several of the outcomes, women have slightly higher percentages than men. For each outcome, the difference is small – sometimes so small that it seems unimportant. However, the fact that the pattern repeats itself for each outcome suggests a meaningful difference. The downside: This method can be highly subjective. Also, outcomes are sometimes correlated with each other such that if one outcome shows a result, then all the others will too. This tends to exaggerate the consistency of the pattern.

Because of the complexity of our findings, we used the following approach and combination of methods to decide which differences were meaningful:

- Interpret differences on a case-by-case basis, based on clinical, research or policy experience using one or more of the following four approaches: absolute difference, difference ratio, eyeball method and pattern approach; and
- Provide readers with the actual percentages or numbers so that they can decide if they agree with our interpretation or not.

2. Definitions of Health and Health Care Outcomes

Why are these outcomes important?

This report focuses on five important health and health care outcomes that are potentially preventable and may point to opportunities for health care improvements.

We were interested in examining the proportion of adults with DD impacted by each of the five outcomes. As noted earlier, the studies that already exist about these outcomes have been produced in a way that reinforces information, policy and planning silos. Consequently, in this report we studied each health and health care outcome for all adults with DD in Ontario, and not just for those who had an emergency department visit or were hospitalized, for example. This means that our results are reported as a percentage of the entire population of Ontario adults with DD.

For each outcome, we examined the six years after 2009/10 (the year for which data were used to create the adults with DD group). This was done in order to have large enough numbers to report, particularly for the rarer outcomes. Because many planners use one-year results, we also report findings for 2015/16 alone.

These outcomes and the reasons they are particularly concerning for adults with DD are described below.

30-Day repeat emergency department visits

This outcome is defined as a return to the emergency department within 30 days after a previous visit or, if that first visit led to a hospital admission, after discharge from that hospitalization.

In 2014/15, 5.9 million visits were made to Ontario emergency departments[9] at a significant cost to the health care system. Returning to the emergency department shortly after a prior visit is not only stressful to the patient and hospital staff but in some cases might be avoidable. Repeat emergency department visits can be a signal that the initial emergency department treatment was not adequate or that the individual did not receive appropriate care in the community after the first emergency department visit. This indicator is monitored by the Ontario Ministry of Health and Long-Term Care and by Health Quality Ontario.

Our prior work, as well as research in other jurisdictions, has shown that recurrent emergency department use is a major concern for adults with DD.[10] The emergency department environment can be stressful, both because deficits associated with DD hamper these individuals' ability to communicate their concerns[11] and because staff often do not have the skills needed to work with them.[12-15] In addition, adults with DD may be discharged from the emergency department with unclear or limited connections to community resources, which can lead them to return to the emergency department, sometimes without the underlying cause of the distress ever being addressed. Both patients and caregivers have expressed concerns about this experience.[16,17]

To measure repeat emergency department visits, we counted the number of individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) who had made an emergency department visit followed by another emergency department visit within 30 days of discharge (from either the first emergency department visit or a hospital admission resulting from the first emergency department visit). This count was then divided by the total number of individuals in the group of interest. This method was applied to the six years between 2010/11 and 2015/16 and to 2015/16 alone.

30-Day repeat hospitalizations

This outcome is defined as a readmission to hospital within 30 days after being discharged from a previous hospital stay.

In 2016/17, 9.2% of Ontario residents were readmitted to hospital within 30 days of their initial discharge, at a significant emotional and financial cost.[18] While a repeat hospitalization may sometimes be necessary, this outcome is often used as a marker for health system failure that can be attributed to problems in how care is provided both during and after a hospital stay and in how services are integrated between the hospital and the post-discharge setting.

For individuals with DD, returning to hospital within 30 days may be especially problematic. Several studies have highlighted the poor hospital experiences that adults with DD have[12] and the challenges that staff have supporting them in inpatient settings.[13]

Readjusting to hospital and readjusting to community can both be difficult, as can the change in supports and routines in either setting. Successful discharges for this group require coordination, not only between hospital and community but also across different funders and sectors.

To measure repeat hospitalizations, we counted the number of individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) who had an admission to hospital, followed by another admission within 30 days after being discharged from the first admission. This count was then divided by the total number of individuals in the group of interest. This method was applied to the six years between 2010/11 and 2015/16 and to 2015/16 alone.

Alternate level of care

This outcome is defined as the situation when a patient occupies a bed in a hospital but does not require the intensity of resources or services provided in that setting as determined by the attending physician.[19]

The proportion of inpatients who are designated as alternate level of care during their hospital stay and the number of alternate level of care days spent in hospital have become important performance indicators across Canada.[19,20] This is because alternate level of care is costly, prevents new people from being admitted to hospital and signals the possibility that appropriate discharge placements are not available outside of the hospital setting. In Ontario, hospitals regularly report alternate level of care days for patients in acute, complex continuing, rehabilitation and mental health beds to the Local Health Integration Networks. This information is tracked by Cancer Care Ontario, and investments have been made in hospitals to prioritize discharging alternate level of care patients.

A number of studies and reports[21-23] have indicated that individuals with DD are at higher risk for experiencing alternate level of care days because the necessary social and health supports are not available to them in the community. Indeed, in 2016 the Ontario Ombudsman flagged this as an important concern for adults with DD and recommended that the then Ministry of Community and Social Services (now the Ministry of Children, Community and Social Services) prioritize such patients as urgent for community placements (recommendation 18).[24]

To measure alternate level of care, we counted the number of individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) who had been discharged from hospital having experienced one or more alternate level of care days. This count was then divided by the total number of individuals in the group of interest. This method was applied to the six years between 2010/11 and 2015/16 and to 2015/16 alone.

Long-term care

This outcome measures the number of people living in Ontario's long-term care facilities.

Living at home for as long as possible and receiving needed care and support in the home setting is both a personal desire of many individuals and a strategic priority of the Government of Ontario.[25]

Higher rates of admission to long-term care, particularly in younger adults, may signal problems with the services and supports available in the community. A policy guideline developed jointly by the health and social service sectors outlines when and how long-term care should be used for individuals with a developmental disability.[26]

While it is well recognized that aging adults with DD may require long-term care just as other aging adults do, admission to long-term care facilities can be problematic for individuals with DD as these settings are typically not designed to accommodate their particular needs.[24] Research has shown that long-term care use occurs at a higher rate and at a younger age on average for people with DD compared to those without DD.[27] In *Nowhere to Turn*, the Ontario Ombudsman suggested that in some situations, long-term care could be "another form of institutionalized care often used as a stopgap solution when more appropriate residential placements are unavailable." The Ombudsman recommended that the then Ministry of Community and Social Services (now the Ministry of Children, Community and Social Services) monitor long-term care use, particularly among younger adults, and review all current and future long-term care placements to make sure they were appropriate (recommendations 20–24).[24]

To measure long-term care, we counted the number of individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) who were in a long-term care facility. This count was then divided by the total number of individuals in the group of interest. This method was applied to the six years between 2010/11 and 2015/16 and to 2015/16 alone.

Premature mortality

Premature mortality is a measure of the number of deaths occurring before the age of 75 in a given population over a specific period of time.[28]

Mortality rates have long been used as indicators of the state of health of a population.[29,30] They are associated with a number of interrelated factors which are thought to either increase the risk of early death or protect against it. These include social factors (e.g., income, education, living conditions), individual factors (e.g., presence of comorbidity), health behaviours (e.g., tobacco use, exercise) and the quality and quantity of health services.[31] Differences in mortality rates can signal inequities in these underlying factors and therefore flag areas needing further investigation and intervention. In Canada, the Canadian Institute for Health Information (CIHI) tracks different types of mortality when describing the health of Canadians and the health system, including premature mortality (which is included in this report) as well as avoidable and preventable mortality.[28]

Internationally, it has been well documented that adults with DD experience death at an earlier age[32] and at a higher rate than the general population.[33,34] It has been suggested that high mortality rates may be attributed both to the disability itself as well as the poor quality of health care they receive. Indeed, many deaths have been categorized as preventable within the DD population.[35] Canadian research suggests that mortality is a concern for adults with DD,[36] but few comparisons have been made between subgroups of individuals with DD.

Because all of the individuals in our analyses were younger than age 75, any deaths qualify for CIHI's definition of premature mortality. Our measure was defined as the number of deaths occurring among the individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) divided by the total number of individuals in that group. This method was applied to the six years between 2010/11 and 2015/16 and to 2015/16 alone.

BRENDA'S STORY

I can't breathe: Repeated emergencies

Brenda*, a woman in her late fifties with a developmental disability, lived in a group home with 24-hour support. She was a happy, lively person who loved country music and dancing. She started to exhibit some distressing behaviours and possible signs of dementia but could not communicate what was wrong using words. After a choking incident, Brenda visited the hospital emergency department and received follow-up care from her family doctor. As well, group home staff implemented recommendations from a swallowing assessment. Brenda went back to the emergency department less than a month later with problems breathing, was assessed by hospital staff and sent home with follow-up care from her family doctor.

Always loved, never forgotten

On her third visit two weeks later, Brenda presented to the hospital with laboured breathing. She was given oxygen therapy, and when her breathing returned to normal, she was discharged home with flu-like symptoms. But within two days, support staff thought something was seriously wrong and called the paramedics to take Brenda back to the hospital. She was diagnosed with aspiration pneumonia and died in hospital less than 48 hours later. Her death was shocking and heartbreaking to the people who knew her. Bereavement counseling was arranged for the people with disabilities at her agency and for her support team.

* Based on a real case. The name and details have been changed for privacy.

3. Outcomes for Adults With and Without Developmental Disabilities

30-Day repeat emergency department visits

Prevalence: Adults with DD, compared to adults without DD, were more likely to have at least one 30-day repeat emergency department visit in the six years studied (respectively, 34.5% vs. 19.6%; see **Exhibit 1**). The same pattern was found in each of the six years (data not shown).

In 2015/16, 11.2% of the DD population had at least one repeat emergency department visit compared to 4.6% of the population without DD. When considering only those who visited emergency departments in 2015/2016, 32.6% of emergency department visitors with DD had a repeat visit compared to 22.0% of emergency department visitors without DD.

The higher rates of 30-day repeat emergency department visits for adults with DD were observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.

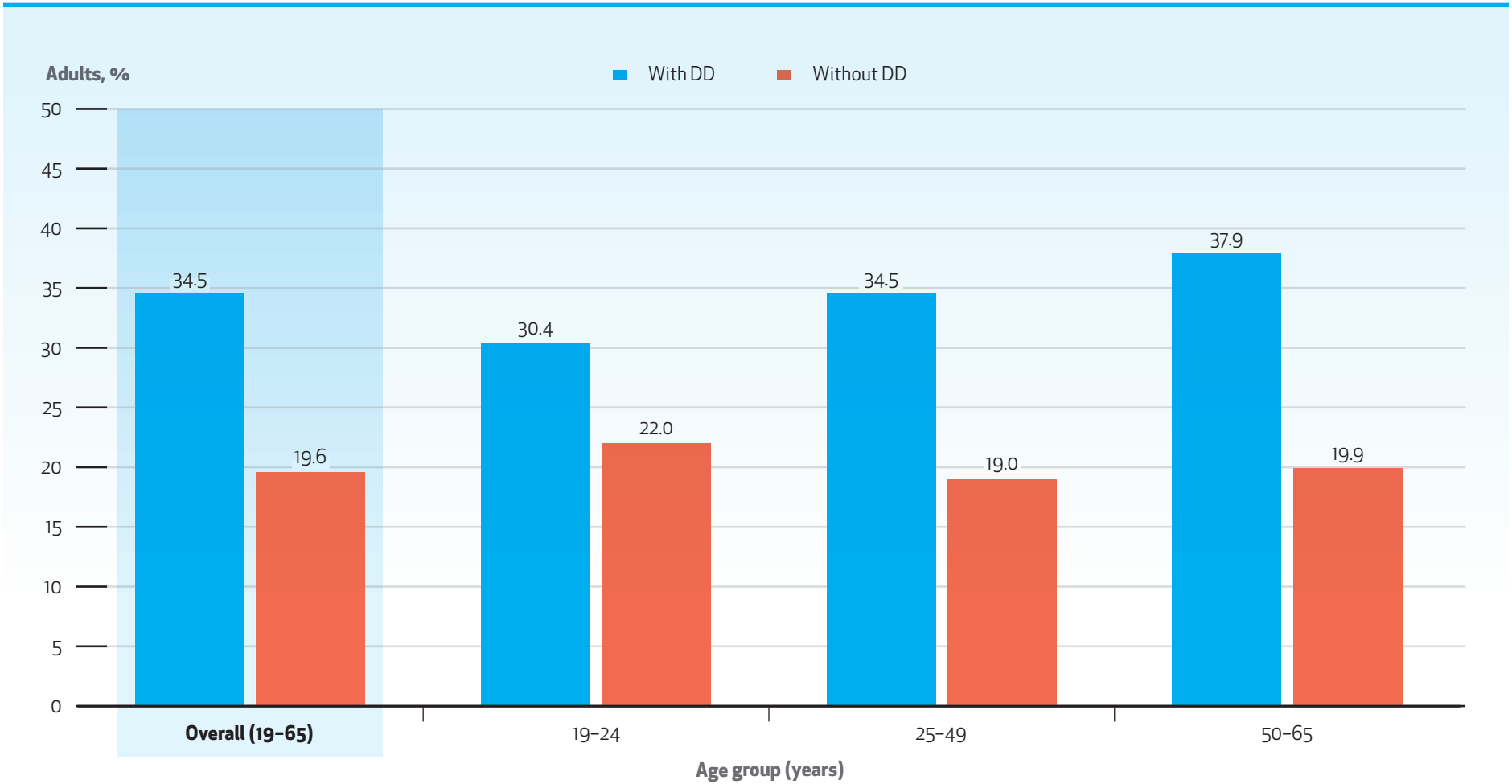
- Age: The difference between those with DD and without DD was present for all age groups but was most evident in the oldest age group (37.9% for adults with DD vs. 19.9% for adults without DD).

  Among adults with DD, the prevalence of repeat emergency department visits increased with age while it remained relatively stable (between 19.0% and 22.0%) across age among those without DD.

- Sex (data not shown): For both groups, return to the emergency department was slightly more common among women than men (respectively, 36.9% vs. 32.8% for adults with DD and 20.7% vs. 18.5% for adults without DD).

- Neighbourhood income level (data not shown): For both groups, there was a noticeable pattern in that the rates of repeat emergency department visits decreased steadily as wealth of the neighbourhood increased. Those living in the poorest neighbourhoods were the most likely to have had at least one repeat emergency department visit over the six years while those living in the wealthiest neighbourhoods were the least likely (39.3% vs. 29.7% for adults with DD and 23.8% vs. 16.3% for adults without DD).

EXHIBIT 1 Proportion of adults aged 19 to 65 years with or without developmental disabilities who had a 30-day repeat emergency department visit, overall and by age group, in Ontario, 2010/11 to 2015/16



30-Day repeat hospitalizations

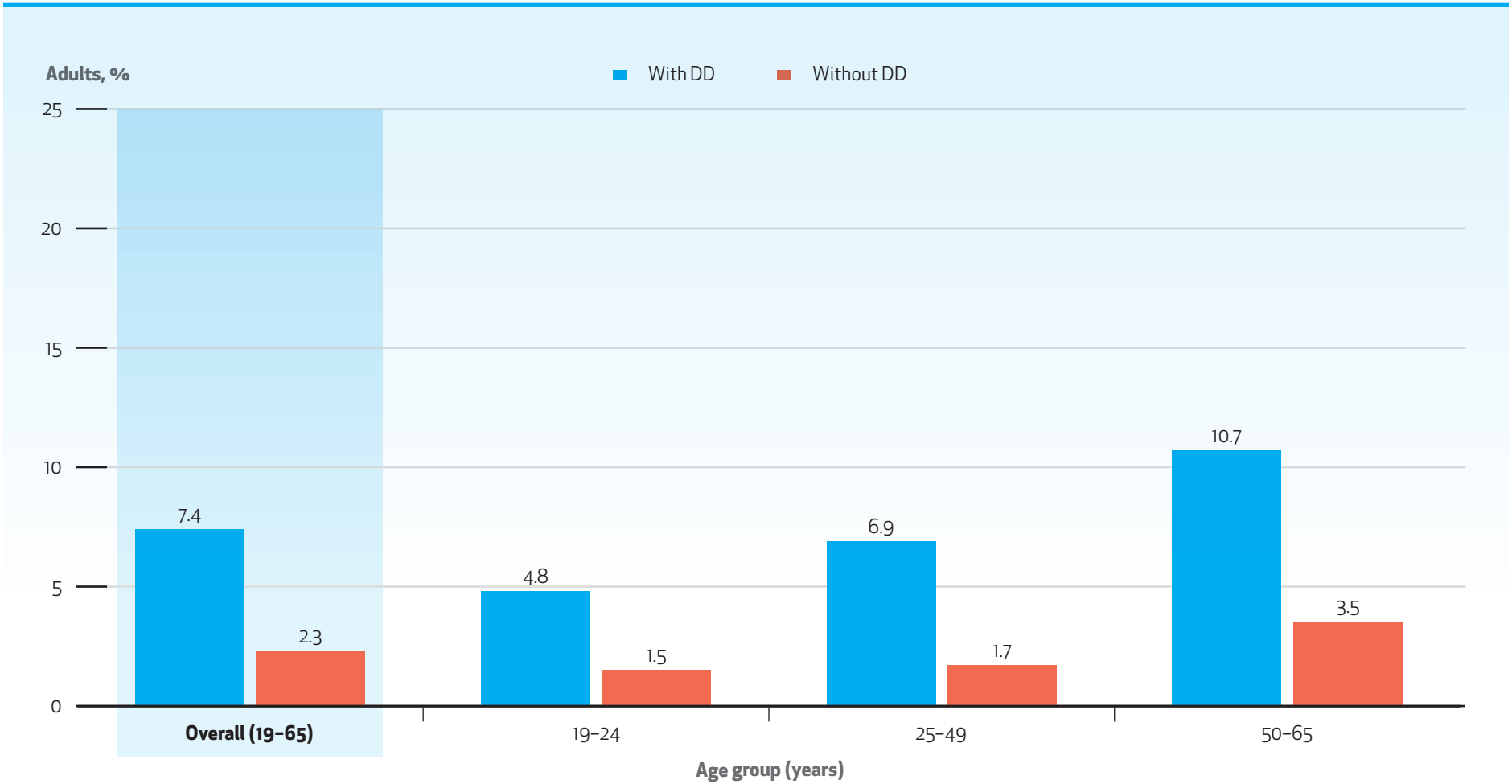
Prevalence: Adults with DD, compared to adults without DD, were more likely to be readmitted to hospital within 30 days of their initial discharge in the six years studied (7.4% vs. 2.3%; see **Exhibit 2**). The same pattern was found in each of the six years (data not shown).

In 2015/16, 1.8% of the DD population had a repeat hospitalization compared to 0.5% of the population without DD. When considering only those who had at least one hospitalization in 2015/2016, 17.7% of those with DD who were hospitalized had a repeat hospitalization compared to 9.4% of those without DD who were hospitalized.

The higher rates of 30-day repeat hospitalizations for adults with DD were observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.

- Age: For both groups of adults (with and without DD), the rate of repeat hospitalization increased with age; however, the patterns differed. For adults with DD, the rate increased steadily from the youngest age group (4.8%) to the oldest (10.7%). For adults without DD, the rate did not increase until the oldest age group (3.5% for those aged 50-65). The largest difference between adults with and without DD occurred in the 25- to 49-year-old age group where the difference ratio was 4.1 (6.9% for adults with DD vs. 1.7% for those without DD).
- Sex (data not shown): For both groups, repeat hospitalizations were slightly more common among women than men (respectively, 8.2% vs. 6.9% for adults with DD and 2.4% vs. 2.1% for adults without DD).
- Neighbourhood income level (data not shown): For both groups, the rate of returning to hospital showed a small but steady decrease as the wealth of their neighbourhood increased. The rates were highest for adults living in the poorest neighbourhoods and lowest for those living in the wealthiest areas (respectively, 8.2% vs. 6.8% for adults with DD and 3.0% vs. 1.9% for adults without DD).

EXHIBIT 2 Proportion of adults aged 19 to 65 years with or without developmental disabilities who had a 30-day repeat hospitalization, overall and by age group, in Ontario, 2010/11 to 2015/16



Alternate level of care

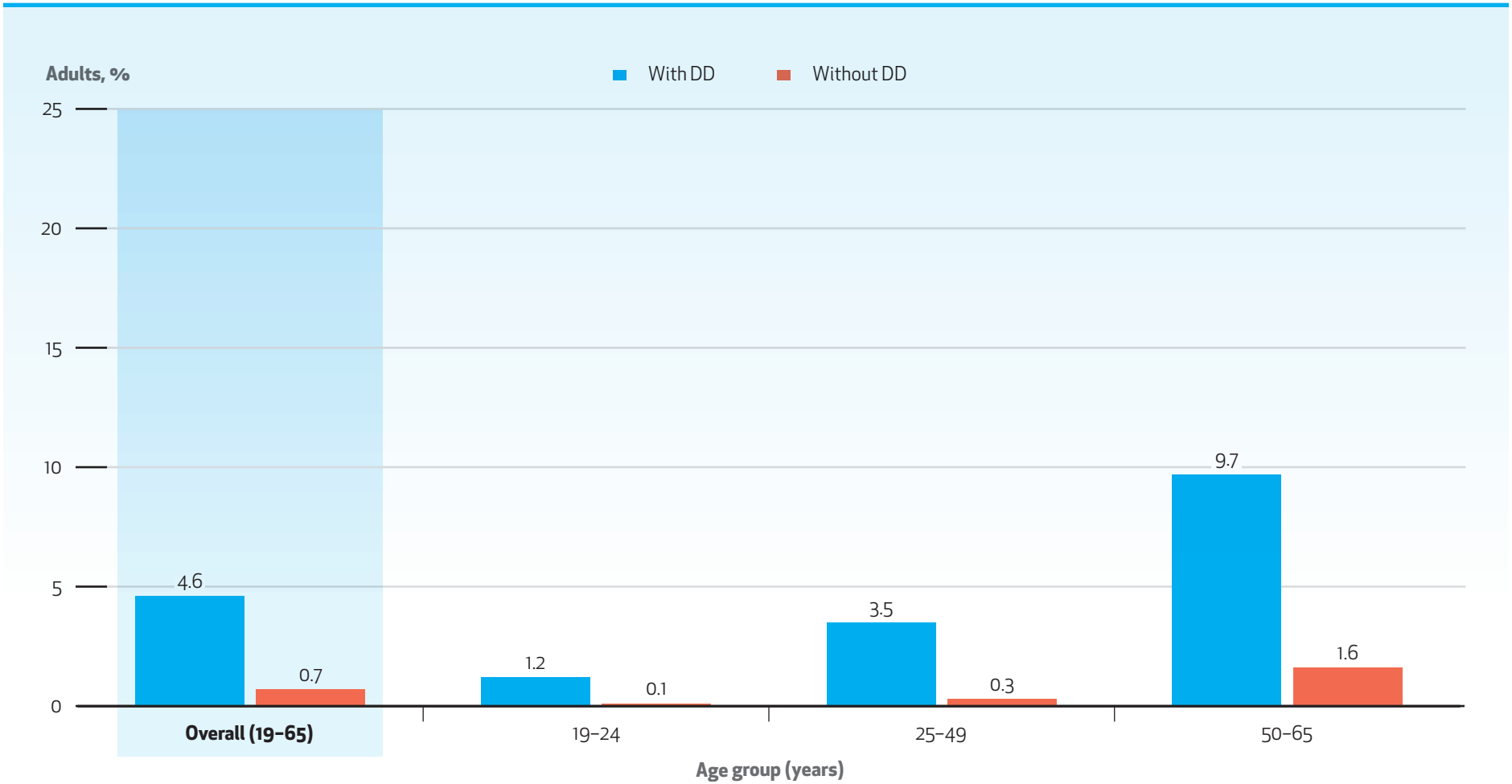
Prevalence: Adults with DD, compared to adults without DD, were more likely to have at least one alternate level of care day over the six years studied (4.6% vs. 0.7%; see **Exhibit 3**). The same pattern was found in each of the six years (data not shown).

In 2015/16, 1.0% of the DD population had an alternate level of care day compared to 0.2% of the population without DD. When considering only those who were hospitalized in 2015/2016, 10.4% of those with DD who were hospitalized had an alternate level of care day compared to 3.1% of those without DD who were hospitalized.

The higher rates of alternate level of care for adults with DD were observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.

- Age: For both adults with and without DD, the highest prevalence occurred in the oldest age group: 9.7% of adults with DD aged 50-65 years had an alternate level of care episode compared to 1.6% of adults without DD aged 50-65 years, a difference ratio of 6.1. While the younger age groups had lower rates of alternate level of care, the difference ratio for those with and without DD was larger. The prevalence of alternate level of care for adults with DD was 12 times higher than the prevalence for adults without DD for both the 19-24 year olds (respectively, 1.2% vs. 0.1%) and the 25-49 year olds (respectively, 3.5% vs. 0.3%).
- Sex (data not shown): Alternate level of care rates were similar for women and men in both groups (respectively, 4.7% vs. 4.5% for adults with DD and 0.6% vs. 0.8% for adults without DD).
- Neighbourhood income level (data not shown): For both groups, the rate of alternate level of care showed a small but steady decrease as the wealth of the neighbourhood increased. Those living in the poorest neighbourhoods had the highest percentages of having at least one alternate level of care day while those living in the wealthiest neighbourhoods had the lowest (respectively, 5.1% vs. 3.7% for adults with DD and 1.0% vs. 0.5% for adults without DD).

EXHIBIT 3 Proportion of adults aged 19 to 65 years with or without developmental disabilities who had an alternate level of care day, overall and by age group, in Ontario, 2010/11 to 2015/16



Long-term care

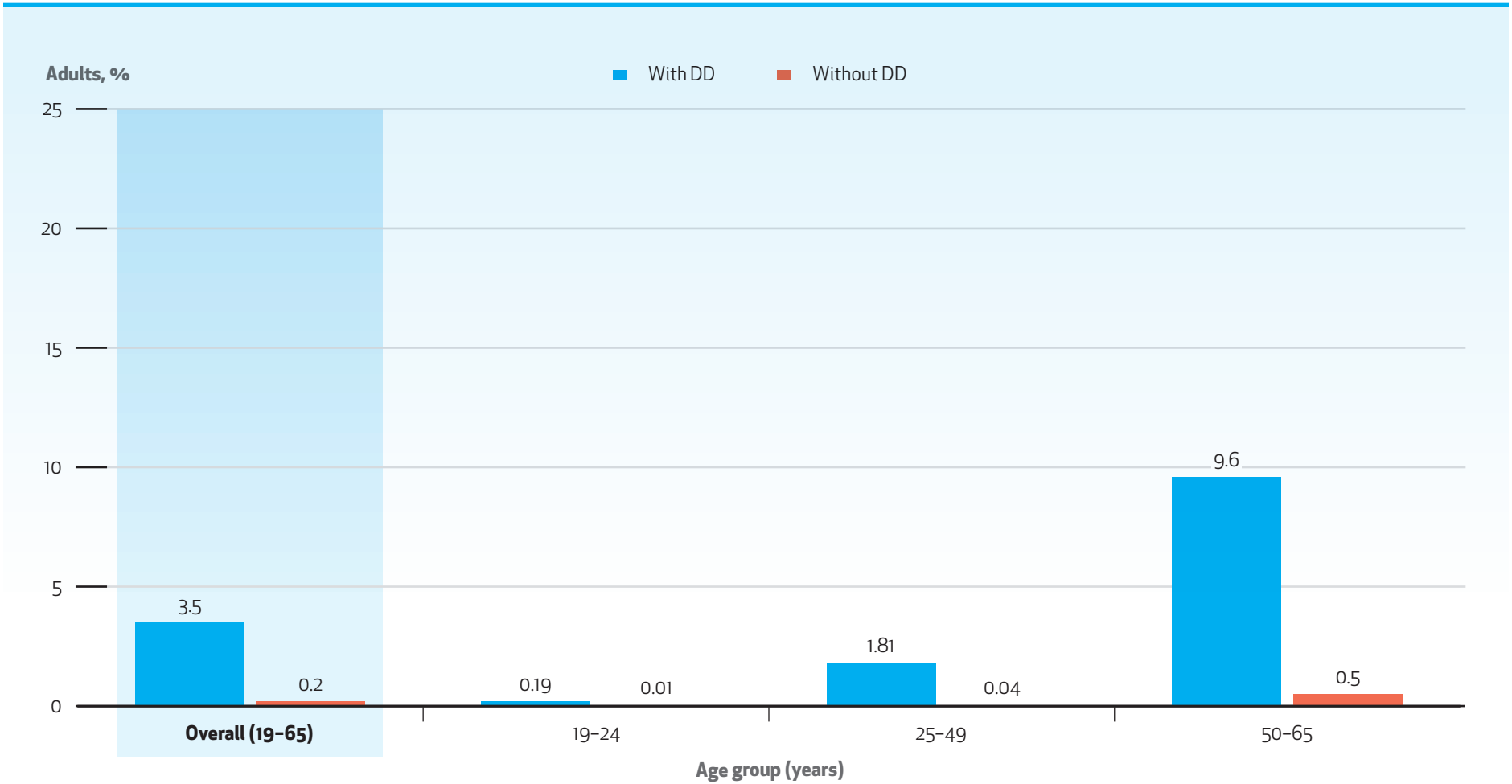
Prevalence: Adults with DD, compared to adults without DD, were more likely to spend at least one day in long-term care over the six years studied (3.5% vs. 0.2%; see **Exhibit 4**). The same pattern was found in each of the six years (data not shown).

In 2015/16, 2.1% of adults with DD had a long-term care day compared to 0.1% of adults without DD.

The higher long-term care rates for adults with DD were observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.

- Age: For both adults with and without DD, the prevalence of long-term care increased with age. The highest rate occurred among the oldest adults with DD (9.6%). Because use of long-term care was practically non-existent among adults without DD, the difference ratios for those with and without DD were high. The largest ratio (45.3) occurred in the 25- to 49-year-old age group (that is, 1.81% divided by 0.04%). For the other two age groups, the difference ratio was 19 (respectively, 0.19% vs. 0.01 % for the youngest age group and 9.6% vs. 0.5% for the oldest age group).
- Sex (data not shown): For adults with DD, long-term care use was slightly more common among women than men (4.3% vs. 2.8%). This differed from the pattern for adults without DD where rates of long-term care use for women and men were identical (0.2%).
- Neighbourhood income level (data not shown): Unlike the patterns found for repeat emergency department visits, repeat hospitalizations and alternate level of care, the wealth or poverty of the neighbourhood where the person lived had little impact on long-term care use among adults with DD in that the percentages of those in long-term care were nearly identical across income levels (between 3.2% and 3.6%). (The percentages for adults without DD were too small – between 0.3% and 0.1% from low- to high-income levels – to allow for any meaningful comparisons.)

EXHIBIT 4 Proportion of adults aged 19 to 65 years with or without developmental disabilities who had a long-term care day, overall and by age group, in Ontario, 2010/11 to 2015/16



Premature mortality

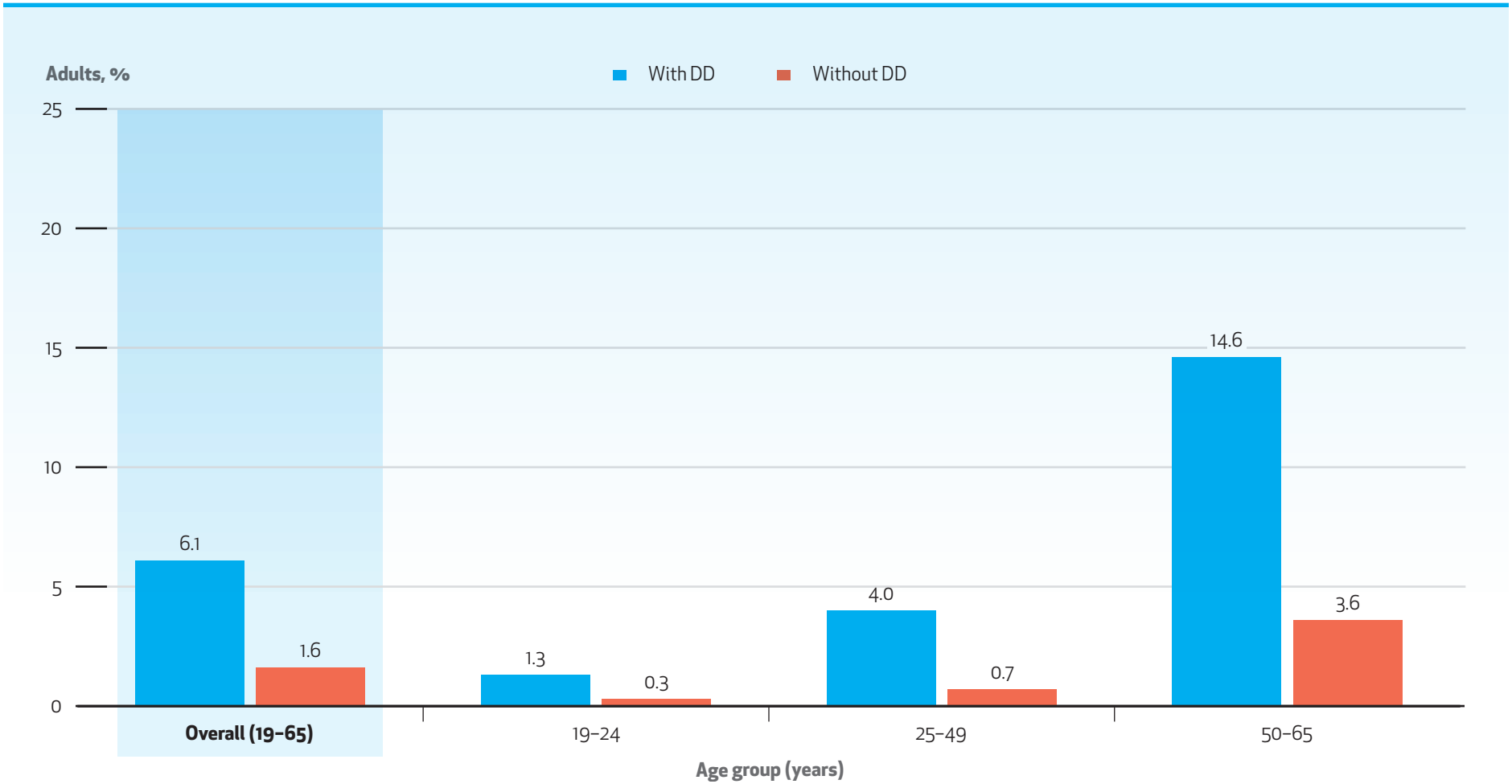
Prevalence: Adults with DD, compared to adults without DD, were more likely to die prematurely (that is, before age 75) over the six-year study period (6.1% vs. 1.6%; see **Exhibit 5**). The same pattern was found in each of the six years (data not shown).

In 2015/16, 1.2% of adults with DD died compared to 0.3% of adults without DD.

The higher rate of premature mortality for adults with DD was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.

- Age: For both adults with and without DD, the prevalence of premature mortality increased with age. The highest rate occurred among the oldest adults with DD (14.6%) which was four times higher than their same aged counterparts without DD (3.6%). Although fewer adults between the ages of 25 and 49 died prematurely than older adults, it is worth noting that adults with DD in that age group were 5.7 times more likely to die than adults without DD.
- Sex (data not shown): For both adults with and without DD, premature mortality rates were similar for men and women. Following the pattern found for other outcomes, the rate for women was very slightly higher for adults with DD (6.3% vs. 6.0% for men). For adults without DD, the reverse was true (1.3% for women vs. 1.9% for men).
- Neighbourhood income level (data not shown): For adults without DD, the pattern for premature mortality across neighbourhood income levels was similar to that found for repeat emergency department visits, repeat hospitalizations and alternate level of care: rates showed a small but steady decrease (from 2.2% to 1.3%) as neighbourhood income increased. However, for adults with DD, there was no obvious pattern across neighbourhood income levels; the percentages fluctuated between 5.8% and 6.3%. Furthermore, the wealthiest neighborhoods exhibited the highest percentage of premature mortality (6.3%).

EXHIBIT 5 Proportion of adults aged 19 to 65 years with or without developmental disabilities who died prematurely, overall and by age group, in Ontario, 2010/11 to 2015/16



Outcomes overview

Prevalence

- Adults with DD were consistently more likely to experience all five of the outcomes we studied compared to adults without DD.
- The disparities between the two groups ranged from a nearly 2-fold difference for 30-day repeat emergency department visits (34.5% vs. 19.6%) to a nearly 18-fold difference for long-term care (3.5% vs. 0.2%).
- In addition to the prevalence rates, **Exhibit 6** shows the total number of adults with DD who experienced each outcome over the six years studied.

Age

- Compared to younger adults, adults aged 50 and older had the highest rates for four of the five outcomes, regardless of whether or not they had DD. The exception was 30-day repeat emergency department visits for adults without DD where the youngest age group had the highest rate (see **Exhibit 1**).
- In addition, older adults with DD had consistently higher rates than their same-aged peers without DD for every outcome.

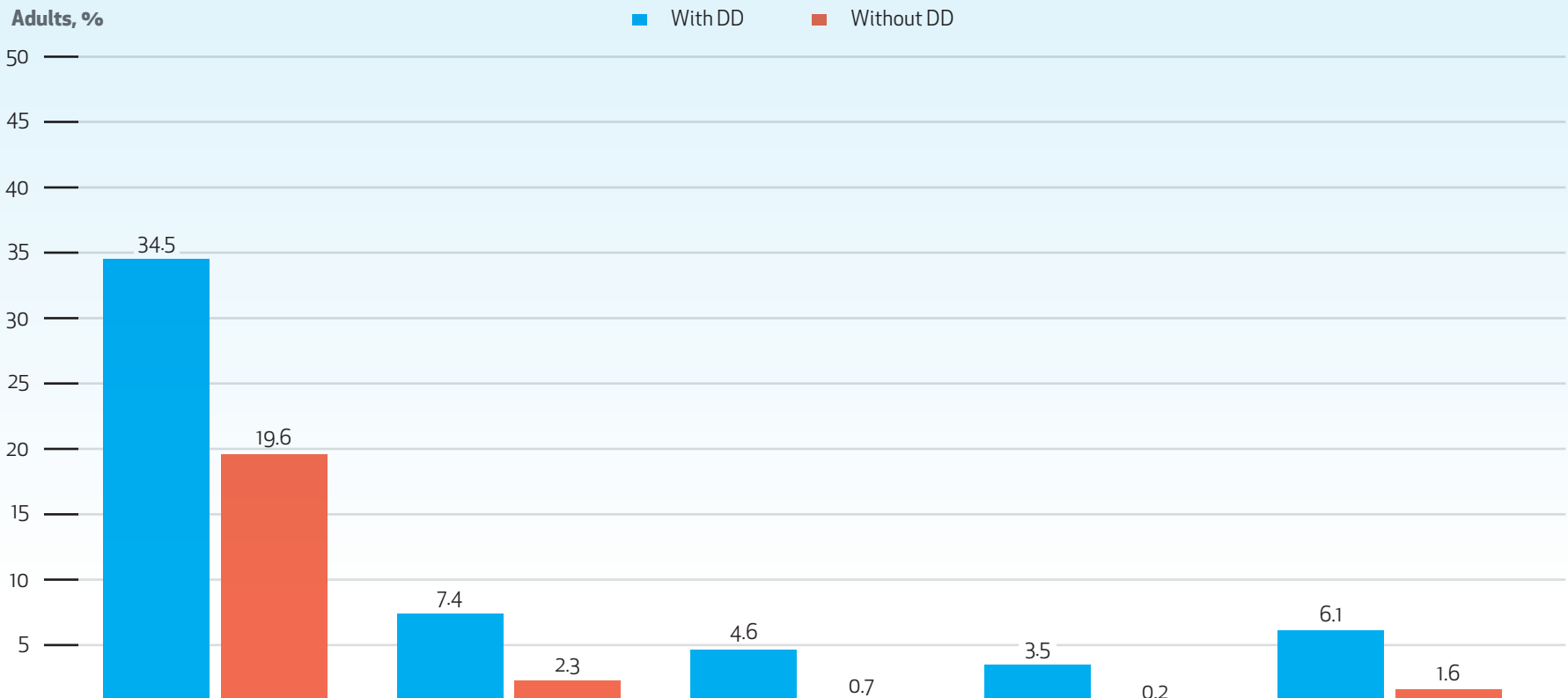
Sex

- Women with DD had slightly higher rates than men with DD for all five outcomes. This was less evident among those without DD (data not shown).

Neighbourhood income level

- The most consistent finding across studies of health status or health care use[37,38] is the existence of a gradient across socioeconomic status, with the poorest individuals having the worst outcomes and the wealthiest individuals having the best. For adults without DD, this pattern held true for all of the five outcomes studied.
- For adults with DD, the same pattern held true for three of the five outcomes. Those living in the poorest neighbourhoods had the highest rates, while those living in the wealthiest neighbourhoods had the lowest rates for 30-day repeat emergency department visits (39.3% vs. 29.7%), 30-day repeat hospitalizations (8.2% vs. 6.8%) and alternate level of care (5.1% vs. 3.7%) (data not shown).
- However, for long-term care and premature mortality, there were different patterns. For long-term care, the percentages for adults with DD were nearly identical across income levels. For premature mortality, the percentages fluctuated, with those living in the wealthiest neighbourhoods having the highest rate (6.3%) (data not shown).

EXHIBIT 6 Proportion and number of adults aged 19 to 65 years with or without developmental disabilities, by health and health care outcome, in Ontario, 2010/11 to 2015/16



Adults, n	22,335	526,449	4,814	60,858	2,957	18,466	2,231	4,577	3,960	42,659

Comparisons across Local Health Integration Networks

For each of the five outcomes we studied, the results for the Local Health Integration Networks (LHINs) (see **Exhibit 7**) mirrored the provincial results: Adults with DD always had a higher rate for a given outcome than the comparison cohort of adults without DD. (See **Exhibit 8** for 2010/11 to 2015/16 results and **Exhibit 14** in Appendix C for 2015/16 results.)

For the five outcomes, the difference ratios (i.e., the rate for adults with DD divided by the rate for adults without DD) were as follows:

- For the province, 30-day repeat emergency department visits were nearly twice as high (that is, 34.5% divided by 19.6%). Across the LHINs, the difference ratios were fairly close to the provincial ratio (between 1.5 and 2 times as high).
- For the province, 30-day repeat hospitalizations were more than three times as high (that is, 7.4% divided by 2.3%). Across the LHINs, the difference ratios were fairly close to the provincial ratio (between 3 and 4 times as high).
- For the province, the rate for any alternate level of care days was almost seven times as high (that is, 4.6% divided by 0.7%). Across the LHINs, the difference ratios ranged between 5 and 9 times as high.
- For the province, the rate for long-term care was nearly 18 times as high (that is, 3.5% divided by 0.2%). Across the LHINs, the difference ratios varied widely compared to the provincial ratio (between 13 and 28 times as high).
- For the province, the rate for premature mortality was almost four times as high (that is, 6.1% divided by 1.6%). Across the LHINs, the difference ratios were fairly close to the provincial ratio (between 3 and 5 times as high).

EXHIBIT 7 Local Health Integration Networks of the Ontario Ministry of Health and Long-Term Care

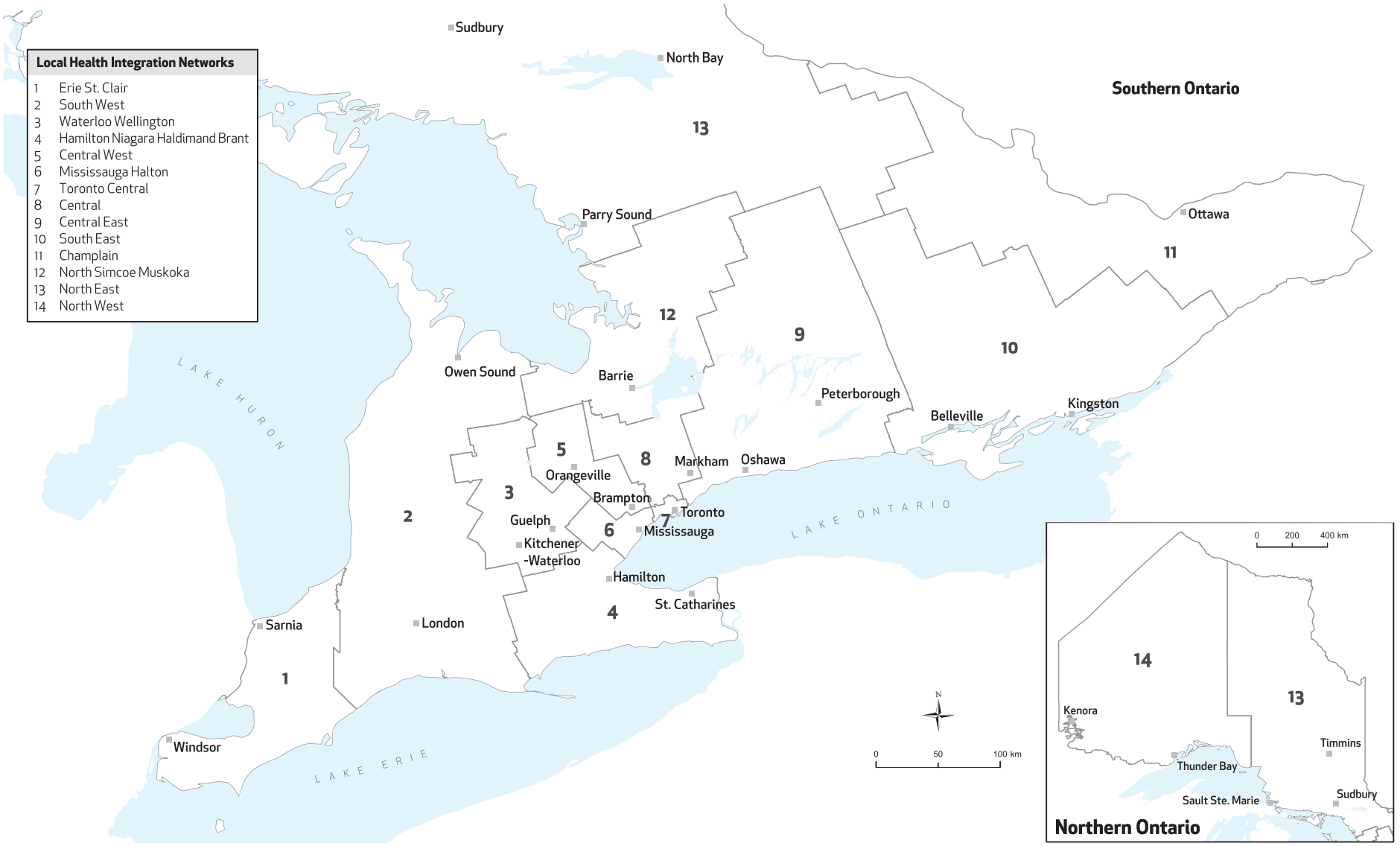


EXHIBIT 8 Number and proportion of adults aged 19 to 65 years with or without developmental disabilities, by health and health care outcome and by Local Health Integration Network, in Ontario, 2010/11 to 2015/16

Local Health Integration Network	Status	Cohort size in 2010	30-Day repeat emergency department visits, n (%)	30-Day repeat hospitalizations, n (%)	Alternate level of care, n (%)	Long-term care, n (%)	Premature mortality, n (%)
Ontario	With DD	64,699	22,335 (34.5)	4,814 (7.4)	2,957 (4.6)	2,231 (3.5)	3,960 (6.1)
	Without DD	2,683,532	526,449 (19.6)	60,858 (2.3)	18,466 (0.7)	4,577 (0.2)	42,659 (1.6)
1. Erie St. Clair	With DD	40,120	1,545 (38.4)	275 (6.8)	175 (4.4)	151 (3.8)	270 (6.7)
	Without DD	129,316	29,546 (22.9)	3,062 (2.4)	1,063 (0.8)	250 (0.2)	2,532 (2.0)
2. South West	With DD	6,113	2,460 (40.2)	474 (7.8)	312 (5.1)	280 (4.6)	422 (6.9)
	Without DD	188,377	48,432 (25.7)	4,927 (2.6)	1,067 (0.6)	418 (0.2)	3,604 (1.9)
3. Waterloo Wellington	With DD	3,242	935 (28.8)	214 (6.6)	121 (3.7)	93 (2.9)	185 (5.7)
	Without DD	152,862	26,613 (17.4)	3,092 (2.0)	1,108 (0.7)	257 (0.2)	2,283 (1.5)
4. Hamilton Niagara Haldimand Brant	With DD	8,981	3,087 (34.4)	674 (7.5)	421 (4.7)	307 (3.4)	591 (6.6)
	Without DD	277,019	57,439 (20.7)	6,916 (2.5)	2,585 (0.9)	572 (0.2)	5,321 (1.9)
5. Central West	With DD	2,262	563 (24.9)	150 (6.6)	69 (3.1)	64 (2.8)	106 (4.7)
	Without DD	172,381	28,822 (16.7)	3,705 (2.2)	909 (0.5)	206 (0.1)	267 (1.2)
6. Mississauga Halton	With DD	2,990	684 (22.9)	166 (5.6)	83 (2.8)	83 (2.8)	140 (4.7)
	Without DD	234,979	36,125 (15.4)	4,079 (1.7)	1,015 (0.4)	240 (0.1)	2,627 (1.1)
7. Toronto Central	With DD	4,431	1,356 (30.6)	408 (9.2)	249 (5.6)	112 (2.5)	233 (5.3)
	Without DD	251,177	38,898 (15.5)	5,673 (2.3)	2,069 (0.8)	380 (0.2)	3,608 (1.4)

EXHIBIT 8 *continued*

Local Health Integration Network	Status	Cohort size in 2010	30-Day repeat emergency department visits, n (%)	30-Day repeat hospitalizations, n (%)	Alternate level of care, n (%)	Long-term care, n (%)	Premature mortality, n (%)
8. Central	With DD	5,187	1,374 (26.5)	387 (7.5)	204 (3.9)	135 (2.6)	258 (5.0)
	Without DD	354,144	51,112 (14.4)	6,378 (1.8)	1,988 (0.6)	399 (0.1)	3,795 (1.1)
9. Central East	With DD	6,496	2,039 (31.4)	440 (6.8)	241 (3.7)	249 (3.8)	380 (5.9)
	Without DD	312,609	58,569 (18.7)	6,559 (2.1)	1,800 (0.6)	537 (0.2)	4,931 (1.6)
10. South East	With DD	4,619	1,755 (38.0)	326 (7.1)	172 (3.7)	121 (2.6)	276 (6.0)
	Without DD	99,258	25,050 (25.2)	2,483 (2.5)	632 (0.6)	230 (0.2)	2,136 (2.2)
11. Champlain	With DD	6,707	2,408 (35.9)	450 (6.7)	306 (4.6)	244 (3.6)	389 (5.8)
	Without DD	254,543	50,102 (19.7)	5,636 (2.2)	1,426 (0.6)	500 (0.2)	3,906 (1.5)
12. North Simcoe Muskoka	With DD	2,756	1,080 (39.2)	211 (7.7)	154 (5.6)	103 (3.7)	195 (7.1)
	Without DD	90,002	21,453 (23.8)	2,375 (2.6)	778 (0.9)	165 (0.2)	1,791 (2.0)
13. North East	With DD	5,102	2,181 (42.8)	474 (9.3)	304 (6.0)	227 (4.5)	368 (7.2)
	Without DD	117,817	37,651 (32.0)	4,303 (3.7)	1,283 (1.1)	316 (0.3)	2,919 (2.5)
14. North West	With DD	1,793	868 (48.4)	165 (9.2)	146 (8.1)	62 (3.5)	147 (8.2)
	Without DD	49,046	16,636 (33.9)	1,669 (3.4)	743 (1.5)	107 (0.2)	1,139 (2.3)

Comparisons across Ministry of Children, Community and Social Services regions

Similar to the pattern found for the LHINs, the results for the Ministry of Children, Community and Social Services (MCCSS) regions (see **Exhibit 9**) also mirrored the provincial results: For every outcome we studied, adults with DD always had a higher rate than the comparison group of adults without DD (see **Exhibit 10** for 2010/11 to 2015/16 results and **Exhibit 15** in Appendix C for 2015/16 results).

The difference ratios (i.e., the rates for adults with DD divided by the rate for adults without DD) for the five outcomes were as follows:

- For the province, 30-day repeat emergency department visits were nearly twice as high (that is, 34.5% divided by 19.6%). Across the MCCSS regions, the difference ratios were fairly close to the provincial ratio (between 1.5 and 2 times as high).
- For the province, 30-day repeat hospitalizations were more than three times as high (that is, 7.4% divided by 2.3%). Across the MCCSS regions, the difference ratios were fairly close to the provincial ratio (between 2.5 and 4 times as high).
- For the province, the rate for any alternate level of care days was almost seven times as high (that is, 4.6% divided by 0.7%). Across the MCCSS regions, the difference ratios ranged between 5 and 7 times as high.
- For the province, the rate for long-term care was nearly 18 times as high (that is, 3.5% divided by 0.2%). Across the MCCSS regions, the difference ratios varied widely compared to the provincial ratio (between 13 and 30 times as high).
- For the province, the rate for premature mortality was almost four times as high (that is, 6.1% divided by 1.6%). Across the MCCSS regions, the difference ratios were fairly close to the provincial ratio (between 3 and 4 times as high).

EXHIBIT 9 Regions of the Ontario Ministry of Children, Community and Social Services

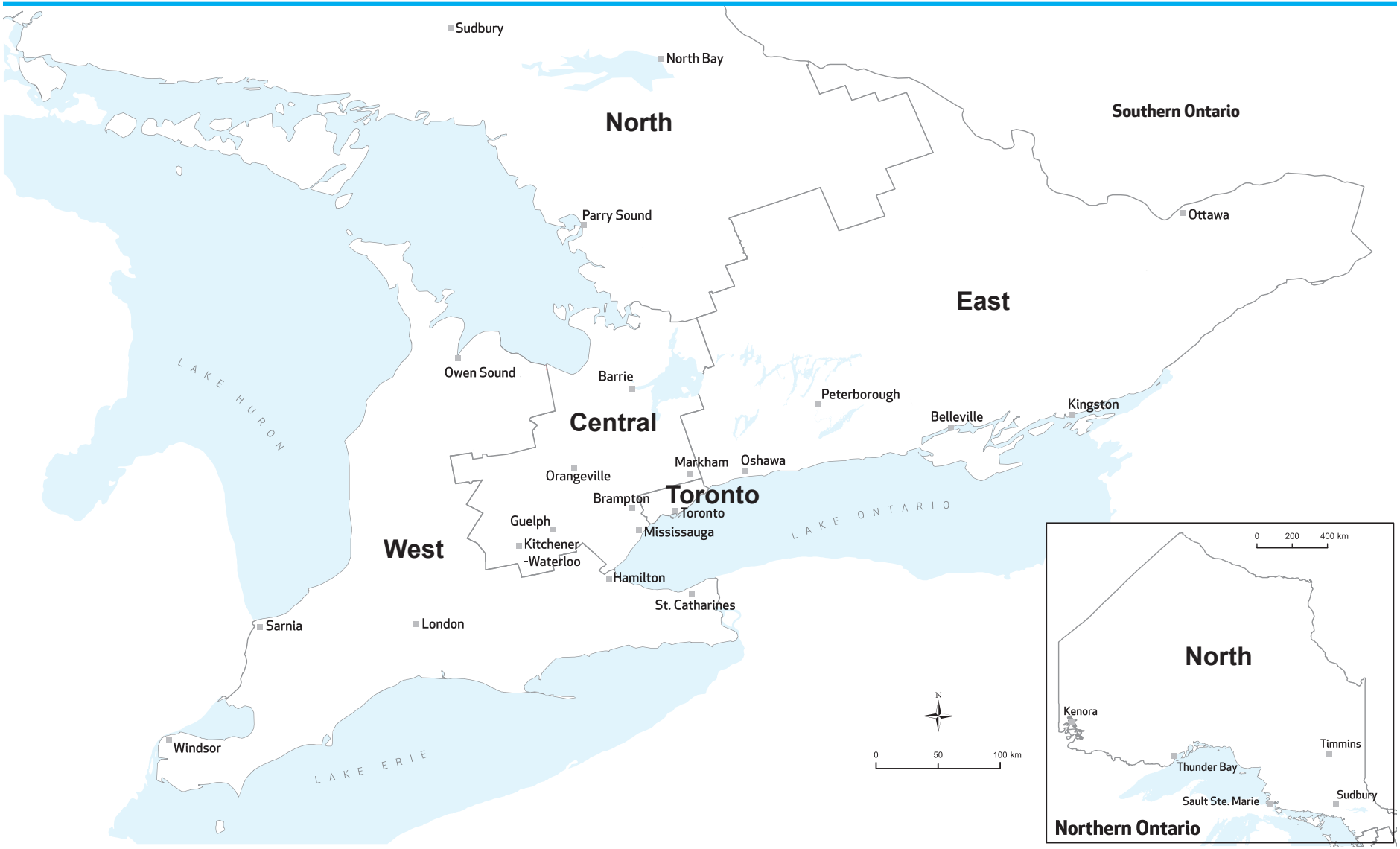


EXHIBIT 10 Number and proportion of adults aged 19 to 65 years with or without developmental disabilities, by health and health care outcome and by Ministry of Children, Community and Social Services region, in Ontario, 2010/11 to 2015/16

Ministry of Children, Community and Social Services Region	Status	Cohort size in 2010	30-Day repeat emergency department visits, n (%)	30-Day repeat hospitalizations, n (%)	Alternate level of care, n (%)	Long-term care, n (%)	Premature mortality, n (%)
Ontario	With DD	64,699	22,335 (34.5)	4,814 (7.4)	2,957 (4.6)	2,231 (3.5)	3,960 (6.1)
	Without DD	2,683,532	526,449 (19.6)	60,858 (2.3)	18,466 (0.7)	4,577 (0.2)	42,659 (1.6)
Central	With DD	13,628	3,859 (28.3)	938 (6.9)	510 (3.7)	403 (3.0)	768 (5.6)
	Without DD	843,529	136,301 (16.2)	16,222 (1.9)	4,643 (0.6)	1,006 (0.1)	10,505 (1.3)
East	With DD	15,789	5,680 (36.0)	1,085 (6.9)	658 (4.2)	551 (3.5)	939 (6.0)
	Without DD	540,023	115,206 (21.3)	12,275 (2.3)	3,149 (0.6)	1,052 (0.2)	9,328 (1.7)
North	With DD	7,298	3,204 (43.9)	660 (9.0)	470 (6.4)	311 (4.3)	534 (7.3)
	Without DD	178,592	57,322 (32.1)	6,279 (3.5)	2,151 (1.2)	455 (0.3)	4,306 (2.4)
Toronto	With DD	9,408	2,647 (28.1)	755 (8.0)	430 (4.6)	245 (2.6)	477 (5.1)
	Without DD	557,216	85,496 (15.3)	11,741 (2.1)	3,956 (0.7)	873 (0.2)	7,452 (1.3)
West	With DD	18,552	6,940 (37.4)	1,373 (7.4)	886 (4.8)	720 (3.9)	1,236 (6.7)
	Without DD	564,136	132,119 (23.4)	14,339 (2.5)	4,566 (0.8)	1,191 (0.2)	11,064 (2.0)

4. Outcomes by Subgroup

Adults with Down syndrome

Down syndrome is the most common chromosomal cause of developmental disability. Compared to the general population, individuals with Down syndrome experience higher rates of some medical comorbidities, including congenital heart defects, respiratory diseases, hearing problems, Alzheimer's disease, childhood leukemia and thyroid conditions.[39,40] The greater likelihood of comorbidities means that they use more health services and are more likely to be hospitalized.[41] Not long ago, it was common for individuals with Down syndrome to die early in life; however, while their rate of premature mortality still remains high,[42] life expectancy has improved dramatically.[43,44] With improvements in both health and the social determinants of health, a life span extending into their sixties is now not uncommon among individuals with Down syndrome.[45,46]

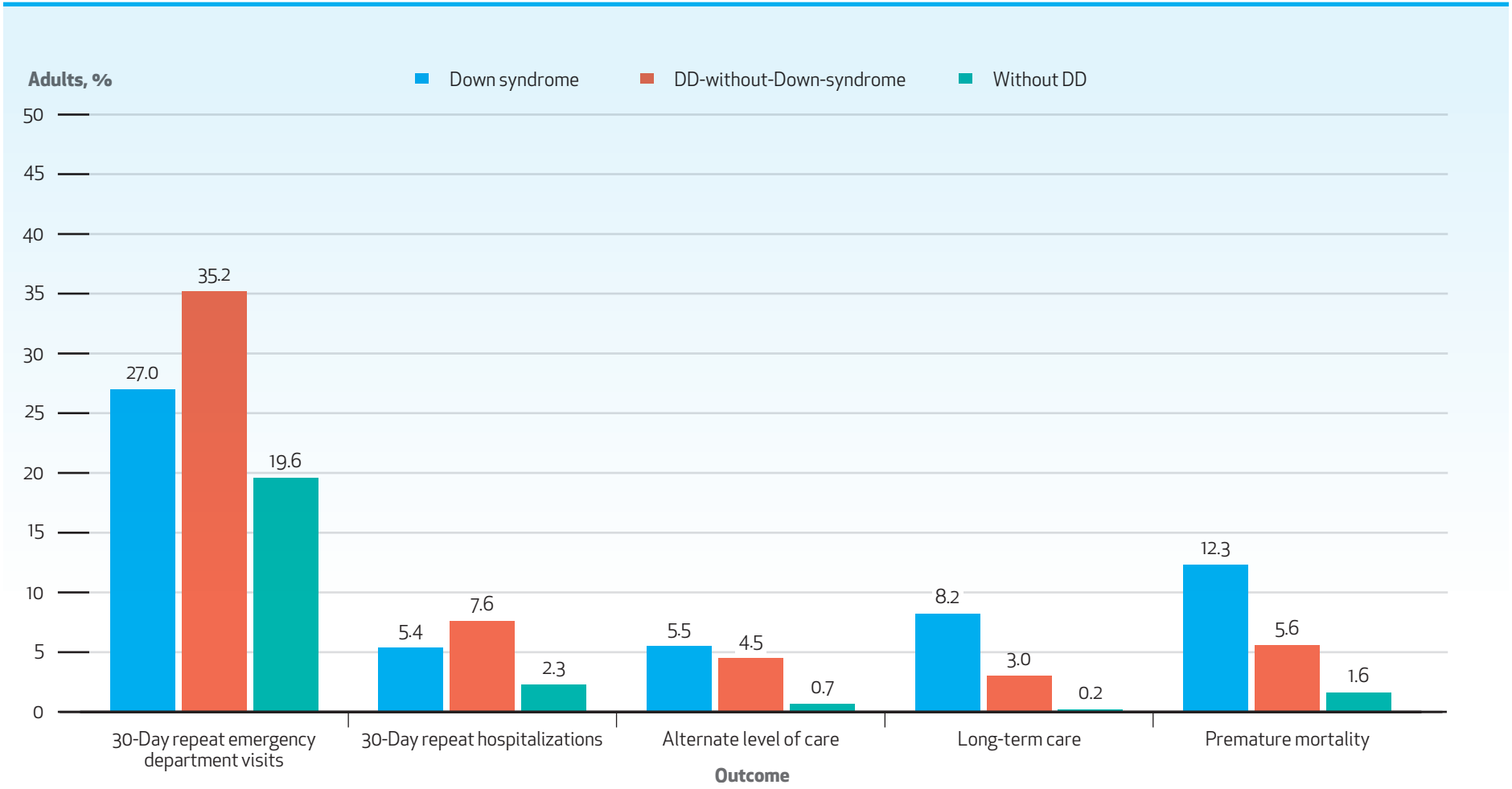
There were 5,432 adults with Down syndrome, which represented 8.4% of the adults with DD in our cohort (see **Appendix A** for more details). Within this subgroup, records showed that 2.1% also had an autism diagnosis, and 29.9% also had a mental health and/or addictions diagnosis.

The subgroup of adults with Down syndrome when compared to adults without DD was slightly more likely to be male (52.3% vs. 49.0%) and more likely to be younger (younger than 25 years: 17.7% vs. 12.2%). Neighbourhood income levels were relatively evenly distributed among both groups. When compared to other adults with DD (labeled DD-without-Down-syndrome), the subgroup with Down syndrome had a more even sex ratio than those without Down syndrome (male/female; 1.1 for adults with Down syndrome vs. 1.4 for the DD-without-Down-syndrome subgroup) and fewer individuals in the youngest (17.7% vs. 21.6%) and oldest (21.0% vs. 25.9%) age groups. They also differed in the kinds of neighborhoods they lived in, with the subgroup with Down syndrome having a lower proportion living in the poorest income areas (18.7% vs. 31.5%). Any differences highlighted in terms of health outcomes for the subgroup with Down syndrome should take these demographic differences into account.

Key findings (Exhibit 11)

Adults with Down syndrome were more likely to experience each of the five outcomes compared to adults without DD. When compared to adults with DD but without Down syndrome, adults with Down syndrome were nearly three times as likely to be admitted to long-term care and almost twice as likely to die prematurely. When these results were broken down by age (data not shown), the difference between adults with Down syndrome and adults in the DD-without-Down-syndrome subgroup was particularly evident among those aged 50 to 65: respectively, long-term care, 24.7% vs. 8.5%; and premature mortality, 38.3% vs. 12.8%.

EXHIBIT 11 Proportion of adults aged 19 to 65 years with Down syndrome, with developmental disabilities but without Down syndrome, and without developmental disabilities, by health and health care outcome, in Ontario, 2010/11 to 2015/16



Adults with autism

Autism is a common developmental disability involving impairments in social communication and a restricted range of interests. It is described as a spectrum, recognizing that how it presents varies greatly, and we have only recently begun to appreciate this full variation. It occurs in as many as 1 in 66 children;[47] little is known about its occurrence in adults. Indeed, because our understanding of what autism is has changed over time, there are many adults whose autism was not recognized as such in childhood.[48] Understanding health outcomes for adults with autism is critical and is an emerging research area. Recent research in the United States[49] and the United Kingdom[50] has suggested that health problems are common among adults with autism, particularly mental health problems, epilepsy and gastrointestinal disorders. Adults with autism are more likely than other adults to use health care services,[7] visit the emergency department[51] and experience premature mortality.[52] Although adults with autism die up to 20 years younger than the general population,[53] studies comparing health use between adults with autism and adults with other kinds of DD are quite limited.

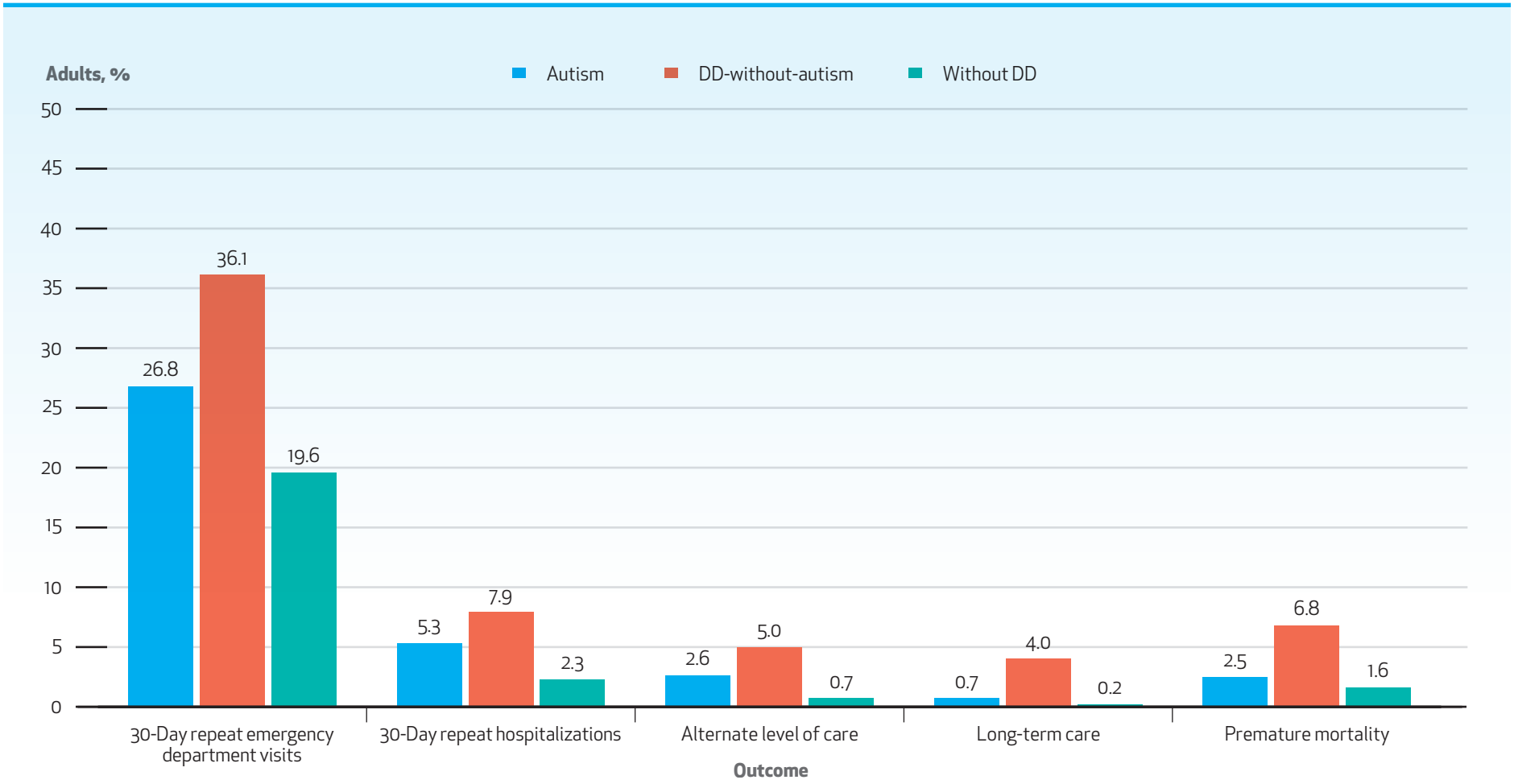
Our study looked at 10,695 adults with autism, which represents 16.5% of the adults with DD group (see **Appendix A** for more details). Within this subgroup, records show that 1.1 % also had a Down syndrome diagnosis and 53.0% also had a mental health and/or addictions diagnosis.

Compared to adults without DD, adults with autism were much more likely to be male (69.7% vs. 49.0%) and considerably younger (less than 25 years: 42.3% vs. 12.2%). For both groups, neighbourhood income levels were relatively evenly spread. When compared to other adults with DD (labeled DD-without-autism), the subgroup with autism was more likely to be male (69.7% vs. 54.8%) and considerably younger (less than 25 years old: 42.3% vs. 17.2%). They also differed in the kinds of neighborhoods they lived in, with the DD-without-autism subgroup having a greater proportion living in the lowest-income areas (21.5% vs. 32.2%). Any differences highlighted in terms of health outcomes for the subgroup with autism should take these demographic differences into account.

Key findings (Exhibit 12)

Adults with autism were more likely to experience each of the five outcomes studied compared to adults without DD, but less likely compared to the DD-without-autism subgroup. Because this subgroup has a very different age-sex profile than the two comparison groups, further analyses were done to determine if being younger or male might explain these differences. (Younger people generally have better outcomes than older adults). However, these patterns remained consistent across all age groups and for both sexes. The most striking finding was that adults with autism were consistently disadvantaged compared to adults without DD despite the fact that they were much younger. Further exploration is needed to explain these findings.

EXHIBIT 12 Proportion of adults aged 19 to 65 years with autism, with developmental disabilities but without autism, and without developmental disabilities, by health and health care outcome, in Ontario, 2010/11 to 2015/16



Adults with developmental disabilities and a mental health and/or addictions diagnosis

Psychiatric disorders (mental illness or addiction) are the most commonly diagnosed comorbidities experienced by children, youth and adults with DD.[2,54,55] This co-occurrence is sometimes referred to as a dual diagnosis. Proper assessment and treatment of these disorders can be complicated because of limited training available to the mental health profession.[56] Rarely do these conditions occur in isolation: Many adults with DD who have a psychiatric disorder also have medical problems.[55,57] Prior research from H-CARDD and international colleagues suggests that having both a developmental disability and a psychiatric condition increases the likelihood and frequency of emergency department visits and hospitalizations.[10,58,59] Whether this kind of comorbidity is associated with long-term care use over time has yet to be determined; however, one study has demonstrated that the presence of both conditions is associated with higher rates of mortality when compared to mental health alone but lower rates of mortality when compared to DD alone.[60]

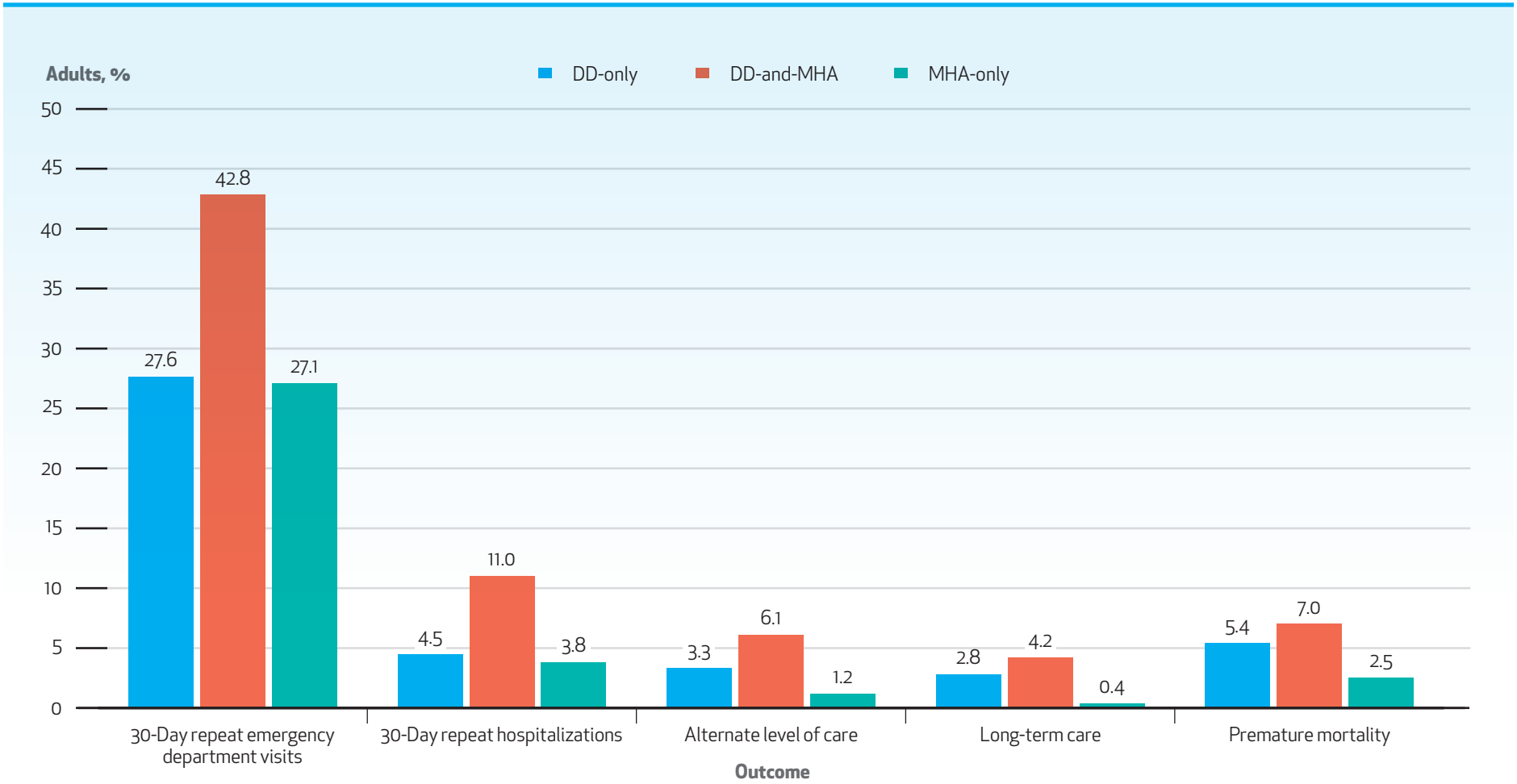
There were 29,476 adults who had the combination of DD and a mental health and/or addictions diagnosis (labeled as DD-and-MHA). They constituted 45.6% of the adults with DD group (see **Appendix A** for details). Within this subgroup, records showed that 5.5% also had a Down syndrome diagnosis and 19.2% also had an autism diagnosis.

Unlike the Down syndrome and autism subgroups, we did not compare this subgroup to adults without DD. Instead, we thought a more meaningful comparison would be with adults who either had DD but no mental health and/or addictions diagnosis (labeled DD-only) or who had a mental health and/or addictions diagnosis but no DD (labeled MHA-only). In terms of demographic characteristics, adults with DD-and-MHA and those with DD-only had similar profiles, especially when compared to the subgroup with MHA-only. They were younger (20.8% and 21.7% were less than age 25 for DD-and-MHA and for DD-only, respectively, vs. 9.9% for MHA-only) and somewhat more likely to be male (55.7% and 58.6%, respectively, vs. 41.8% for MHA-only). They were also more likely to live in the poorest neighbourhoods (32.1% and 29.0%, respectively, vs. 20.4% for MHA-only). Any differences highlighted in terms of health outcomes for the subgroup with DD-and-MHA should take these demographic differences into account.

Key findings (Exhibit 13)

Adults with DD-and-MHA had the highest rates for all five outcomes studied when compared to those with DD-only and especially when compared to those with MHA-only. Compared to the MHA-only subgroup, adults with DD-and-MHA are five times more likely to have an alternate level of care day, nearly 11 times more likely to be in a long-term care facility and almost three times as likely to die prematurely.

EXHIBIT 13 Proportion of adults aged 19 to 65 years with developmental disabilities but without a mental health and/or addictions diagnosis, with developmental disabilities and a mental health and/or addictions diagnosis, and with a mental health and/or addictions diagnosis but without developmental disabilities, by health and health care outcome, in Ontario, 2010/11 to 2015/16



5. Conclusion and Recommendations

Overview

In this report, we have examined five health and health care outcomes: 30-day repeat emergency department visits, 30-day repeat hospitalizations, alternate level of care, long-term care and premature mortality.

These were chosen for two reasons. First, they are often used as flags for areas where actions could be taken to improve the health care system. Second, they are outcomes which are especially problematic and relevant to people with DD. While we have analyzed and described each outcome separately in this report, we also have examined them as a group because we believe that this could reveal common gaps that are system-wide.

Our main finding is that adults with DD consistently fare worse across all five outcomes compared to adults without DD. This pattern holds true regardless of age, sex or the income level of the neighbourhood where they live and also regardless of their type of DD. Our second finding is that the pattern of poor outcomes differs depending on which DD subgroup is considered. The implications of these findings are twofold. First, consistent with our previous work and the results from other studies and reports, adults with DD are a highly vulnerable group with complex needs requiring multifaceted solutions that address a range of health care outcomes. Second, because adults with DD are a heterogeneous group, these solutions need to be tailored to specific subgroup needs to increase their impact and relevance.

The next section of this report summarizes our findings for each of the five outcomes, describes how our results compare with other studies and makes recommendations specific to each outcome. The evidence for each recommendation is also provided so that readers can understand the context. This is then followed by a discussion of overarching recommendations.

30-Day repeat emergency department visits

A repeat emergency department visit within 30 days is interpreted as an indicator of potential issues with the quantity and quality of support and services received. These repeat visits are partly due to individuals not receiving adequate discharge planning or community care after an initial emergency department contact.

Our results show that over a six-year period, 30-day repeat emergency department visits occurred more frequently among adults with DD compared to those without DD (34.5% vs.19.6%). This pattern persisted across all age groups and for both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. While all of the DD subgroups had higher rates of repeat emergency department visits compared to adults without DD, the patterns varied by subgroup. Notably, the subgroup with DD-and-MHA had a higher rate of repeat emergency department visits (42.8%) than the subgroups with DD-only (27.6%) or MHA-only (27.1%).

Other research has reported that people with DD are more likely to visit the emergency department and have multiple emergency department visits compared to adults without DD.[10] Specifically, individuals with DD and mental health and/or addictions issues were more likely to visit the emergency department than those with either DD or psychiatric disorders alone in Ontario,[10] and DD was identified as a predictor of repeat emergency department visits following hospitalization in an Australian cohort.[59] However, no other studies have looked at repeat emergency department visits for individuals with DD by age, sex or socioeconomic status or by clinical subgroup (such as Down syndrome or autism).

Because repeat emergency department visits are potentially avoidable, they are a practical target for intervention. Several steps may help to improve emergency department assessment, treatment and discharge processes for individuals with DD. These include 'flagging' (that is, screening for and documenting the presence of DD in hospital charts), the use of health passports and the availability of providers such as liaison nurses in the emergency department who have specialized knowledge about DD.

"People [in the emergency department] who take care of people with DD … do not understand them. They [people with DD] cannot explain the problem. That is why they come back."
— *Nelson, self-advocate*

Research conducted in the United Kingdom on the impact of flagging the presence of DD in hospital medical charts has highlighted its importance but notes that it must be combined with clinician knowledge of what to do once the patient is flagged.[61] In Ontario[62] and the United Kingdom,[63] health

passports, which are completed by the individual and shared with the health care provider, have been found to be acceptable to adults with DD and to care providers as helpful aids to improve emergency department visit quality. In the United Kingdom, patients with DD, their caregivers and hospital staff have reported that the presence of liaison nurses in hospitals improved communication and promoted holistic care.[64,65] Similar roles have not yet been implemented in Canada.

The combination of such interventions for individuals with DD has been explored in three Ontario hospital emergency departments, using an approach that includes flagging, communication passports, and the identification of champions in the emergency department and in the community with expertise in DD.[66] Based on an evaluation of this approach,[67] the H-CARDD Program team curated a toolkit of resources now available to all Ontario hospitals. It includes educational materials, tools and tips for emergency department staff, as well as for adults with DD and their caregivers – all designed to improve the quality and experience of care they receive during their emergency department visit. A clear and timely process for accessing these tools needs to be developed in order for this effort to spread and be maintained over time.[67]

In terms of future interventions, a next step to decrease repeat emergency department visits is to develop and update cross-sector crisis, safety or care plans for all individuals with DD following their initial emergency department visit, together with their hospital and community-based providers. A 2012 study found that adults with DD who did not have such plans in place were more likely to visit the emergency department when in crisis.[10] Debriefing and care planning are now recommended in the Canadian 2018 primary care guidelines for such adults following emergency department visits.[68] A related next step is assessing the impact of these interventions on the prevention of repeat emergency department visits. Finally, identification and inclusion of adults with DD and partners from the DD sector in the current quality review processes in Ontario hospitals for patients with repeat emergency department visits could help improve the quality of emergency department care provided as well as its continuity with other services.

30-Day repeat hospitalizations

Like repeat emergency department visits, a readmission to hospital within 30 days of the initial discharge is interpreted as an indicator of poor care – including the quality of inpatient care and the quality and continuity of follow-up care after discharge.

Our results show that over a six-year period, adults with DD were more likely to experience a repeat hospitalization within 30 days of their initial discharge than adults without DD (a difference ratio of 3.2 based on percentages of 7.4% and 2.3%). While the rate of repeat hospitalizations was highest among the oldest group of adults with DD (10.7% vs. 3.5% for the oldest adults without DD), the with DD vs. without DD discrepancy was even larger for the 25- to 49-year-old age group where the difference ratio was 4.1 (6.9% for adults with DD vs. 1.7% for those without DD). This pattern was evident for both sexes and held regardless of the income level of the neighbourhood where they lived. All of the subgroups with DD had higher rates of hospital readmission within 30 days compared to adults without DD. Within the subgroups, repeat hospitalizations were particularly prominent for the subgroup with DD-and-MHA (11.0%) compared to adults with DD-only (4.5%) or MHA-only (3.8%).

Internationally, an Australian study focusing specifically on psychiatric rehospitalizations found that DD was a significant predictor.[59] With the exception of prior research from our team highlighting the increased risk of readmission for individuals with a psychiatric disorder,[58] we could not find any reports on readmission for subgroups of individuals with DD, such as those with Down syndrome or autism.

Many of the interventions discussed in the preceding section on repeat emergency department visits are also relevant to readmissions. For instance, flagging that a person has a DD during hospital admission, using a hospital passport and having the support of a liaison nurse who specializes in DD all have the potential to enhance the quality and experience of care during the hospital stay. To reduce repeat hospitalizations, recommendations have also stressed the importance of hospital discharge planning that includes both the health and social service sectors and of increasing the availability of appropriate community housing arrangements.[58] In addition, a U.K. audit study identified the inclusion of the caregiver's concerns in discharge planning as a priority.[69]

Other research, while not specific to individuals with DD, provides instructive examples. One U.S. study found that increased hospital spending on occupational therapy during the hospital stay was associated with decreased readmission rates. This was attributed to occupational therapy's focus on

the functional and social needs of patients.[70] While this study examined readmission for all patients, its findings may also be relevant to the DD population given their combination of medical and non-medical needs. In addition, a recent evaluation of the impact of care transition programs for high-risk elderly inpatients, which included a comprehensive discharge process and a timely follow-up visit, found a difference of almost 40% in 30-day readmission rates between this group of inpatients and a statistically matched control group.[71]

In Ontario, efforts to reduce readmissions have generally focused on identifying and flagging those patients most at risk for readmission and providing them with enhanced cross-sector supports to transition out of hospital.[72] The patient-oriented discharge summary (PODS) is being applied broadly as a plain language way of ensuring that patients understand what follow-up should occur to ease their transition and reduce readmission. There is evidence that this tool – co-designed by patients, caregivers and health providers – helps with patient comprehension of next steps, medical follow-up and medication compliance.[73] Our finding that adults with DD are at higher risk for readmission strongly suggests that DD status should be recognized as a risk factor for readmission and incorporated into these province-wide prevention strategies.

Similar to the recommendations described for repeat emergency department visits, these approaches have not yet been evaluated for their impact. Such evaluations are needed to confirm or deny their suitability and effectiveness for decreasing readmissions among Ontarians with DD and to identify other potentially important contributing factors.

Alternate level of care

In Canada, the term alternate level of care is used to describe the situation where patients remain in hospital even though they no longer require the type or level of care provided in that setting.[19] A common reason for alternate level of care is the lack of an appropriate place for the individual to be discharged to. Thus, high alternate level of care rates are interpreted as a signal that there may be problems with either the availability or accessibility of appropriate community-based supports.

Our results show that over a six-year period, adults with DD were more likely to be classified as alternate level of care compared to adults without DD (a difference ratio of 6.6 based on percentages of 4.6% and 0.7%). While the rate of alternate level of care days was highest among the oldest group of adults with DD (9.7% vs. 1.6% for the oldest adults without DD), the with DD vs. without DD discrepancy was even larger for the two youngest age groups (a difference ratio of 12: for 19- to 24-year-olds based on percentages of 1.2% vs. 0.1%; for 25- to 49-year-olds based on percentages of 3.5% vs. 0.3%). This pattern of higher alternate level of care rates for those with DD compared to those without DD was also evident within both sexes and regardless of the wealth or poverty of the neighbourhood where they lived. All of the subgroups with DD had higher rates of alternate level of care compared to adults without DD. Among the subgroups with DD, those with DD-and-MHA (6.1%) were more likely to receive the alternate level of care designation compared to DD-only (3.3%) and MHA-only (1.2%).

In other countries, alternate level of care is more commonly labeled as bed blocking or delayed discharge.[74] Research in the United Kingdom has also reported a high rate of delayed discharge for individuals with DD in specialized inpatient psychiatric units.[75] In Ontario, a 2009 report found that the combination of DD and a mental health or addictions disorder was a predictor of having a long-stay psychiatric hospitalization (defined as more than 90 days and used as a proxy for alternate level of care). The percentage having this combination among those with long stays was more than triple the percentage among those without long stays (18% vs. 5%, respectively).[22] In a more recent study, DD plus a psychiatric diagnosis was associated with greater odds of alternate level of care in Ontario psychiatric beds.[23]

In terms of interventions for alternate level of care, long-stay inpatients with DD have been a major concern in the United Kingdom after reports of abuse of these patients surfaced.[76] These reports led to a 2012 national commitment to review, reduce and regularly audit inpatient placements for those with these disabilities.[77] Although significant efforts were put into careful planning for the discharge of such individuals, subsequent audits suggest that many still remain in hospital.[78] In fact, according to a 2018 BBC Television documentary, the problems of delayed discharges continue, and there has been a concerning increase in long-stay admissions among young people with DD.[79]

Other important lessons, although not specific to DD, can be learned from other countries. Policies targeting delayed discharge using financial incentives and penalties have been judged successful in some of

the Scandinavian countries and in the United Kingdom, in terms of documented decreases in delayed discharges as well as anecdotal reports of increasing community and hospital capacity to address discharge transitions.[80,81] However, their impact is not always straightforward as increased readmissions and emergency department visits have also been documented over the same time period.[81] As described in the 2018 BBC documentary[79] and in the Ontario Ombudsman's report *Nowhere to Turn*,[24] if the emphasis is on placing those with DD in the community without first building community capacity to support them, not only will placements fail, but new individuals will enter hospital and be unable to leave because of inadequate community supports.

"Being in the hospital … keeps you away from the outside world. Can you imagine if you had to live in the hospital?"
— *Andrew, self-advocate*

A systematic review of the literature and policy and program reports relevant to delayed discharge was commissioned by the Irish Ministry of Health in 2015. The resulting report highlighted both the scarcity of relevant studies (the scope of the report had to be expanded to include hospital readmission) and the mixed or unimpressive evidence for implemented practices (particularly for single, isolated solutions). The authors did identify four themes worthy of further attention: service integration across hospital, community and home-based settings; multi- and interdisciplinary approaches; person-centred and individualized services; and "hospital-initiated discharge support and specialist follow-up."[82]

Other important considerations regarding alternate level of care interventions that are suggested by both the literature and the findings of the Irish report include the need to assess the capacity of family caregivers[22,69,83,84] and to ensure that community- and home-based settings are equipped to address the comorbidities and behavioural challenges faced by many adults with DD.[22] These considerations are also consistent with the approach taken by some Ontario initiatives such as "Home First," which emphasizes giving people the support they need at home rather than in settings such as long-term care to facilitate hospital discharge and prevent alternate level of care days.[85] Adapting existing approaches and evaluating them to determine if they meet the needs of adults with DD should be considered as an alternative to developing completely new interventions. The current effort by Health Quality Ontario to develop 'transitions-in-care' standards is relevant in this regard.[86]

In sum, the experience from the United Kingdom, as well as the research findings for alternate level of care and delayed discharge, suggest that multifaceted, cross-sector and interdisciplinary solutions are more likely to have an impact but that the results are not always straightforward. The comparative lack of grey literature or research knowledge specific to the DD population calls for more directed attention to how such solutions should be tailored. In addition, the scarcity of evaluation or documented outcome results makes it difficult to assess how effective any solutions are in actually decreasing alternate level of care without also increasing other potentially negative outcomes. Without information about how interventions can be effective, and effectively tailored, they may fail to address the unique needs of those with DD. This very failure has gained attention in Nova Scotia, where it has become the subject of a human rights investigation.[87]

Long-term care

Together, Ontario's health and social services ministries support the idea that people with DD should be able to live and age in the community for as long as they are safe, willing and able to do so.[26,88] Thus, high rates of admission to long-term care at younger ages can be interpreted as signaling a problem with the community- and home-based supports available for individuals with DD and their caregivers.

Our results show that over a six-year period, adults with DD were more likely than adults without DD to reside in a long-term care setting (3.5% vs. 0.2%, a difference ratio of 17.5). While the highest rate of long-term care use occurred among the oldest age group of adults with DD (9.6% vs. 0.5% for the oldest age group of adults without DD), the with DD vs. without DD difference was larger among adults in the 25-49 age group (1.81% vs. 0.04%, a difference ratio of 45.3). Similar to the other outcomes we studied, there was a small difference by sex for those with DD (4.3% of women vs. 2.8% of men); however, this was not true for adults without DD where the prevalence was equal across sexes (0.2%). In terms of the effect of neighbourhood income level, long-term care use showed a gradient for adults without DD (with residents of poorer neighbourhoods having the highest percentage and those living in the wealthiest neighbourhoods having the lowest) but little effect for adults with DD for whom admission

TERESA'S STORY

Moving into long-term care too early

Teresa, an artist, poet and musician with Down syndrome, is in her early 50s. She lives with her sister and brother-in-law in Vancouver, but this was not always the case. When she was in her late 40s and living with her father in Ontario, she was assessed by someone in the home care sector to determine her eligibility for additional supports. Through this process, it was incorrectly determined that Teresa needed to move to a long-term care setting. From Teresa's perspective, this was not appropriate, given her age and the many activities she was able to perform independently. She found the long-term care setting frightening and restrictive and very much wanted to move back home.

Returning to the community

After some intense advocacy from her family, Teresa was able to move back to her family home, and from there she moved with her sister to Vancouver. As Teresa described in a letter, "I did not want to live in a nursing home. I am capable. I am an artist and a poet and I am an author." Her sister Franke explained, "Teresa has lots of abilities. She flourishes when we support her to live in the community. It's education and support that's needed, people willing to support someone to live in the community. It is their human right."

Teresa

to long-term care was consistent across income levels. Among the subgroups that were analyzed, adults with Down syndrome were particularly prominent users of long-term care (8.2%).

These findings are consistent with other reports in the literature. Higher rates of long-term care admissions in Ontario were also found by Ouellette-Kuntz et al. (2017); they reported that over a four-year timeframe, 4.5% of adults with DD were admitted to long-term care compared to 0.9% of adults without DD.[27] Their proportion of admissions to long-term care was higher than what was found in this study, likely because their cohort included a greater number of individuals over the age of 65. Studies in other jurisdictions have also found that adults with DD are admitted to long-term care at younger ages than other adults.[89] This is problematic in that long-term care is designed to meet the needs and interests of older adults. In addition, no studies have considered how often specific subgroups of individuals with DD move into long-term care settings.

Intervention efforts should focus on two issues. First, consistent with existing strategies and policies, it is important that people with DD are supported to age at home for as long as possible and that moves to long-term care be planned and undertaken only when appropriate. Knowing that health conditions associated with aging can happen sooner,[90] individuals with DD and their families should prepare for aging by addressing emerging health problems early. This is particularly relevant to adults with Down syndrome who are the most likely to live in long-term care settings. The second focus should be on putting DD-relevant supports into place within long-term care to make these accommodations age- and developmentally appropriate. Current guidelines allow for the inclusion of DD service–related supports while residing in LTC;[26] therefore, it is important that those who live in long-term care receive supports appropriate to their needs. According to the guidelines, this would include "enhanced staff training and education as well as additional supports to maintain health and quality of life such as behavioural therapists, therapeutic recreationalists, social workers, rehabilitative assistants, developmental service workers and modified equipment," all of which would require cross-sector collaboration.[26]

Premature mortality

Mortality statistics are commonly used to measure the overall health status of populations and subpopulations.[91] We report on premature mortality, that is, death before age 75.[28] Disproportionate numbers of premature deaths in a subpopulation, such as people with DD, is a strong signal that there are underlying inadequacies that need attention, including disparities in health and health services.

Our results show that over a six-year period, premature mortality in adults with DD was almost four times more frequent than in adults without DD (a difference ratio of 3.8 based on 6.1% and 1.6%). While the highest rate of premature death occurred in the oldest adults with DD (14.6% vs. 3.6% for the oldest adults without DD), the DD vs. without DD difference was larger in the two younger age groups (difference ratios of 4.3 for those aged 19 to 24 based on 1.3% vs. 0.3% and 5.7 for those aged 25 to 49 based on 4.0% vs. 0.7%). The pattern of higher rates for those with DD compared to those without DD also held for both sexes and regardless of the wealth or poverty of the neighbourhood where they lived or their type of DD. Among the subgroups with DD, premature mortality was most noticeable among persons with Down syndrome (12.3%) compared to the subgroup without Down syndrome (5.6%) and the adults without DD group (1.6%).

A recently published systematic review found that in high-income countries, death among individuals with DD occurs 20 years earlier, on average.[35] The limited Canadian research has found that, similar to their counterparts in other high-income countries, Canadians with DD have higher rates of mortality.[36,92] As with our findings in this report, other studies have reported the risk of death to be 3 to 4 times higher among those with DD compared to the general population.[42,93,94] In Canada[92] and internationally,[32,33] studies consistently report that respiratory and circulatory diseases are the most common causes of death among those with DD.

"People with a disability should not die earlier."

— Linda, self-advocate

Our finding that adults with Down syndrome were more likely to experience premature mortality has also been reported in other jurisdictions.[42] As noted earlier, this subgroup has higher rates of respiratory diseases, childhood leukemia and thyroid conditions, all of which contribute to poorer health. In addition, an important factor is the significantly higher prevalence and earlier

occurrence of dementia, in particular Alzheimer's disease. The presence of dementia among adults with Down syndrome has been found to increase the risk of mortality between two- and five-fold.[95,96]

Initiatives have been launched internationally to track mortality, with an emphasis on preventable deaths.[97] In the United Kingdom, a highly publicized 2007 report described case studies of people with DD who died unnecessarily.[98] The report led to an independent inquiry that made important recommendations, including improving the inadequacies identified in the health services provided to people with DD and establishing a national mortality review program.[99,100] Disturbingly, a 2018 follow-up report suggested that only a portion of the reviews had been conducted and that, although lessons were being learned at the local level, preventable deaths were still occurring at a high rate.[101] A particularly sobering point illustrated by these and other reports is that repeated recommendations for improvement have failed to result in long-term system wide changes. Following the release of the 2018 report, the National Health Service has prioritized people with DD in its 10-year plan in an effort to improve health and reduce preventable deaths.[102] Experts in the United States and Australia have also argued that a national system of reporting deaths among individuals with DD is urgently needed.[32,93]

As a next step, Canada would benefit from research that looks at the causes of death and factors contributing to higher rates of premature mortality among people with DD, with a particular focus on factors that are preventable, as has been done in Australia and the United Kingdom.[32,33] Perhaps such information could then foster cross-sector mortality reviews with lessons learned for policy-makers and service providers. Studies about how such information could be successfully translated into practice in the health service system could help decrease mortality among people with DD in the long-term.

Cross-outcome implications and guiding principles

Many of the recommendations for the five outcomes described in the previous section overlap. For example, the need for proactive interprofessional health care that addresses the unique needs of individuals with DD is noted for all five outcomes. The importance of planning for transitions in care that involves multiple parties (for example, the person with DD, family caregivers and members of informal support networks and providers from both the discharging and receiving health care settings) is highlighted for repeat emergency department visits, hospital readmission, alternate level of care and long-term care. In addition, because adults with DD need and receive services and supports from both the health and social services sectors, intersectoral cooperation is essential across outcomes.

This overlap, from our perspective, points to the need to adopt a broader system perspective when considering interventions. Otherwise, solutions run the risk of being implemented in an uncoordinated and siloed fashion. We recommend that four system-wide guiding principles be kept in mind when considering and implementing solutions. These principles are consistent with the 2006 *United Nations Convention on the Rights of Persons with Disabilities,* the *Ontario Human Rights Code* and the 2005 *Accessibility for Ontarians with Disabilities Act.*[103–105]

1. Follow the rule of *Nothing about us without us.*[106] People with disabilities and their families and supporters should have full and meaningful involvement in the development of policies, programs and services that affect their lives.

This principle focuses on who should be involved in deciding how changes to the system occur. People with DD are not just recipients of care; they should be active participants in any efforts aimed at them. For them to understand and meaningfully contribute to the decision-making process, they do require more time. To help with this, family members and other supporters may also need to be involved since they are commonly important partners in the care and support of adults with DD.

"Doctors should make sure they talk to people with disabilities and not just with caregivers, because we know what we need the best."
— *Andrew, self-advocate*

2. A range of proactive supports and health care services should be provided in the community that are appropriate for or accommodate the specific needs of people with DD.

This principle focuses on supporting the individual in his or her community and addresses one of the contributors to the five health outcomes discussed in this report. Specifically, it aims to prevent or delay the need for hospital-based and long-term care services by proactively addressing health service needs and social service needs (e.g., appropriate financial, residential, vocational and other support needs). This means that community health care providers must be equipped to properly care for adults with DD and that the social service supports they require must also be available and accessible.

Importantly, because of the reliance of many people with DD on either family or paid caregivers, proactive services and supports should also be available and accessible in a timely manner to caregivers.

"It does not matter if it is expensive. We want people to get the proper care they need."
—*Sarah, self-advocate*

3. Appropriate supports and health care services should be available and accessible to people with DD in emergency department, hospital and long-term care settings.

This principle focuses on the provision of health care that addresses the unique needs of those with DD and particular types of DD once an individual has been admitted to an emergency department, inpatient hospital or long-term care setting. Specifically, it aims to prevent early return or lengthy stays in these settings through quality care, tailored to those with DD. These supports or accommodations include changes to the physical environment and communication approach, an allowance for additional people to support the person and an increase in time to carry out health care procedures.

"I would like doctors to have a little more time for people with disabilities, and be more understanding. We're a little slower than other people are. We need more time to talk to them."
— *Michael, self-advocate*

4. When adults with DD transition between different health care services or between health care and community settings, these transitions should be planned, well-coordinated and seamless.

This principle focuses on the interconnection and cooperation within and between sectors, programs and interventions. Specifically, it aims to make the journey across services and supports as seamless as possible and thus addresses one of the contributors to the five outcomes discussed in this report. Success requires that those involved in the transition process remain involved before, during and immediately after the transition period.

"They had to change my IV in the hospital, but then I needed it changed at home, too. A nurse came to my house."
— *Rachel, self-advocate*

Critical enabling ingredients

From our perspective, achieving these four principles requires three critical enabling ingredients: a province-wide information infrastructure, education of all stakeholders and specialized expertise. Developing a full description of and plan for these ingredients is beyond the scope of this report and, indeed, should be addressed through cooperative discussion and

decision-making among all stakeholders. However, our work and discussions in the literature suggest several important points to be considered.

Province-wide information infrastructure

To ensure that the care and supports provided to adults with DD are appropriate and effective, system-wide processes that routinely gather and monitor information and incorporate it into decision-making are necessary.

There are several kinds of information that are important to collect and at least two key groups of information users. Important information includes flagging who has a developmental disability, documenting what their needs are and identifying what gaps in care and support need to be addressed. This information should be routinely given to care providers so that they can make timely and tailored clinical decisions and to administrators, policy-makers and planners so that they can monitor and evaluate how well existing supports and services are performing for adults with DD.

Examples of existing information initiatives that deliver on some of these functions include the following:

- Coordinated care plans adopted by Health Links.[107] In the Kingston area of Ontario, the coordinated care plan template has been modified to better suit patients with DD, through a collaboration between the Health Links and the Queen's Family Health Team.
- Flags in some electronic medical record software for patients with different types of health, safety or communication support needs (e.g., the cumulative patient profile).[108,109]
- In the United Kingdom, NHS (National Health Service) Digital is developing a nationally available flag to be placed on a person's summary care record that will indicate if the person has been identified by a care provider as being potentially eligible for reasonable adjustments in care and what those reasonable adjustments should be.[110]

An important point to note is that none of these initiatives deliver all the functions of a full information infrastructure – that is, routine collection and timely sharing of information to support clinical decision-making and administrative monitoring and evaluation. How to create and sustain such a complex information infrastructure is an important consideration.

In addition, the evidence for the majority of the recommendations made in this report is often mixed or missing. Indeed, the most consistent findings in both the literature and in policy and practice documents are the lack of outcome studies and the nearly universal calls flagging the need for evaluation. Given the realities of implementing practical solutions, we would recommend that a small but well-designed and time-sensitive evaluation be a mandatory part of any piloted or implemented program or policy related to the population with DD.

Education for all stakeholders

Everyone has a role to play in maintaining good health. Educating people with DD, their families, the individuals in their informal networks, paid caregivers and health care and community service providers about the health needs of those with DD will increase the necessary knowledge and skills that these stakeholders need to ensure good health care. Because stakeholders play different roles and have different perspectives, learning products and opportunities need to be tailored to each audience. In Ontario, the H-CARDD Program continues its efforts to design tailored educational resources through partnerships with target groups, and the Developmental Disabilities Primary Care Program has designed important educational products to assist primary care providers and caregivers in implementing guidelines.[111] Other examples of tailored health education can be found in the efforts of the United Kingdom,[112,113] the United States[114] and Australia.[115] It is essential that any new educational products include the user in their creation and design.

"All doctors in Ontario and around the world should be educated about all disabilities. It should happen more. If we visit hospitals more than anybody, then the hospitals should be educated more so. They should learn how to deal with people with disabilities."

—Nelson, self-advocate

Specialized expertise

While basic education and information about DD is important for all health care providers, the system also needs providers with advanced training and expertise who can act as liaisons and provide specialized care for those with the most complex needs. There is a shortage of such experts across Canada and across health care disciplines. A fully operational system should have a continuum of health care services available for every patient. For the DD population, this will require investment in specialized training.

Final comments

That everyone has a right to excellent health care has been endorsed at the international, national and provincial levels. Too often, however, efforts to act on this endorsement appear to have bypassed individuals with DD. This report documents some specific ways in which health care for adults with DD may have fallen short. That solutions to address these shortfalls are complex and difficult to implement and sustain is clear from the reports from other countries. However, we can learn and build on their experience.

With the results from this report in hand, it is important that we continue to bring stakeholders together to ask questions about what the problems are and to work together to design and implement solutions. As a group, adults with DD have poorer health outcomes in Ontario, and in addition, subgroups within adults with DD have different vulnerabilities that need attention. Solutions must include efforts that are proactive as well as those that focus on specific kinds of health care encounters and points of transition. Change will happen when everyone commits together, and we invest in infrastructure, education and specialized expertise.

TAYDON'S STORY

A young man and his family in crisis

Taydon, a young man with both medical and developmental issues, grew up in the city with his mom, Denise, and his younger brother. After he finished school, Taydon's life became more difficult. Able to speak only a few words, he became frustrated when he could not communicate what he needed. This sometimes led to serious aggression toward his family and others who cared for him. Help was hard to find.

In crisis, Taydon went with his mother to the emergency department several times, only to end up "just getting more medicated rather than solving the problem." Eventually, he was admitted to hospital where his team figured out which of his issues were medical, which were related to his disability and which were due to a lack of needed supports in his home and community. Unfortunately, once these issues were identified, it was clear that Taydon needed more support than his mother could provide on her own. But there was a long wait for support, and Taydon spent a year in hospital, designated as a patient requiring an alternate level of care. This was a very hard time for him and his family because the hospital was not a home, and Taydon needed a home. "For those who cannot speak for themselves, our system is so broken," Denise said.

Returning to the community

During Taydon's hospital stay, a specialized team with expertise in developmental disabilities from health care and social services worked together to build a suite of supports for Taydon to return to the community.

Denise said, "It has been two years since that difficult time, and Taydon is thriving, with no more hospitalizations or medical emergencies. He now gets regular check-ups from his family doctor, and he is so very happy. Since transitioning into his new home, Taydon is doing AMAZING, growing more independent and exploring his community. He is living his best life, the life that he and his family have longed for, for so many years. I am so very proud of him, as I knew as his mother it was possible. As for the system, they need to get it together so that more young adults like my son can get the supports that they need to live their independent lives, sooner rather than later. I am grateful for our happy ending, but for some families, it's not a happy ending unless someone listens to the voices that are speaking for the ones that can't speak for themselves".

Taydon and his mother, Denise

Appendices

APPENDIX A Data Sources and Operational Definitions

Administrative data sources

Linked, anonymized administrative data held at ICES were used for the analyses. Data sources included five administrative health databases, a disability income support database, a registry of persons eligible to receive provincial health insurance benefits (the Registered Persons Database, or RPDB) and data from the Census of Canada. The five administrative health databases capture the vast majority of the formal medical services for which all legal residents of Ontario are eligible to receive health insurance coverage. The Ontario Mental Health Reporting System (OMHRS) and the Canadian Institute for Health Information's Discharge Abstract Database (DAD) capture inpatient discharges for all acute care psychiatric and non-psychiatric 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. Ontario Disability Support Program (ODSP) data are collected by the Ontario Ministry of Children, Community and Social Services and contains information on all individuals who apply and are determined to be eligible for provincial disability income support.

Operational definitions

1. Adults with and without DD

Adults with DD. Also known in other reports and publications as the H-CARDD cohort, this group consists of 66,484 Ontario adults who were between the ages of 18 and 64 on April 1, 2009, and had a DD diagnosis in the administrative data sources used. When originally created, this cohort consisted of 66,484 adults (for cohort details, see the *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario*[2]). For this report, we followed the cohort from 2010/11, with the result that its original size decreased to 64,699 adults as a result of factors such as death, a change in OHIP coverage eligibility or moving out of the province.

Adults without DD. After the original H-CARDD cohort was created, a 20% random sample of the remaining Ontario population who were between the ages 18 and 64 on April 1, 2009, was drawn from the RPDB to serve as a comparison cohort. A random sample was used rather than the entire population as this significantly reduced computation time while still providing a meaningful comparison group.

2. Subgroups within the DD group

Adults with Down syndrome. This subgroup had at least:

- One hospital visit (recorded in the DAD, SDS or OMHRS databases), or
- One emergency department visit (recorded in NACRS) with a Down syndrome diagnosis code, or
- One ODSP record.

with one of the following diagnostic codes:

- ICD-9: 758.0
- ICD-10: Q90.0–Q90.9

Note: Because there is no OHIP code specific to Down syndrome, only hospital, emergency department and ODSP records were used to identify the subgroup with Down syndrome. Use of the ODSP added an additional 1,663 people that were not originally identified by the health administrative data.

Adults with autism. This subgroup had at least:

- One hospital visit (recorded in DAD, SDS or OMHRS), or
- One emergency department visit (recorded in NACRS), or
- Two physician- or nurse practitioner-billed visits (recorded in OHIP), or
- One ODSP record

with one of the following diagnostic codes:

- ICD-9: 299–299.99
- ICD-10: F840, F841, F843, F844, F845, F848, F849

Adults with DD and a mental health and/or addictions diagnosis. This subgroup had a least:

- One hospital visit (recorded in the DAD, SDS or OMHRS databases), or
- One emergency department visit (recorded in NACRS), or
- One physician- or nurse practitioner-billed visit (recorded in OHIP)

with one of the mental health and addictions diagnostic codes listed in Appendix B.

3. Demographic variables

Variable	Derivation	Categories
Age group	Age was calculated as at April 1, 2010, using date of birth recorded in the RPDB.	In transition: 19 to 24 years Middle-aged: 25 to 49 years Older: 50 to 65 years
Sex	Sex was determined using the RPDB.	Male Female
Neighbourhood income	Neighbourhood income quintiles were derived by linking 2006 census data to residential postal codes as of April 1, 2010. 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; this is done to better reflect the relative nature of this measure, and to ensure that each CMA or CA would have an approximately equal percentage of the population in each income quintile.	Quintile 1 (lowest) Quintile 2 Quintile 3 Quintile 4 Quintile 5 (highest)

4. Outcome variables

30-Day repeat emergency department visits	
Definition	An unscheduled return to the emergency department within 30 days after a previous emergency department visit, or if that index emergency department visit led to a hospital admission, after discharge from that hospitalization.
Numerator	Number of individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) who had made an emergency department visit followed by another emergency department visit within 30 days of discharge (from either the first emergency department visit or a hospital admission due to the first visit).
Denominator	Total number of individuals in the group of interest
Data sources	DAD, OMHRS, NACRS
Measurement timeframe	2010/11 to 2015/16
Note	Scheduled emergency department visits were excluded.

30-Day repeat hospitalizations	
Definition	A readmission to hospital within 30 days after being discharged from a previous hospital stay.
Numerator	Number of individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) who were admitted to a hospital within 30 days of being discharged from an initial hospitalization.
Denominator	Total number of individuals in the group of interest.
Data sources	DAD, OMHRS
Measurement timeframe	2010/11 to 2015/16

Alternate level of care	
Definition	The situation when a patient occupies a bed in a facility but does not require the intensity of resources or services provided in that care setting.[19]
Numerator	Number of individuals within a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) who had been discharged from hospital and had experienced one or more alternate level of care days.
Denominator	Total number of individuals in the group of interest.
Data source	OMHRS
Measurement timeframe	2010/11 to 2015/16
Note	Percentage of alternate level of care days (yes/no) for cases that were discharged from hospital in the year under study.

Long-term care	
Definition	Long-term care homes provide residents with 24-hour nursing, personal care and help with their daily activities. Also called nursing homes, municipal homes for the aged or charitable homes.[116]
Numerator	Number of individuals in a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome) residing in a long-term care facility.
Denominator	Total number of individuals in the group of interest.
Data source	Continuing Care Reporting System – Long-Term Care (CCRS-LTC)
Measurement timeframe	2010/11 to 2015/16
Note	Individuals were included if they were admitted to long-term care and assessed during the follow-up period. They must have had an admission assessment.

Premature mortality	
Definition	This is a measure of the frequency of deaths occurring before age 75 in a given population over a specific period of time. Since only persons younger than age 70 are included in this study, all deaths in the analysis are considered premature.
Numerator	Number of deaths occurring among the individuals in a group of interest (e.g., adults with DD, adults without DD, adults with Down syndrome).
Denominator	Total number of individuals in the group of interest.
Data source	RPDB
Measurement timeframe	2010/11 to 2015/16
Note	Death year must have occurred on or before March 31, 2016, and so by definition, the maximum age at death was 70.

APPENDIX B Mental Health and Addictions Diagnostic Codes Used

Category	Coding System and Condition	Code
Mental Illness: Psychotic Disorders	OHIP	
	Schizophrenia	295
	Paranoid states	297
	Other psychoses	298
	Childhood psychoses (e.g., autism) (299)	Excluded
	ICD-9	
	Schizophrenic disorders	295
	Delusional disorders	297
	Other organic psychoses	298
	ICD-10	
	Schizophrenia, schizotypal, delusional, other psychotic, schizoaffective	F2
	DSM-IV	
	Psychotic disorders due to medical conditions	293.81, 293.82 (298.83 is coded under Other)
	Schizophrenia, schizophreniform, schizoaffective	295 (inclusive)
	Delusional, shared psychotic disorder	297 (inclusive)
	Brief and psychotic disorders	298 (inclusive)
	OMHRS provisional diagnosis (use only if no DSM-IV diagnosis)	
	DSM: Schizophrenia, other psychotic disorder	Q1E = 1
Mental Illness: Non-psychotic Disorders	OHIP	
	Senile/presenile dementia	290
	Manic depressive psychosis, involutional melancholia	296
	Anxiety neuroses, reactive depression, etc.	300
	Personality disorders	301
	Sexual deviations	302
	Psychosomatic disturbances	306
	Habit spasms, tics, stuttering, tension headaches, anorexia nervosa, sleep disorders, enuresis	307
	Adjustment reaction	309
	Depressive or other non-psychotic disorders, not elsewhere classified	311
	Behaviour disorders of childhood and adolescence*	313
	Hyperkinetic syndrome of childhood*	314
	Specific delays in development (e.g., dyslexia, motor retardation)	Excluded
	Mental retardation (319)	Excluded
	ICD-9	
	Dementias	290
	Other transient disorders (e.g., delirium)	293
	Persistent mental illnesses due to other conditions (e.g., amnestic disorders, Alzheimer's)	294
	Episodic mood disorders	296
	Anxiety states -- also includes Dissociative, conversion and factitious disorders (300.1) Phobic disorders (300.2) OCD (300.3) Dysthymia (note: this is a mood disorder - 300.4) Neurasthenia, derealization, hypochondriasis, somatoform, unspecified non-psychotic (300.5–300.9)	300
	Personality disorders	301
	Sex and gender-related disorders	302
	Psychogenic malfunction from mental factors	306
	Specific symptom not elsewhere classified (e.g., stuttering, eating disorders, tics)	307
	Acute stress reaction	308
	Adjustment reaction	309
	Non-psychotic conditions due to brain damage	310
	Depressive disorder, not elsewhere classified	311
	Disturbance of conduct*	312
	Disturbance of emotions specific to childhood*	313
	Hyperkinetic syndrome of childhood (e.g., ADD)*	314
	Specific delays in development (e.g., reading) (315)	Excluded
	Psychic factors associated with diseases classified elsewhere	316
	ICD-10	
	Organic, including symptomatic, mental disorders, also includes Dementias (F00–F03) Organic amnesic syndrome (F04) Delirium (F05) Other mental disorders due to brain damage, etc (F06) Personality and behavioural disorders due to brain disease, etc. (F07) Unspecified organic or symptomatic mental disorder (F09)	F0 (includes F00–F09)

Category	Coding System and Condition	Code
Mental Illness: Non-psychotic Disorders	Manic, bipolar, depressive disease, cyclothymia	F3
	Mental retardation (F7); disorders of psychological development, scholastic skills, pervasive developmental disorders (F8)	Excluded
	Eating disorders, nonorganic sleep, sexual dysfunction, associated with puerperium, etc.	F50–F53
	Obsessive compulsive disorder	F42
	Stress reaction, PTSD, etc. (includes adjustment disorder – F43.2)	F43
	Dissociative, somatoform, other (neurasthenia, depersonalization)	F44–F46, F48
	Psychological and behavioural factors associated with disorders of diseases classified elsewhere; abuse of non-dependence-producing substances; unspecified behavioural syndromes	F54, F55, F59
	Personality disorders, mixed personality disorders, enduring personality change	F60–F62
	Habit and impulse disorders	F63
	Gender identity disorders, disorders of sexual preference, disorders associated with sexual development and orientation	F64–F66
	Other disorders of adult personality and behavior (including Munchhausen's); unspecified	F68, F69
	Hyperkinetic conduct disorders, separation anxiety, attachment disorders, tic disorders, stammering*	F90–F95, F98
	Mental disorder not otherwise specified	F99
	DSM-IV	
	Mood disorder, not otherwise specified	206.90
	Dementias	290
	Mental conditions due to medical conditions	293 (excluding 293.81 and 293.82)
	Dementia/amnestic disorders due to medical conditions	294
	Major depressive, bipolar disorder	296 (including 296.00–296.89)
	Anxiety disorders, as well as: Conversion disorders (300.11) Dissociative (300.12–300.15) Factitious (300.16, 300.19) Dysthymic disorder (300.4) Depersonalization, body dysmorphic, hypochondriasis, somatoform (300.6, 300.7, 300.81) Unspecified mental disorder (300.9)	300
	Cyclothymic disorder	301.13
	Personality disorders	301 (excluding 301.13)
	Sexual dysfunction, pedophilia, paraphilia, etc.	302
	Vaginismus (not due to a general medical condition)	306
Mental Illness: Non-psychotic Disorders	Eating disorders, tic disorder, Tourette's, insomnia, sleep disorders	307
	Acute stress disorder	308.3
	Adjustment disorders, as well as: PTSD (309.81)	309
	Personality change due to medical condition	310 (inclusive)
	Depressive disorder not otherwise specified	311
	Impulse control disorders (e.g., kleptomania, conduct disorder)*	312
	Other disorders usually diagnosed in infancy (e.g., selective mutism, oppositional defiant disorder)*	313
	ADHD*	314
	Psychological factor affecting a medical condition	316
	Mental retardation (317–319)	Excluded
	All codes after 319	Excluded
	OMHRS provisional diagnosis (use only if no DSM-IV diagnosis)	
	DSM: Various	If 1 in Q1B, Q1C, Q1F–Q1P
Substance-Related, Addictive Disorders	OHIP	
	Alcoholic psychosis, DTs, Korsakov's	291
	Drug psychosis	292
	Alcoholism, alcohol intoxication/dependence	303
	Drug dependence, drug addiction	304
	Drug, tobacco abuse	305
	ICD-9	
	Alcohol, drug-induced mental disorders	291, 292
	Alcohol, drug dependence	303, 304
	Non-dependent drug abuse	305
	ICD-10	
	Mental disorders due to psychoactive substance use	F1
	DSM-IV	
	Alcohol-related/induced conditions	291
	Other substance-related withdrawal (e.g., amphetamines, opioids, sedatives)	292
	Alcohol intoxication, dependence	303 (inclusive)
	Other substance dependence, abuse	304, 305
	OMHRS provisional diagnosis (use only if no DSM-IV diagnosis)	
	DSM: Substance-related disorder	Q1D = 1

*Some diagnoses (e.g., conduct disorders, hyperkinetic disorders) are inconsistently included because of the differences between ICD-9, ICD-10, OHIP and DSM-IV coding.

APPENDIX C Health and Health Care Outcomes Across Local Health Integration Networks and Across Ministry of Children, Community and Social Services Regions, 2015/16

EXHIBIT 14 Number and proportion of adults aged 19 to 65 years with or without developmental disabilities, by health and health care outcome and by Local Health Integration Network, in Ontario, 2015/16

Local Health Integration Network	Status	Cohort size in 2015	30-Day repeat emergency department visits, n (%)	30-Day repeat hospitalizations, n (%)	Alternate level of care, n (%)	Long-term care, n (%)	Premature mortality, n (%)
1. Erie St. Clair	With DD	3,767	435 (11.6)	54 (1.4)	36 (1.0)	95 (2.5)	43 (1.1)
	Without DD	127,318	6,617 (5.2)	646 (0.5)	263 (0.2)	146 (0.1)	522 (0.4)
2. South West	With DD	5,779	736 (12.7)	105 (1.8)	71 (1.2)	166 (2.9)	79 (1.4)
	Without DD	185,395	11,460 (6.2)	1,037 (0.6)	241 (0.1)	206 (0.1)	730 (0.4)
3. Waterloo Wellington	With DD	3,061	264 (8.6)	46 (1.5)	23 (0.8)	55 (1.8)	36 (1.2)
	Without DD	149,108	5,926 (4.0)	647 (0.4)	234 (0.2)	153 (0.1)	469 (0.3)
4. Hamilton Niagara Haldimand Brant	With DD	8,511	960 (11.3)	162 (1.9)	93 (1.1)	185 (2.2)	100 (1.2)
	Without DD	273,794	13,389 (4.9)	1,444 (0.5)	576 (0.2)	301 (0.1)	1,135 (0.4)
5. Central West	With DD	2,196	148 (6.7)	33 (1.5)	9 (0.4)	38 (1.7)	21 (1.0)
	Without DD	171,653	6,158 (3.6)	742 (0.4)	157 (0.1)	97 (0.1)	393 (0.2)
6. Mississauga Halton	With DD	2,876	206 (7.2)	38 (1.3)	19 (0.7)	44 (1.5)	23 (0.8)
	Without DD	232,518	7,925 (3.4)	818 (0.4)	213 (0.1)	121 (0.1)	543 (0.2)
7. Toronto Central	With DD	4,261	438 (10.3)	104 (2.4)	60 (1.4)	63 (1.5)	52 (1.2)
	Without DD	249,179	8,891 (3.6)	1,125 (0.5)	424 (0.2)	197 (0.1)	720 (0.3)
8. Central	With DD	5,003	374 (7.5)	70 (1.4)	44 (0.9)	76 (1.4)	53 (1.1)
	Without DD	350,983	12,027 (3.4)	1,309 (0.4)	415 (0.1)	173 (0.1)	769 (0.2)
9. Central East	With DD	6,250	643 (10.3)	99 (1.6)	37 (0.6)	146 (2.3)	58 (0.9)
	Without DD	310,736	13,798 (4.4)	1,374 (0.4)	399 (0.1)	288 (0.1)	982 (0.3)
10. South East	With DD	4,289	530 (12.4)	67 (1.6)	26 (0.6)	67 (1.6)	41 (1.0)
	Without DD	9,5437	5,694 (6.0)	522 (0.6)	131 (0.1)	133 (0.1)	418 (0.4)
11. Champlain	With DD	6,406	723 (11.3)	104 (1.6)	74 (1.2)	136 (2.1)	86 (1.3)
	Without DD	250,563	11,413 (4.6)	1,144 (0.5)	356 (0.1)	251 (0.1)	748 (0.3)
12. North Simcoe Muskoka	With DD	2,565	324 (12.6)	53 (2.1)	37 (1.4)	64 (2.5)	43 (1.7)
	Without DD	87,017	5,034 (6.0)	433 (0.5)	149 (0.2)	78 (0.1)	362 (0.4)
13. North East	With DD	4,791	763 (15.9)	100 (2.1)	73 (1.5)	118 (2.5)	61 (1.3)
	Without DD	115,496	10,088 (8.7)	838 (0.7)	291 (0.3)	176 (0.2)	576 (0.5)
14. North West	With DD	1,668	306 (18.4)	40 (2.4)	31 (1.9)	34 (2.0)	27 (1.6)
	Without DD	47,981	4,399 (9.2)	337 (0.7)	185 (0.4)	59 (0.1)	223 (0.5)

EXHIBIT 15 Number and proportion of adults aged 19 to 65 years with or without developmental disabilities, by health and health care outcome and by Ministry of Children, Community and Social Services region, in Ontario, 2015/16

Ministry of Children, Community and Social Services Region	Status	Cohort size in 2015	30-Day repeat emergency department visits, n (%)	30-Day repeat hospitalizations, n (%)	Alternate level of care, n (%)	Long-term care, n (%)	Premature mortality, n (%)
Central	With DD	13,003	1,116 (8.6)	212 (1.6)	113 (0.9)	226 (1.7)	153 (1.2)
	Without DD	830,858	30,675 (3.7)	3,242 (0.4)	944 (0.1)	522 (0.1)	2,120 (0.3)
East	With DD	15,002	1,751 (11.7)	245 (1.6)	129 (0.9)	315 (2.1)	169 (1.1)
	Without DD	529,721	26,444 (5.0)	2,561 (0.5)	709 (0.1)	575 (0.1)	1,812 (0.3)
North	With DD	6,858	1,115 (16.3)	142 (2.1)	106 (1.6)	166 (2.4)	95 (1.4)
	Without DD	174,879	15,183 (8.7)	1,237 (0.7)	497 (0.3)	253 (0.1)	845 (0.5)
Toronto	With DD	9,058	781 (8.6)	166 (1.8)	93 (1.0)	137 (1.5)	93 (1.0)
	Without DD	557,185	19,808 (3.6)	2,379 (0.4)	840 (0.2)	400 (0.1)	1,527 (0.3)
West	With DD	17,502	2,087 (11.9)	310 (1.8)	192 (1.1)	437 (2.5)	213 (1.2)
	Without DD	554,535	30,709 (5.5)	2,997 (0.5)	1,044 (0.2)	629 (0.1)	2,286 (0.4)

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