Health Care Access Research and Developmental Disabilities: Providing Evidence of Health Disparities

Outline

- The creation of a unique research partnership
- The making of an Atlas
- The use of research to change practice

But first…..the WHY

- At **increased risk** for some health problems (e.g. mental illness, gastrointestinal disorders, seizure disorders)
- **Higher use** of some health care services
- **Greater difficulty** navigating their way through health services

Journal of Intellectual & Developmental Disability, Vol. 24, No. 4, pp. 283–297, 1999

Health targets for people with an intellectual disability[1]

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The University of Queensland

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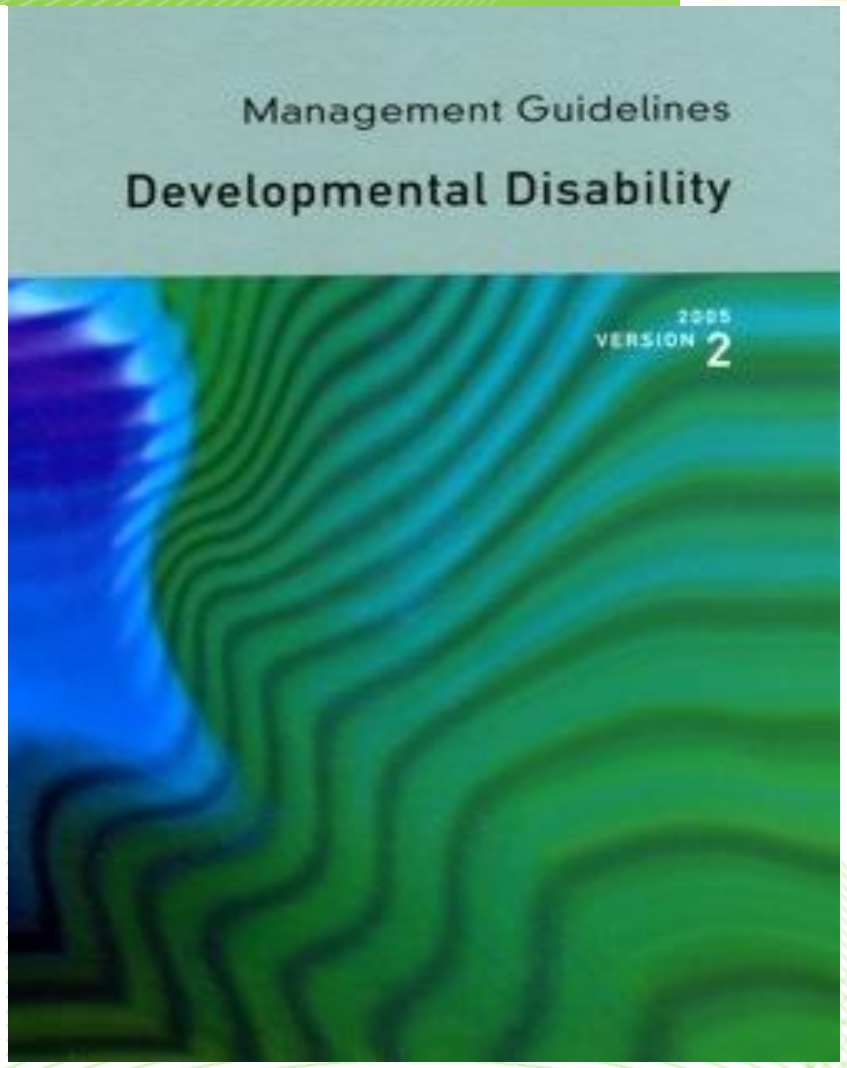
Centre for Developmental Disability Studies, Sydney

This article describes the development and identification of a set of health targets for adults with an intellectual disability. The authors developed the targets through a process of collaboration, consultation and literature review. The targets were included if reliable studies had shown the conditions to be highly prevalent, easily detected, and amenable to treatments that are readily available. It is envisaged that these targets will be further refined and eventually endorsed by IASSID for presentation to the World Health Organisation in the year 2000.



CLOSING THE GAP:

A National Blueprint to Improve the Health of Persons with Mental Retardation

Report of the Surgeon General's Conference on Health Disparities and Mental Retardation

U.S. Department of Health and Human Services • 2002

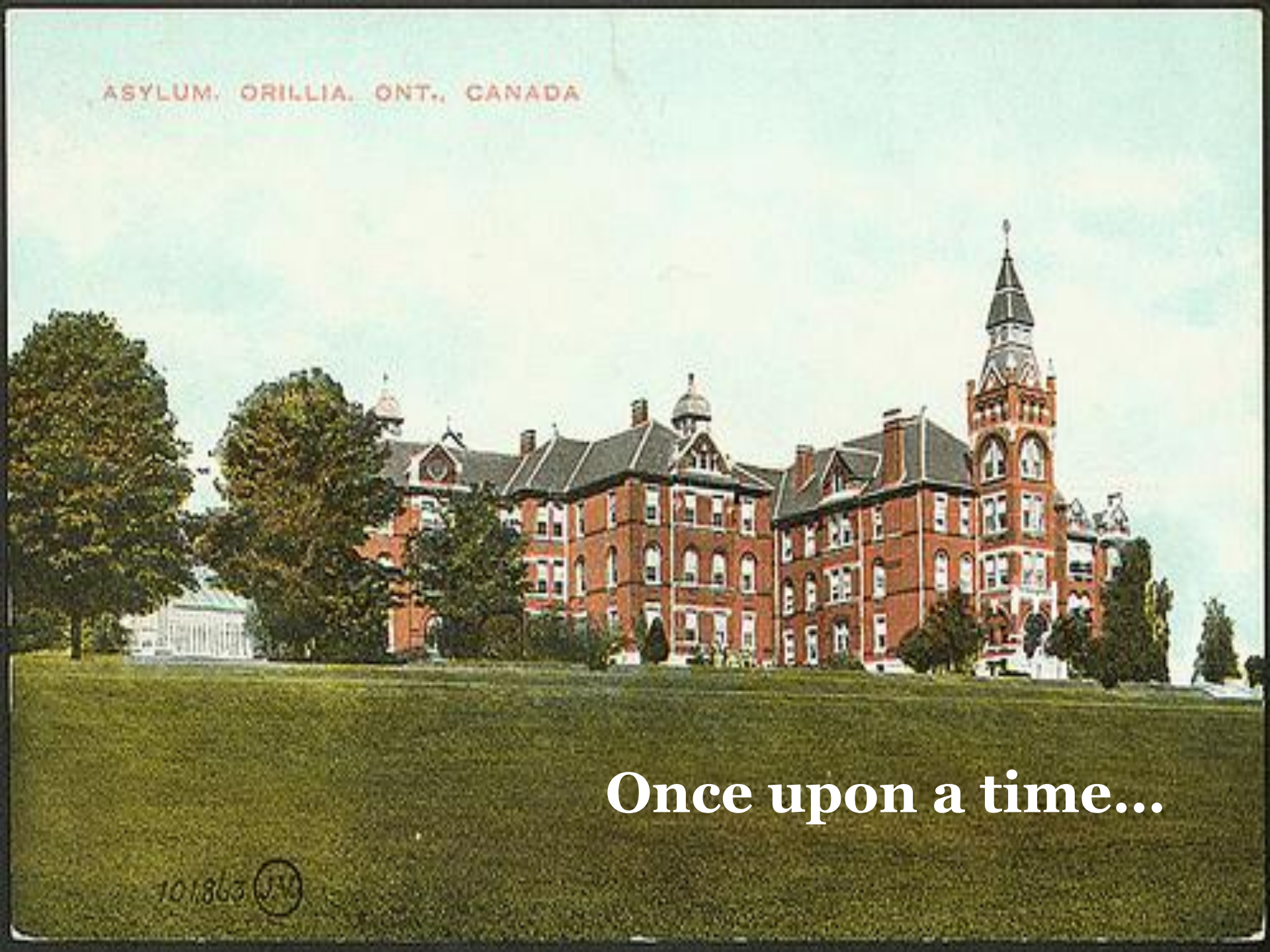
Death by indifference

As a result of receiving unequal healthcare, people with a learning disability are dying when their lives could be saved.

In 2007, following the deaths of six people with a learning disability in NHS care, Mencap published Death by indifference which exposed the unequal healthcare and institutional discrimination that people with learning disabilities often experience within the NHS. Death by indifference played an important role in influencing the Department of Health to commission the Confidential Inquiry into premature deaths of people with a learning disability.

mencap

The voice of learning disability


ASYLUM. ORILLIA. ONT., CANADA
Once upon a time...

CME

Consensus guidelines for primary health care of adults with developmental disabilities

William F. Sullivan, MD, CCFP, PHD John Heng, MA Donna Cameron, MD, CCFP Yona Lunsky, PHD, CPSYCH
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MAIN MESSAGE People with DD have complex health issues, some differing from those of the general population. Adequate primary health care is necessary to identify these issues and to prevent morbidity and premature death. Physical, behavioural, and mental health difficulties should be addressed, and primary health care providers should be particularly attentive to the interactions of biological, psychological, and social factors contributing to health, since these interactions can easily be overlooked in adults with DD. Attention must also be paid to such ethical issues as informed consent and avoidance of harm. Developmental disabilities are not grounds for care providers to withhold or to withdraw medically indicated interventions, and decisions concerning such interventions should be based on patients' best interests.

CONCLUSION Implementing the guidelines proposed here would improve the health of adults with DD and minimize disparities in health and health care.

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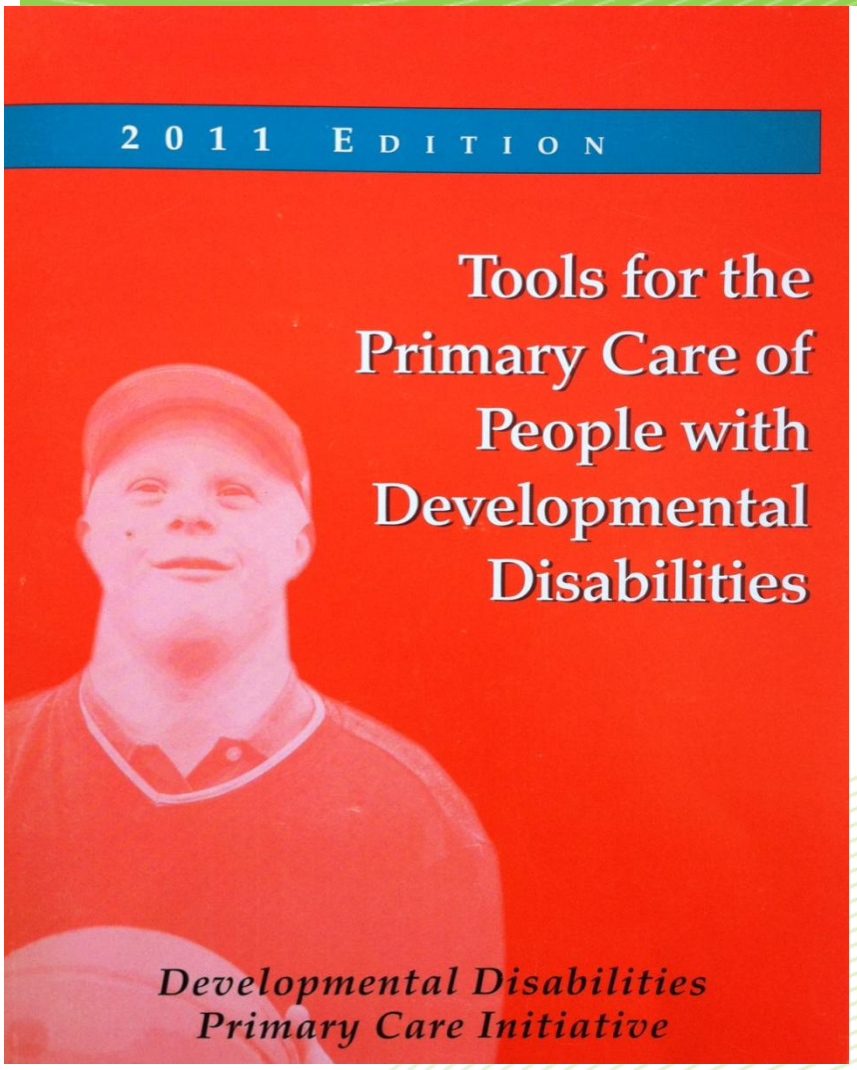

Clinical Review

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Canadian consensus guidelines

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Main message Adults with DD have complex health issues, many of them differing from those of the general population. Good primary care identifies the particular health issues faced by adults with DD to improve their quality of life, to improve their access to health care, and to prevent suffering, morbidity, and premature death. These guidelines synthesize general, physical, behavioural, and mental health issues of adults with DD that primary care providers should be aware of, and they present recommendations for screening and management based on current knowledge that practitioners can apply. Because of interacting biologic, psychoaffective, and social factors that contribute to the health and well-being of adults with DD, these guidelines emphasize involving caregivers, adapting procedures when appropriate, and seeking input from a range of health professionals when available. Ethical care is also emphasized. The guidelines are formulated within an ethical framework that pays attention to issues such as informed consent and the assessment of health benefits in relation to risks of harm.

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KEY POINTS As a group, adults with developmental disabilities (DD) have poorer health and greater difficulty accessing primary care than does the general population. They have different patterns of illness and complex interactions among comorbidities. These guidelines update the general, physical, behavioural, and mental health recommendations for adults with DD, especially for those conditions not screened for by routine health assessments of the general population. Ethical issues, such as informed consent and assessment of benefits in relation to risks, are addressed. Among the most important updates are consideration of atypical manifestations of pain and distress in adults with DD and a strong recommendation to avoid inappropriate long-term use of antipsychotic medications to address behavioural issues.

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Can Fam Physician 2011;57:541-53

La traduction en français de cet article se trouve à www.cfp.ca dans la table des matières du numéro de mai 2011 à la page e154.

Health Care Capacity

Developmental Disabilities Primary Care Initiative

Information Bulletins

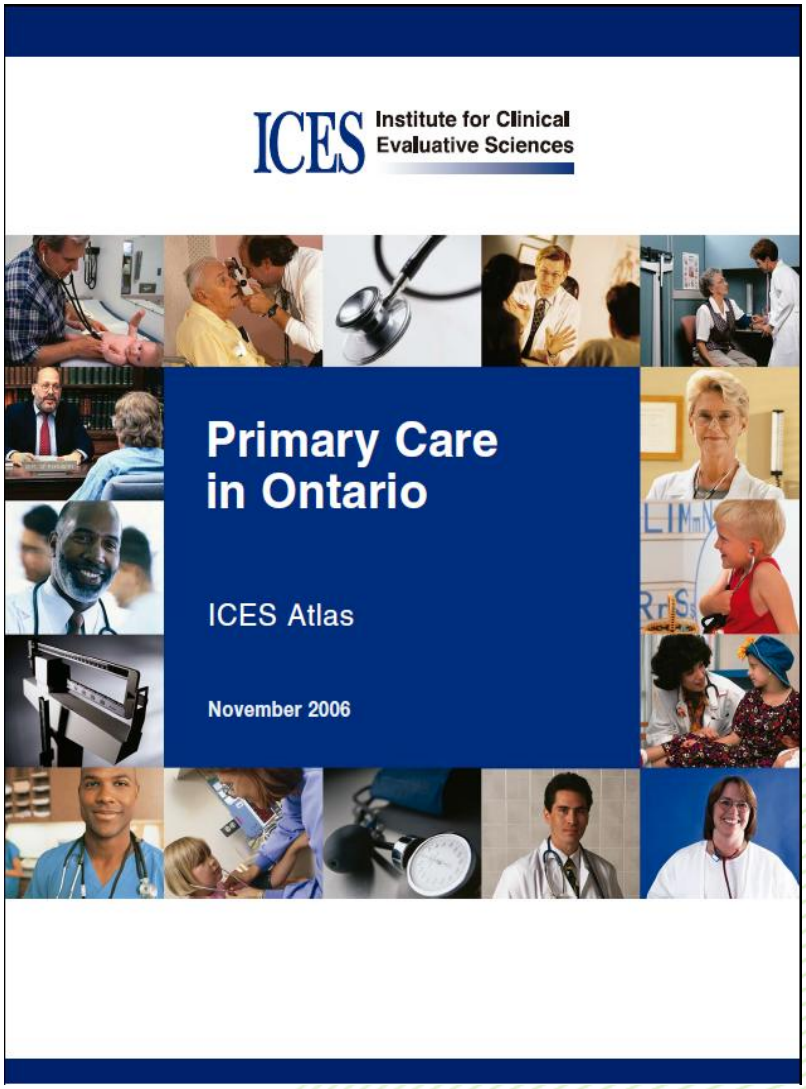
Health Care Capacity

Through a small team of Health Care Facilitators, CNSC is working to improve access to primary care for individuals with a developmental disability, and to build capacity with health care professionals through training, education and support.

Working collaboratively with the Developmental Disability Primary Care Initiative, CNSC is using the new Primary Care Guidelines and accompanying tools to assist health care professionals, caregivers and families in enhancing the primary care experience for individuals with developmental disabilities.

Consistent with the provincial mandate, the Health Care Facilitators continue to partner with community agencies, service providers, caregivers and provincial Ministries to ensure current best practices in providing health care to individuals with developmental disabilities are available, and integrated into care.

Click here for Health Care Facilitators contact information.



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BUT…

CARDD

- NO POPULATION-BASED STUDY OF HEALTH CARE ACCESS IN ONTARIO
- NO ONE SECTOR HAS ALL THE NEEDED DATA!

Health Care Access Research and Developmental Disabilities (H-CARDD)

www.hcardd.ca

CARDD

CARDD

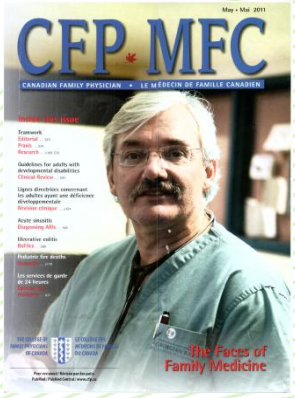
The making of an Atlas

CARDD

1. Create and evaluate cohorts of adults with developmental disabilities in Ontario using different administrative (health and social service) datasets and algorithms

2. Describe primary care use among adults with developmental disabilities in Ontario

3. Evaluate guideline-recommended primary care for adults with developmental disabilities in Ontario



The making of an Atlas

1. Create and evaluate cohorts of adults with developmental disabilities in Ontario using different administrative (health and social service) datasets and algorithms

MERGED cohort

ICES cohort

ICES Data Holdings

Data taken from:

Hospital stays

Visits to Doctors' offices

Emergency department visits

April 2009 – March 2010

MCSS cohort

SDMT Database

Database from MCSS

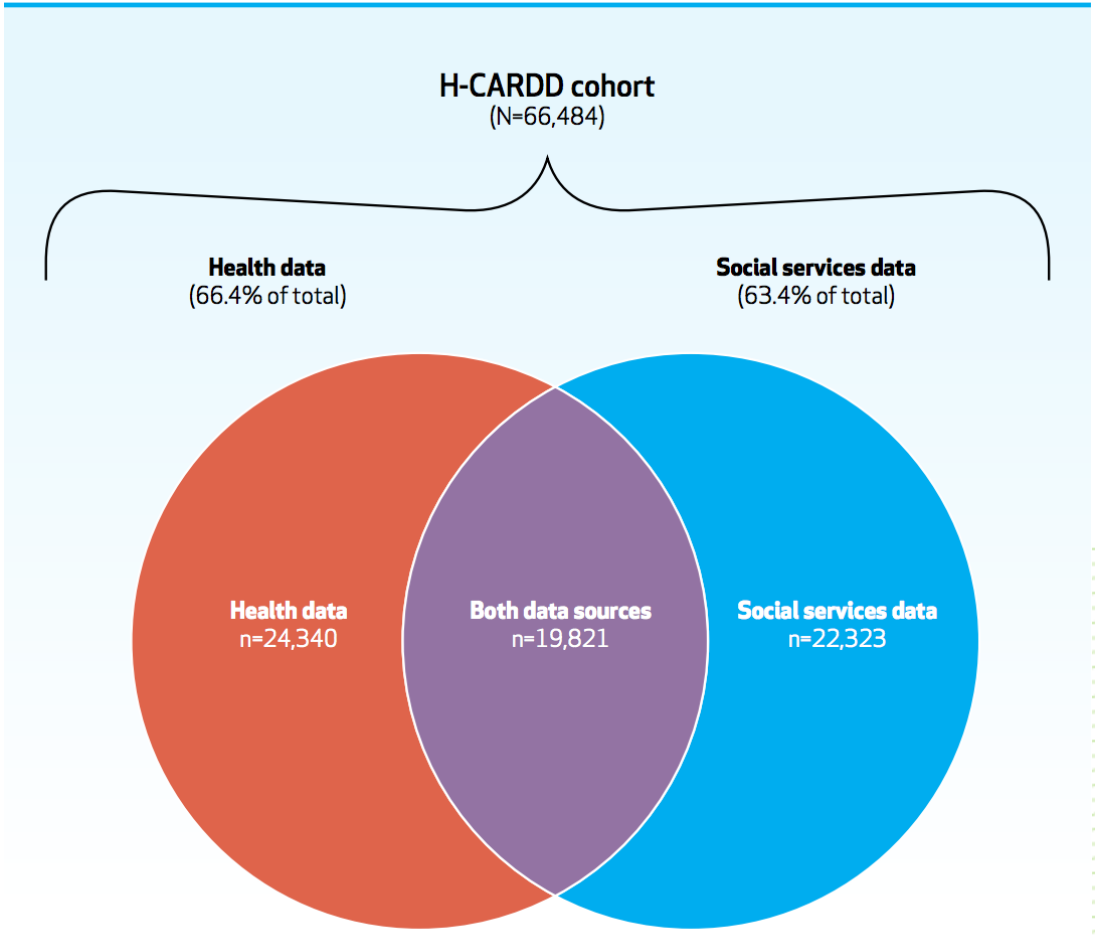
OW, ODSP

April 2009 – March 2010

Data Linkage Process (CHAPTER 1)

- Privacy Impact Assessment completed Spring 2011 by consultants (10 months)
- Data Sharing Agreement between MCSS and ICES signed December 2011 (18 months)
- Transfer of disability income support data from MCSS to ICES done January 2012
- Final linkage completed June 2012 (2 years)

Data Linkage Results (CHAPTER 2)



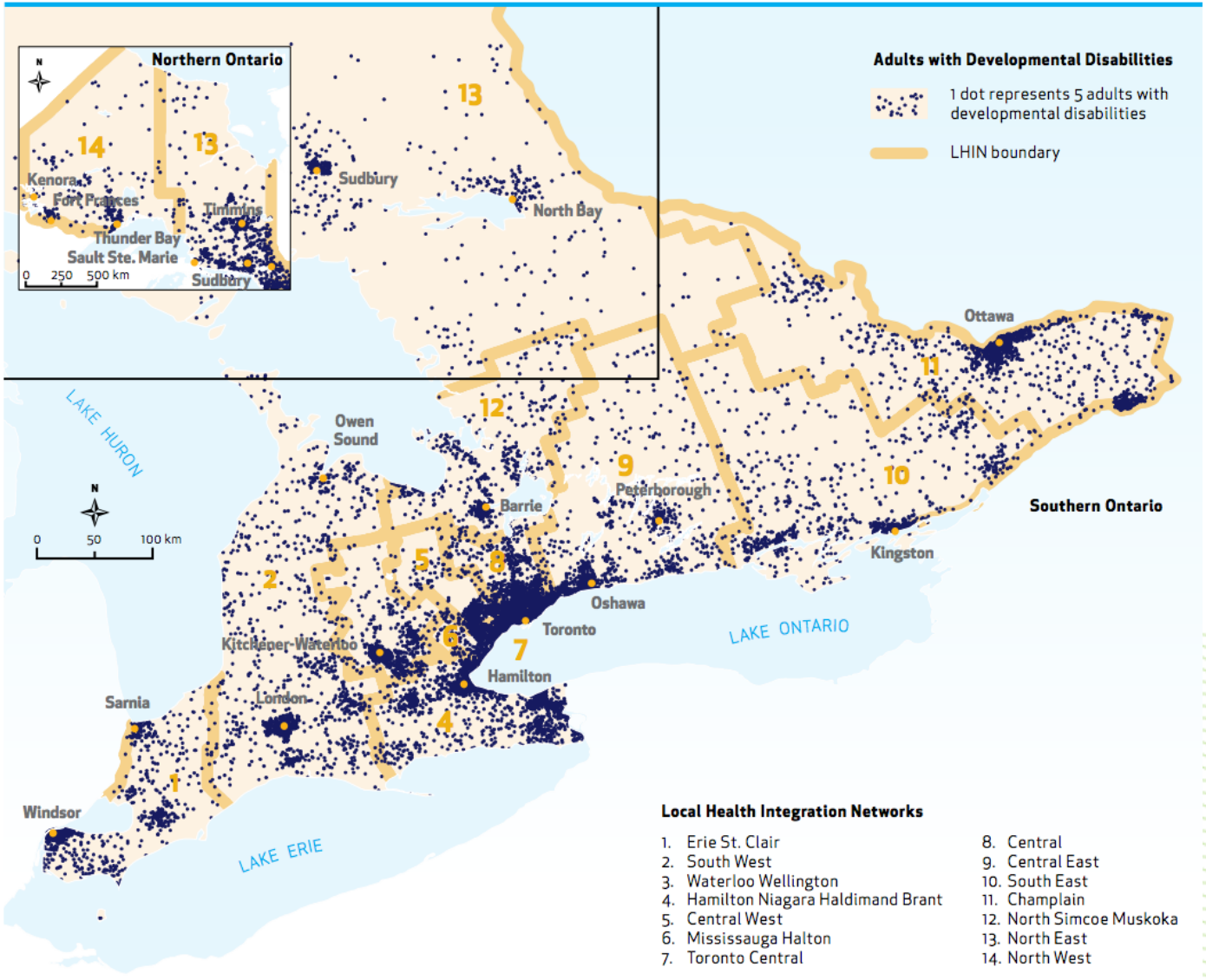
Prevalence

Health: 0.52

Disability Income: 0.49

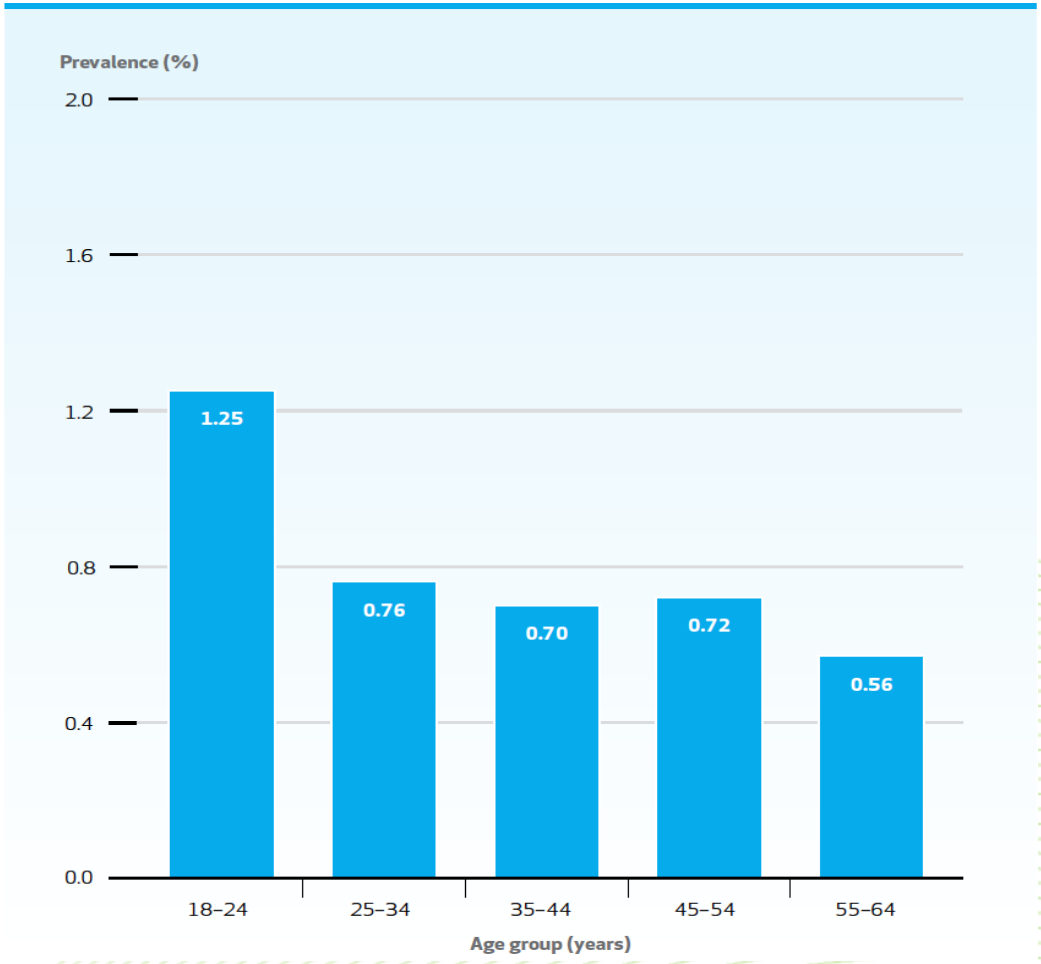
MERGED: 0.78
(n = 66,000+)

Prevalence of DD in Ontario



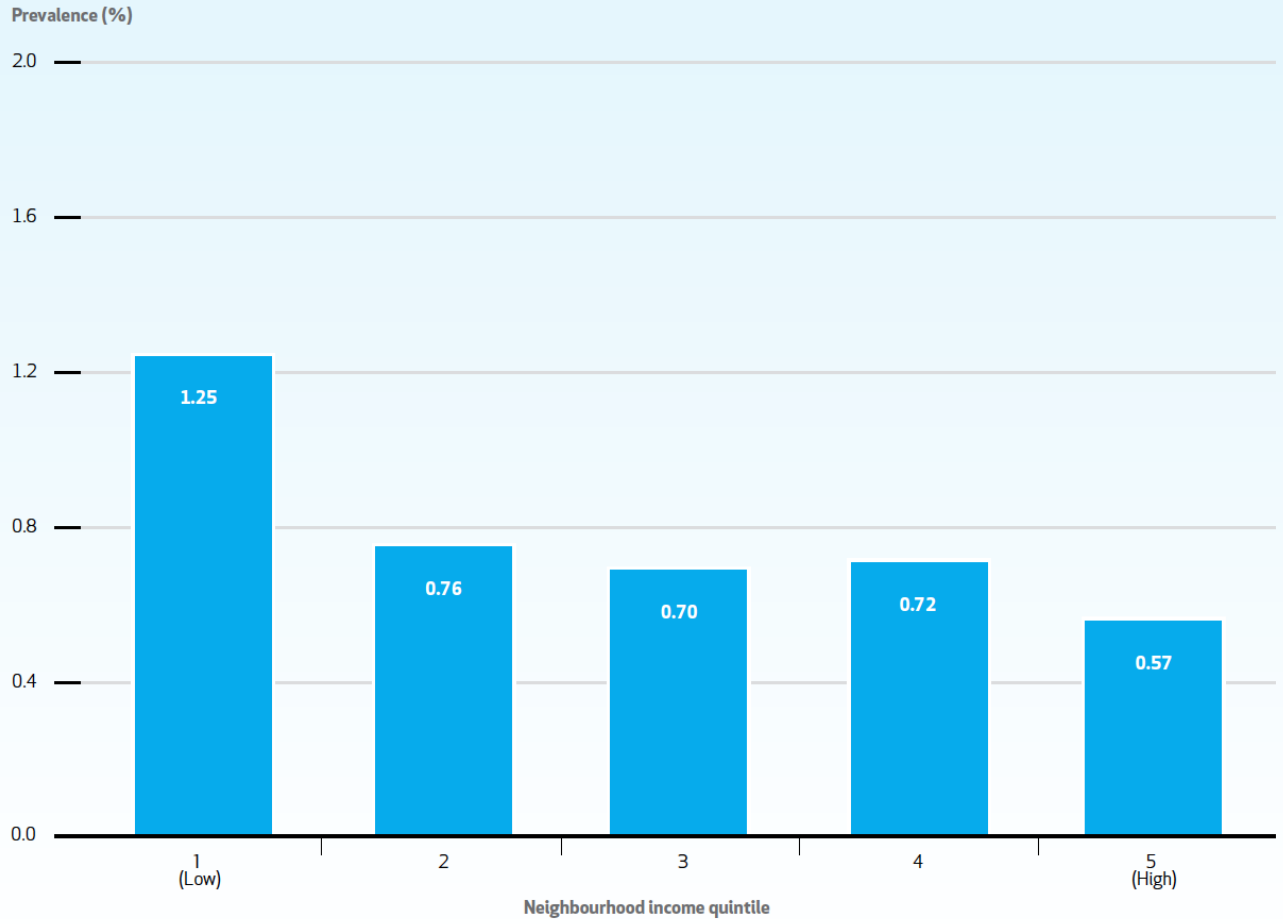
Adults with DD in Ontario

Proportion of Adults Aged 18 to 64 with or without Developmental Disabilities, by Age Group, in Ontario, 2009/2010



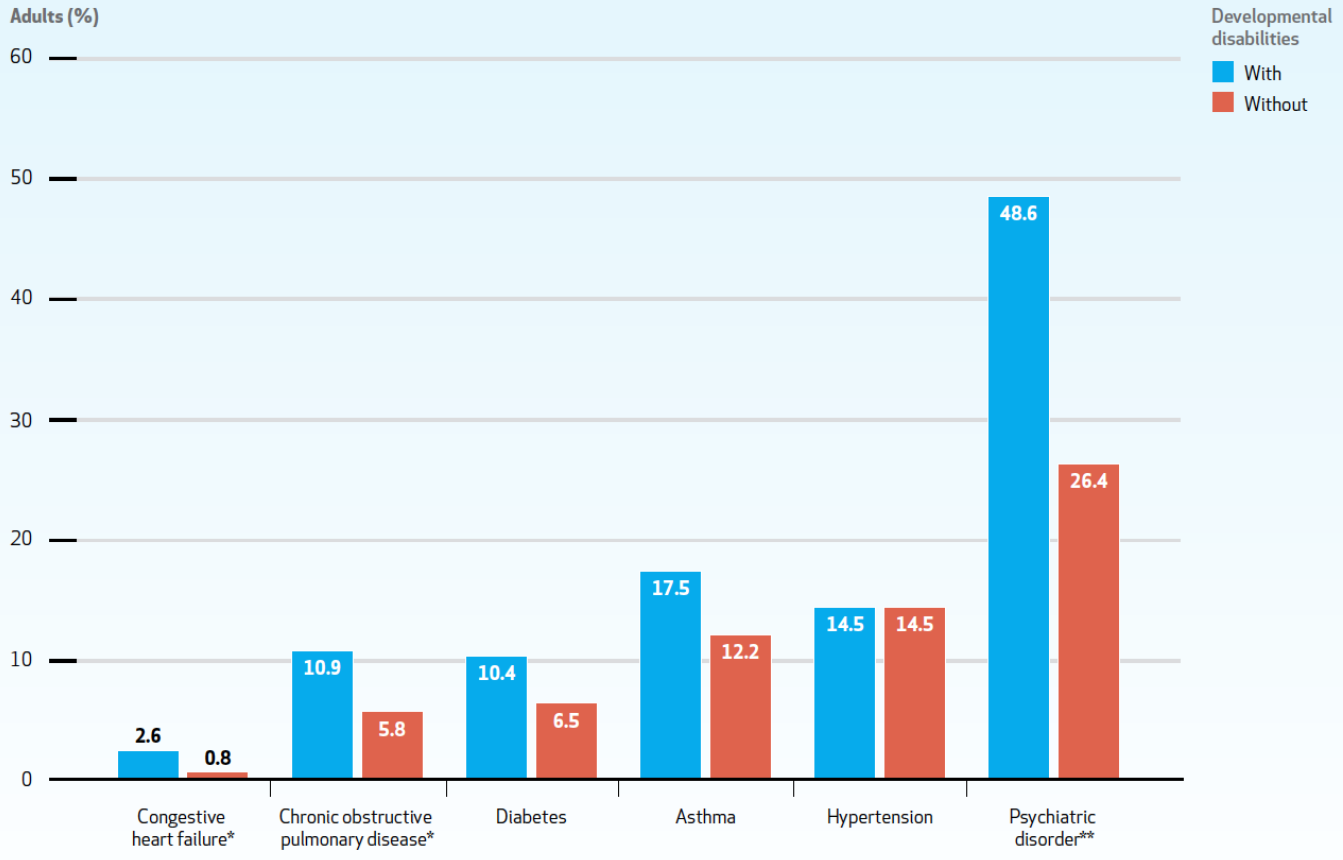
Adults with DD in Ontario

Proportion of Adults Aged 18 to 64 with Developmental Disabilities, by Neighbourhood Income Quintile, in Ontario, 2009/2010



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

Proportion of Adults Aged 18 to 64 with or without Developmental Disabilities, by Chronic Disease, in Ontario, 2009/2010



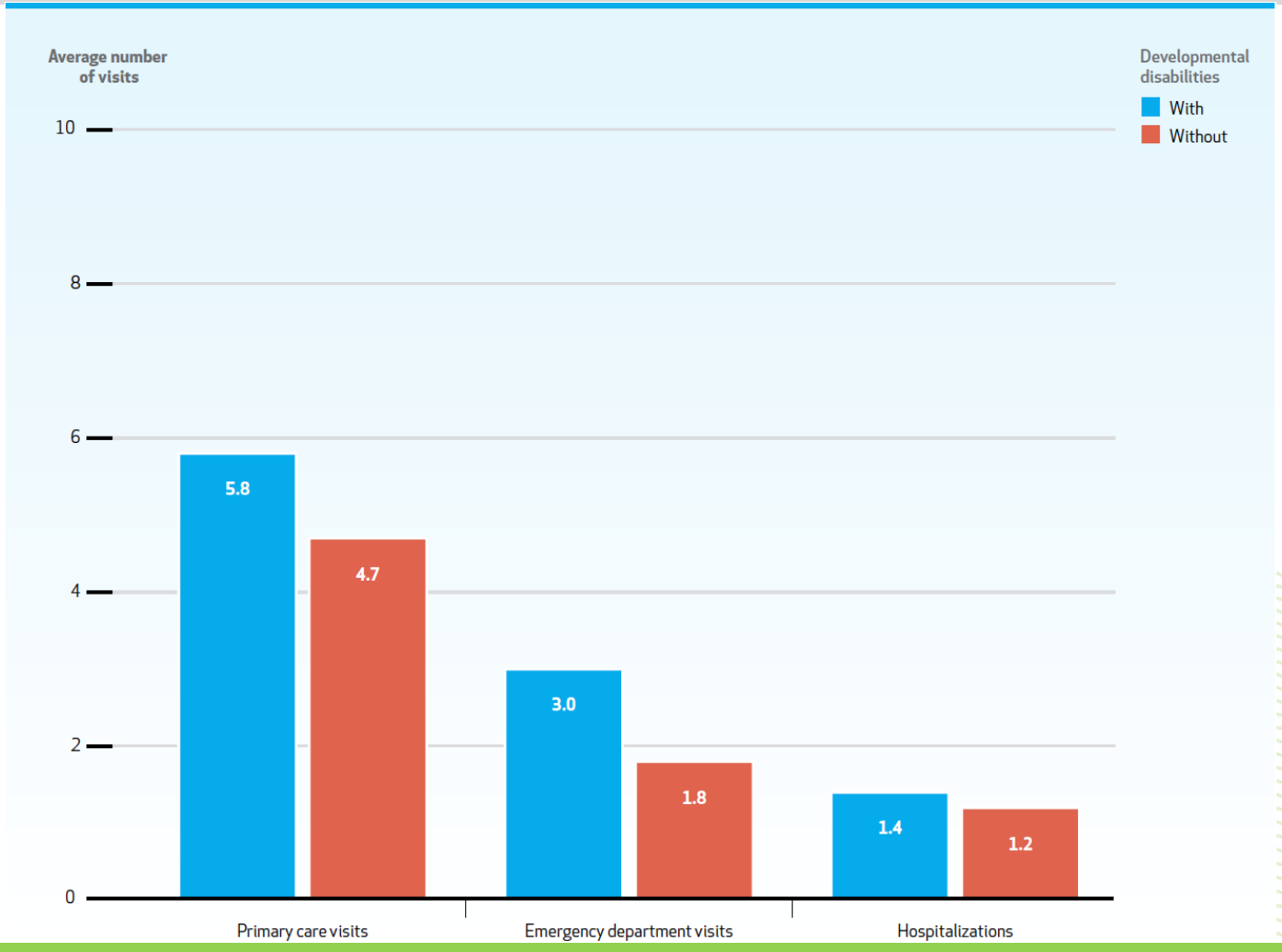
Ratio (With/Without)	3.3	1.9	1.6	1.4	1.0	1.8

The making of an Atlas

2. Describe primary care use among adults with developmental disabilities in Ontario
   - CHAPTER 3: Health Service Utilization
     - Patient Enrolment Models
     - Family Health Teams
     - Continuity of Care
   - CHAPTER 4: Secondary Preventi
   - CHAPTER 5: Chronic Disease Ma
   - CHAPTER 6: Medication Use

Health Service Utilization

Average Number of Primary Visits, Emergency Department Visits or Hospitalizations for Adults Aged 18 to 64 with or without Developmental Disabilities, in Ontario, 2009/2010



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3. Evaluate guideline-recommended primary care for adults with developmental disabilities in Ontario (CHAPTERS 4, 5 AND 6)

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CMAJ REVIEW

2010 clinical practice guidelines for the diagnosis and management of osteoporosis in Canada: summary

Alexandra Papaioannou MD MSc, Suzanne Morin MD MSc, Angela M. Cheung MD PhD, Stephanie Atkinson PhD, Jacques P. Brown MD, Sidney Feldman MD, David A. Hanley MD, Anthony Hodsman MD, Sophie A. Jamal MD PhD, Stephanie M. Kaiser MD, Brent Kvern MD, Kerry Siminoski MD, William D. Leslie MD MSc; for the Scientific Advisory Council of Osteoporosis Canada

Table 3. Preventive care checklist for adults with developmental disabilities: *The level of evidence is indicated for each recommendation and is based on the cited reference or references.*

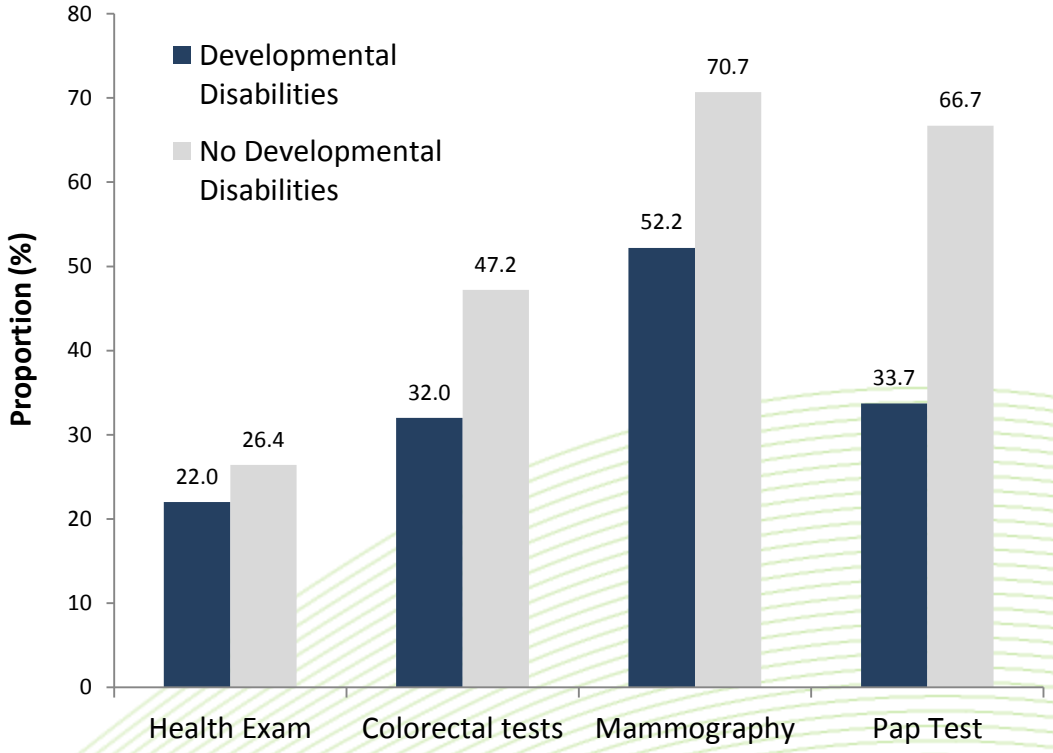
CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
GENERAL ISSUES IN PRIMARY CARE OF ADULTS WITH DD		
1. Disparities in primary care exist between adults with DD and the general population. The former often have poorer health, increased morbidity, and earlier mortality.[2] Assessments that attend to the specific health issues of adults with DD can improve their primary care.[9]	a. Apply age- and sex-specific guidelines for preventive health care as for adults in the general population.[10,11] Perform an annual comprehensive preventive care assessment including physical examination and use guidelines and tools adapted for adults with DD.[9]	I
2. Etiology of DD is useful to establish, whenever possible, as it often informs preventive care or treatment.[12-14]	a. Contact a genetics centre for referral criteria and testing protocols concerning etiologic assessment of adults whose DD is of unknown or uncertain origin.[15-17]	III
Advances in genetic knowledge continue to enhance detection of etiology.[13,18]	b. Consider reassessment periodically if a previous assessment was inconclusive, according to the criteria of the genetics centre.[19]	III
3. Adaptive functioning can decline or improve in some adults with DD. A current assessment of intellectual and adaptive functioning helps to determine necessary care and supports, and establishes a baseline for future assessment.[1,20,21]	a. Refer to a psychologist for assessment of functioning if the patient has never been assessed during adolescence or adulthood, or if a considerable life transition is expected (eg, cessation of schooling or transition from middle to old age).	III
	b. Consider reassessment if indicated, comprehensively or in specific areas, to determine contributing factors to problem behaviour (see guideline 22).[22]	III
4. Pain and distress, often unrecognized,[23] might present atypically in	a. Be attentive to atypical physical cues of pain and distress using	III

Table 3 *contiued from page 546*

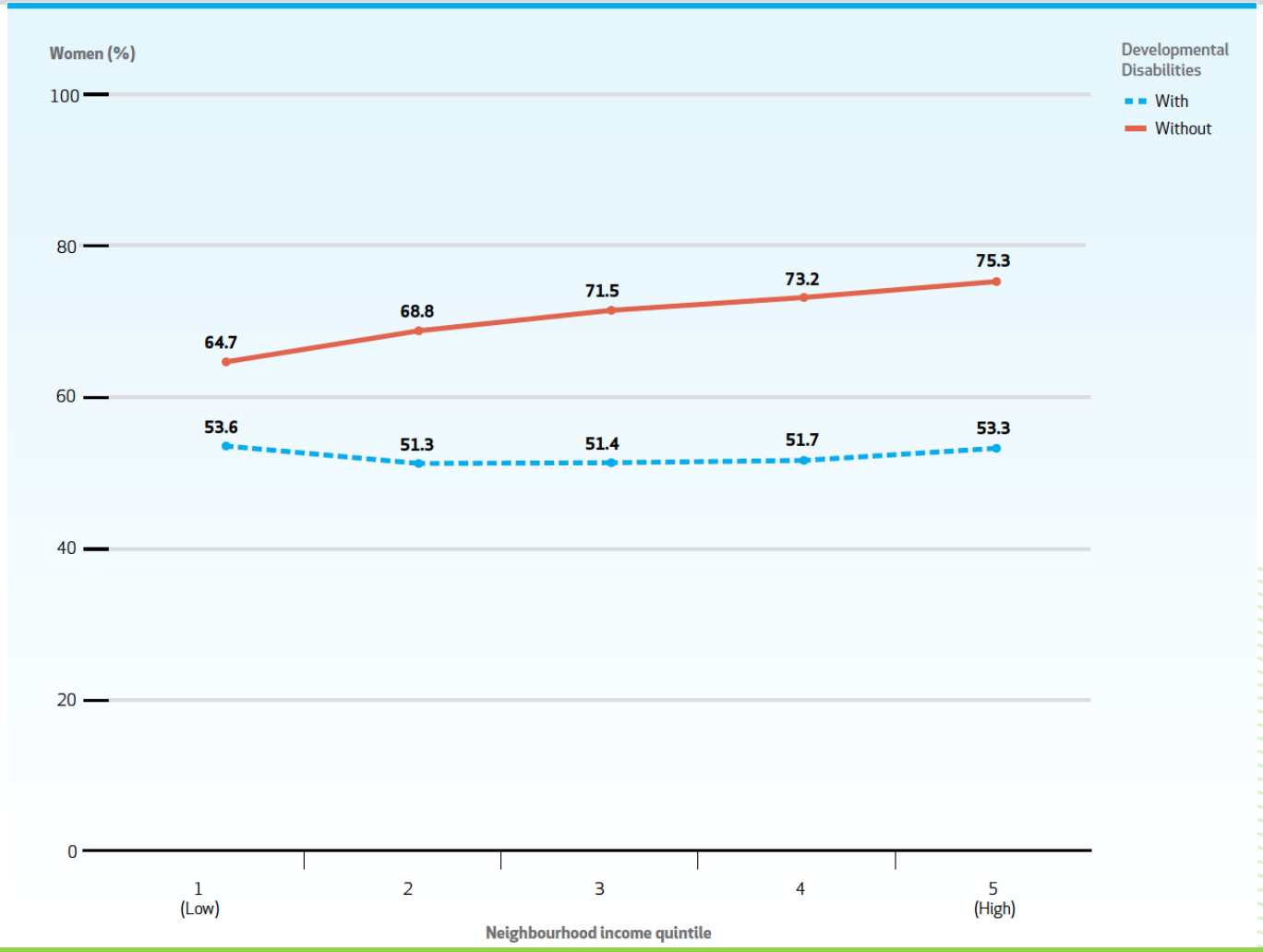
CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
20. Infectious disease prevention and screening. Even though immunization is a crucial component of preventive care, adults with DD might have limited awareness of immunizations.[9,33,113]	a. Follow guidelines for routine immunization of adults.[114,115]	III
	b. Ensure influenza and *Streptococcus pneumoniae* vaccinations are current and offered when appropriate.[116]	III
	c. Discuss the human papillomavirus vaccine with female patients with DD between the ages of 9 and 26 y and, if appropriate, their substitute decision makers.[117]	III
It is important to screen for infectious diseases (eg, hepatitis B, HIV, and *H pylori*) in adults with DD. Some adults with DD have an increased risk of exposure to infectious diseases (eg, hepatitis A and B).[118,119]	d. Screen for infectious diseases based on the patient's risk factors for exposure (for *H pylori* see 15c, 15d).	III
	e. Offer hepatitis A and B screening and immunization to all at-risk adults with DD,[117-119] including those who take potentially hepatotoxic medications or who have ever lived in institutions or group homes.[115]	III
21. Cancer screening is an essential aspect of preventive care. However, adults with DD are less likely than those in the general population to be included in preventive screening programs such as cervical screening,[113] breast examination, mammography, and digital rectal examination.[2] They are also less likely to do self-examination or to report abnormalities. Colorectal cancer risk is considerably greater for women than for men with DD.[120]	a. Perform regular cervical screening for all women who have been sexually active.[121]	I
	b. Perform annual breast screening, including mammography, for female patients with DD aged 50-69 y.[122]	III
	c. Perform an annual testicular examination for all male patients with DD.[123]	III
	d. Screen for prostate cancer annually using digital rectal examination from age 45 y for all male patients with DD.[124]	II
	e. Screen for colon cancer regularly in all adult patients with DD older than 50 y.[120,125]	I
BEHAVIOURAL AND MENTAL HEALTH GUIDELINES FOR ADULTS WITH DD		
22. Problem behaviour, such as aggression and self-injury, is not a psychiatric disorder but might be a symptom of a health-related	a. Before considering a psychiatric diagnosis, assess and address sequentially possible causes of problem behaviour, including	II

Secondary Prevention

Proportion of Eligible Population with or without Developmental Disabilities who had a Periodic Health Examination or Screening for Colorectal, Breast or Cervical Cancer



Proportion of Women Aged 50 to 64 Years With or Without Developmental Disabilities Who Had a Mammogram in the Previous Two Years, by Neighbourhood Income Quintile, in Ontario, 2009/10 to 2010/11



Chronic Disease Management

Chronic Disease Management

Canadian Diabetes Association Clinical Practice Guidelines

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

In effect during the period of study; updated in 2013

Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities

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

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

Clinical Practice Guidelines for the Diagnosis and Management of Osteoporosis

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

In effect during the period of study; updated in 2010.

Chronic Disease Management

Proportion of Eligible Population with or without Developmental Disabilities who had Recommended Management of Diabetes (eye exam), Psychiatric Emergency Visit Follow-up or Fracture follow-up.

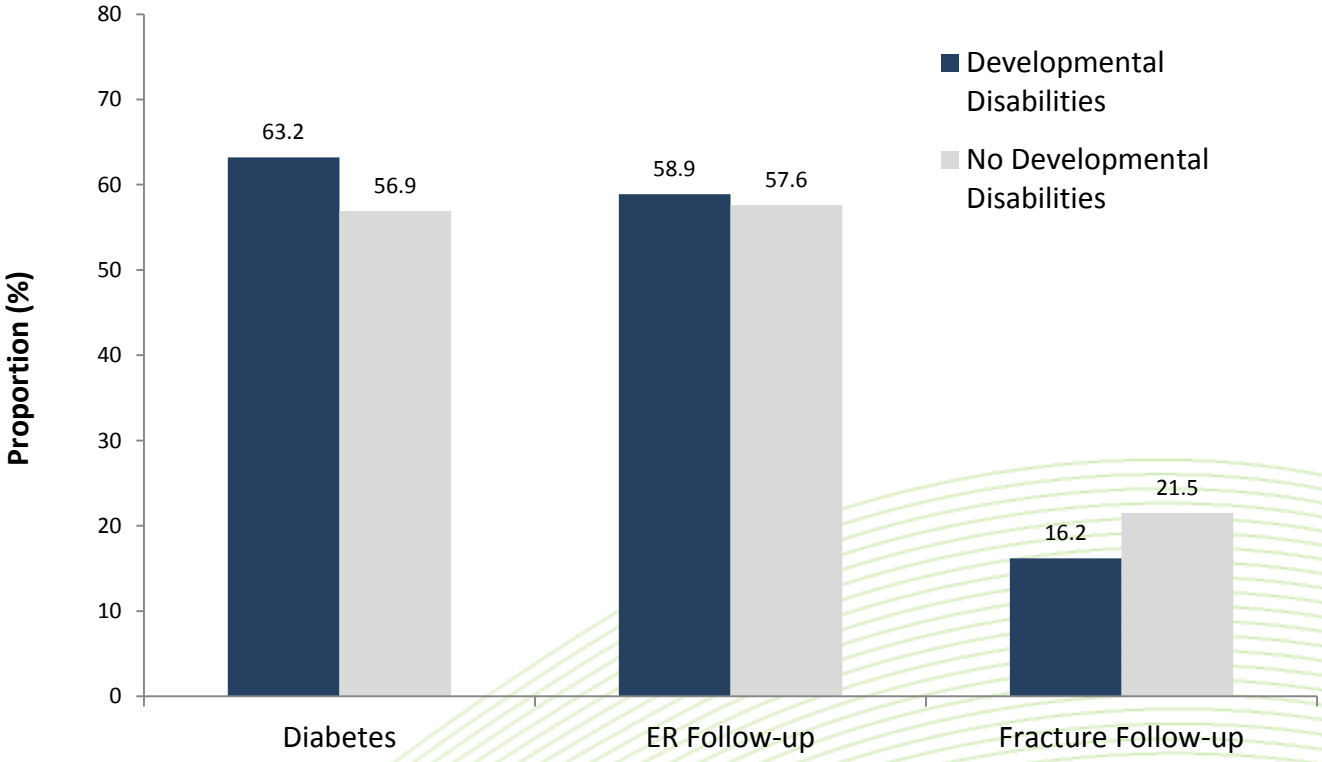
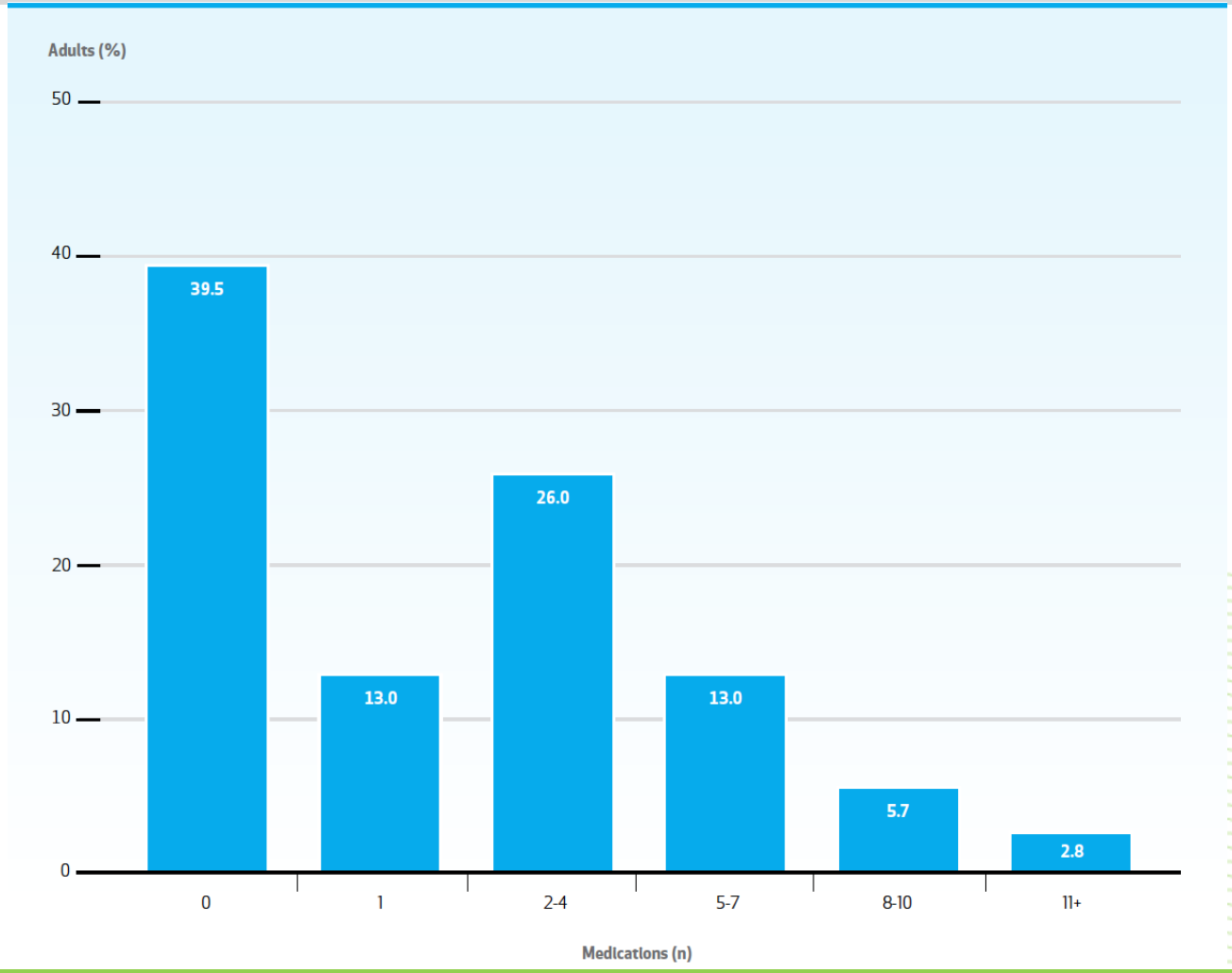


Table 3 *contiued from page 547*

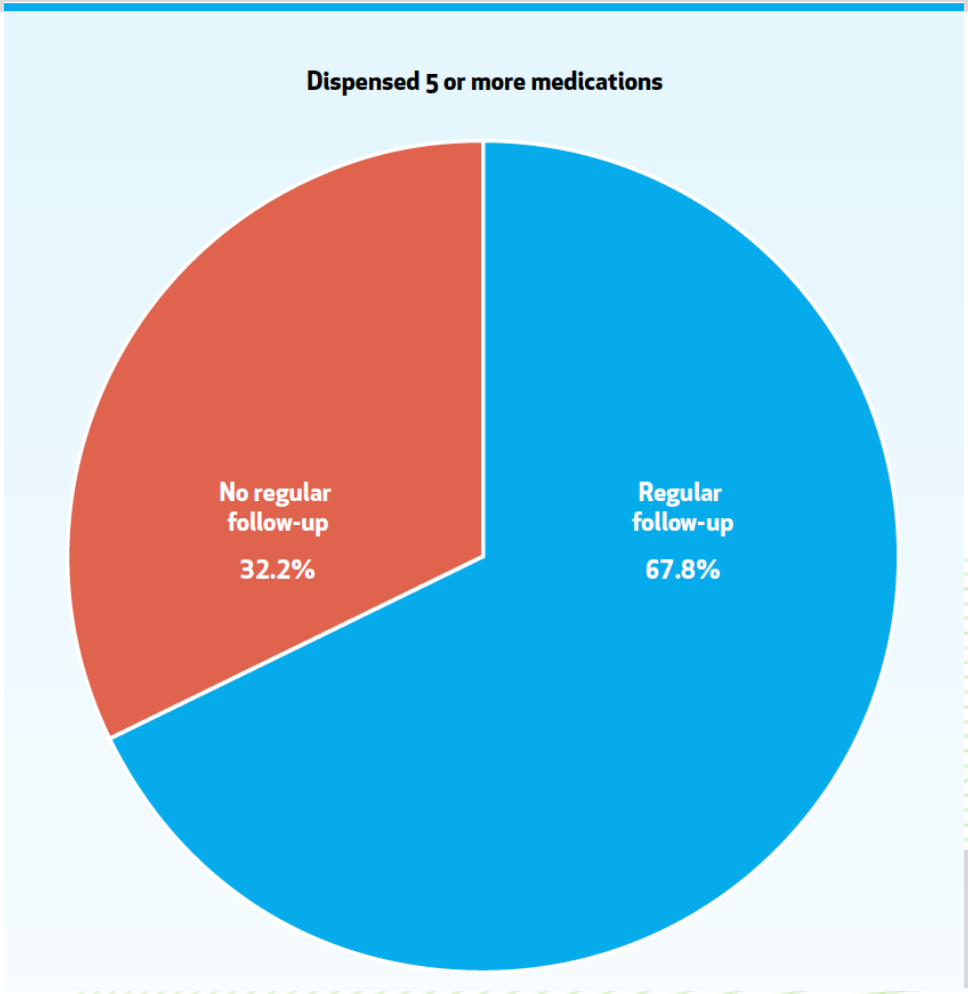
CONSIDERATIONS	RECOMMENDATIONS	LEVEL OF EVIDENCE
26. Interventions other than medication are usually effective for preventing or alleviating problem behaviours.[133,144,155]	a. To reduce stress and anxiety that can underlie some problem behaviours, emotional disturbances, and psychiatric disorders, consider such interventions as addressing sensory issues (eg, underarousal, overarousal, hypersensitivity), environmental modification, education and skill development, communication aids, psychological and behaviour therapies, and caregiver support.[144]	III
	b. Cognitive behavioural therapy can be effective in decreasing anger and treating anxiety and depression in adults with DD.[156,157]	III
	c. There is increasing evidence of the efficacy of psychotherapy for emotional problems (eg, related to grief, abuse, trauma) that might underlie aggression, anxiety, and other such states.[158-162]	III
27. Psychotropic medications (eg, antidepressants) are effective for robust diagnoses of psychiatric disorders in adults with DD[163] as in the general population.[164]	a. When psychiatric diagnosis is confirmed after comprehensive assessment, consider psychotropic medication along with other appropriate interventions as outlined in guideline 26.[165]	III
Psychotropic medications, however, can be problematic for adults with DD and should therefore be used judiciously. Patients might be taking multiple medications and can thus be at increased risk of adverse medication interactions. Some adults with DD might have atypical responses or side effects at low doses. Some cannot describe harmful or distressing effects of the medications that they are taking.[34,166]	b. "Start low, go slow" in initiating, increasing, or decreasing doses of medications.[167]	III
	c. Arrange to receive regular reports from patients and their caregivers during medication trials in order to monitor safety, side effects, and effectiveness.[133]	III
	d. In addition to reviews every 3 mo (see guideline 5), also review the psychiatric diagnosis and the appropriateness of prescribed medications for this diagnosis whenever there is a behavioural change.[34,133]	III
When unable to pinpoint a specific psychiatric diagnosis, behaviours of concern might serve as index behaviours against which to conduct a trial of medications.[133,167]	e. Having excluded physical, emotional, and environmental contributors to the behaviours of concern, a trial of medication appropriate to the patient's symptoms might be considered.	III
28. Antipsychotic medications are often inappropriately prescribed for adults with behaviour problems and DD.[168] In the absence of a robust diagnosis of psychotic illness, antipsychotic medications should not be regarded as routine treatments of problem behaviours in adults with DD.[131]	a. Do not use antipsychotic medication as a first-line treatment of problem behaviours without a confirmed robust diagnosis of schizophrenia or other psychotic disorder.[131]	III
Antipsychotic medications increase risk of metabolic syndrome and can have other serious side effects (eg, akathisia, cardiac conduction problems, swallowing difficulties, bowel dysfunction).[34,166]	b. Carefully monitor for side effects of antipsychotic medication, including metabolic syndrome. Educate patients and caregivers to incorporate a healthy diet and regular exercise into their lifestyle.[34]	III
	c. Reassess the need for ongoing antipsychotic medications at regular intervals and consider dose reduction or discontinuation when appropriate (also see guidelines 5 and 27).[34]	III
29. Behavioural crises can occasionally arise that might need management in an emergency department.[169-173]	a. When psychotropic medications are used to ensure safety during a behavioural crisis, ideally such use should be temporary	III

Medication Use

Proportion of Adults aged 18 to 64 years with Developmental Disabilities (ODB Program Eligible) by number of medications dispensed concurrently on Census Date (Oct 1, 2009)



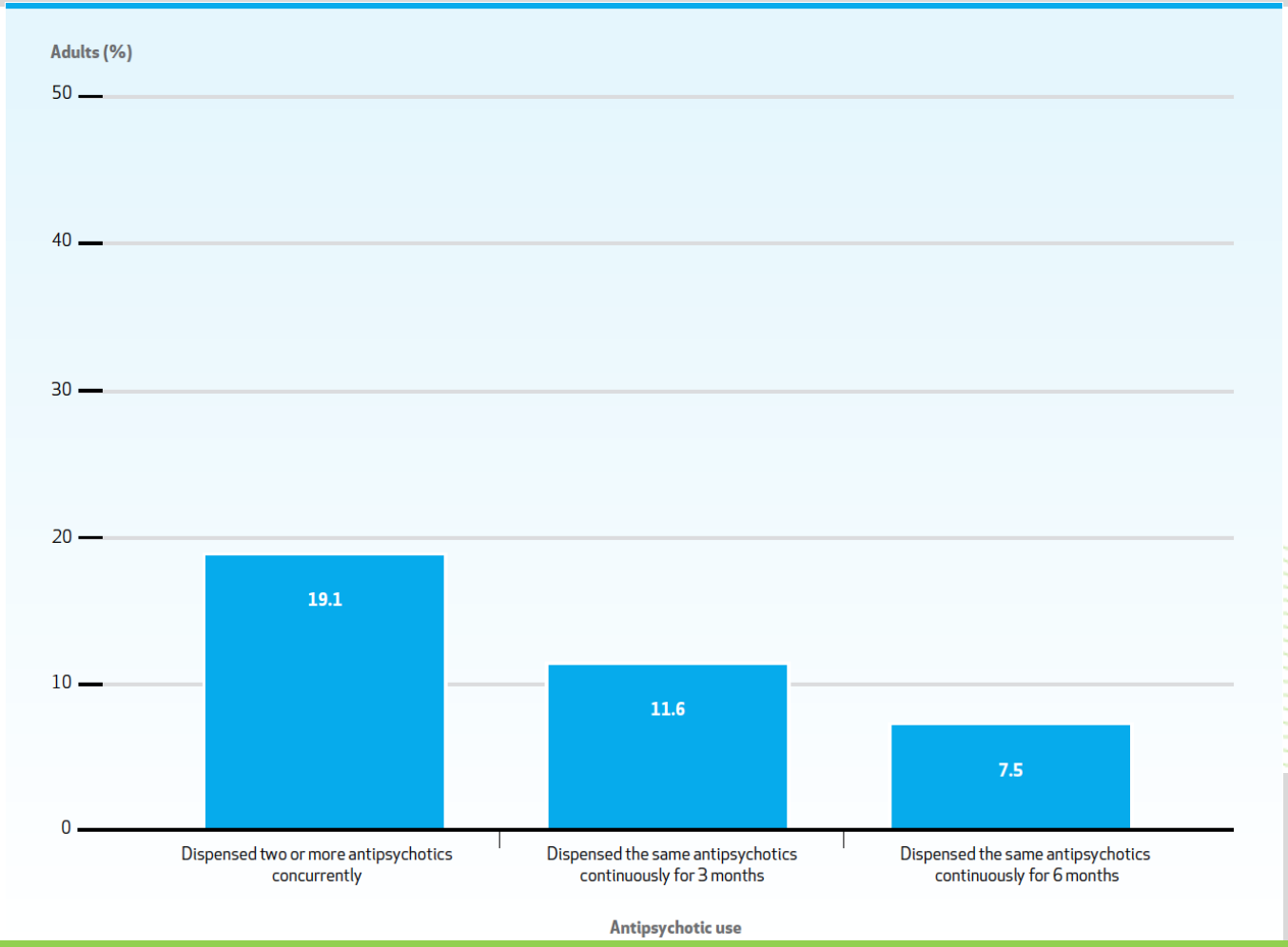
Proportion of Adults aged 18 to 64 with Developmental Disabilities who were eligible for the Ontario Drug Benefit Program AND were dispensed five or more medications*, by regular follow-up (3 or more visits in the year following October 1, 2009) with the same family physician, in Ontario, October 1, 2009



*22%

Medication Use

Proportion of Adults aged 18 to 64 years with Developmental Disabilities (ODB Program Eligible) Dispensed Antipsychotics who are Dispensed 2 or more Antipsychotics concurrently on Census Date* (Oct 1, 2009) and Continuously for 3 or 6 months



***1 in 5 of those prescribed antipsychotics**

“When the doctor writes a prescription, it would be better to have it in terms that people with disabilities can understand, because we can’t always expect our parents to be there to help.”- Andrew

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

Summary

November 2013

camh

ICES

Conclusions

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

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

Next Steps

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

How can we use research to change practice?


Thunder Bay
Fort Albany
ONTARIO
Toronto
Kingston

Guidelines/Lignes directrices

Primary Care of Adults with Developmental Disabilities: Canadian Consensus Guidelines

Soins primaires aux adultes ayant une déficience développemental: Lignes directrices consensuelles canadiennes

Tools/Outils

Tools for caregivers

General Issues in Care of Adults with DD

- it – Main Reason for Today's Visit
- Resources in Ontario

Mental Health Toolbox

- Understanding Behavioural Problems and Emotional
- dults with Developmental Disabilities (DD)
- ent-Behaviour-Consequence) Chart
- ut Emergencies for Caregivers
- th Assessment
- Information
- d Guide
- lan
- es
- s for Caregiver
- g Chart
- nt Monthly Monitoring Chart
- Woman's Menses Yearly Monitoring Chart
- Monthly Sleep Chart
- Seizure Baseline Chart
- Daily Seizure Monitoring Chart
- Seizure Frequency Yearly Summary Sheet

Surrey Place Centre
Centre Surrey Place

http://www.surreyplace.on.ca/Primary-Care/Pages/Tools-for-care-givers.aspx

Core team
Investigative team
Research
Applied Health Research Questions
Communications
Resources and tools
- Tools for people with disabilities
- Tools for caregivers
- Tools for healthcare providers

News
Links
Contact us

Tools for people with disabilities

DD CARES cares about your health!

We are trying to find ways to make it easier for individuals with developmental disabilities to communicate with family doctors and with health care providers (like doctors, nurses and social workers). We have a few ideas that we think will help.

Some things that we have are:

An ***AboutMe*** healthcare passport! This helps you tell healthcare providers how they can best help you.

It includes things like:

- What are things you like?
- What are things you don't like?
- Are you scared of the hospital?
- Do you have any special health information?

Please click **here** if you would like to hear all about the AboutMe passport!

A ***Crisis Plan!*** This is something you can fill out with people in your life who help you. It might help you to prevent a crisis from happening. Or, if a crisis does happen, it can help everyone who supports you to know what to do.

An ***Exit Interview!*** This is something that you can ask the doctor or nurse to fill out after you see them. It can you to better understand what happened during your appointment or hospital visit, and know what you should do afterwards.

If you would like to talk with us, or help us work on the tools, please contact us!

You can call us at (416) 535-8501, extension 77832 (ask for Andrea);
You can email us at ddcares@camh.ca
You can send a letter to DD CARES (Andrea Perry), 501 Queen St. West, Toronto ON, M5V 2B4

www.hcardd.ca

What don't we know?


love
happy
LOVE
happy

We don't know ~~what~~ who we don't know.

Ingredients for Change

Questions?

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Clinician Scientist, Underserved Populations Program
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