

How Can Family Health Teams Promote the Health of People with Developmental Disabilities?

Practical Steps that Teams Can Implement and Extend to Other Special Populations

AFHTO Conference – October 16, 2012

Bill Sullivan, Ian Casson, Angela Gonzales, Rob Balogh
Developmental Disabilities Primary Care Initiative of Ontario



Presenters

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St. Michael's
Inspired Care. Inspiring Science.

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Angela Gonzales, RN MN



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Living Your Potential - All Your Life!
Enabling Full Participation For People With Developmental Disabilities

Agenda

Background

- Research evaluating health of people with developmental disabilities (DD) in Ontario and access to health services
- Primary Care of Adults with DD: Canadian Consensus Guidelines and Tools

Discussion

Implementation

- Caregiver Health Assessment, Cumulative Patient Profile and Preventive Care Checklist for adults with DD
- Use of Consensus Guidelines and Tools in the context of a Family Health Team

Discussion and Conclusion



Background RESEARCH



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Health Care Access Research and Developmental Disabilities: Using the guidelines in Ontario to evaluate health and health services at population level



Project Team



- **Project Lead**
 - Yona Lunsky, CAMH, U of T
- **Core Working Group and Investigative Team**



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Rationale



- Adults with IDD are at increased risk for experiencing health problems compared to the general population
- Healthcare system fragmentation, lack of resources, lack of access to information and inadequate training have all been cited as contributing factors



- Not much Canadian research
- Need for more comprehensive data on individuals with IDD
- In Canada there is evidence that individuals with IDD are more likely to be admitted for preventable hospitalizations than others without IDD (Balogh, 2010)

Indicator of poor primary care

Healthcare Access Research and Developmental Disabilities

Objectives

1. Create and evaluate datasets including anonymized information on large numbers of individuals with IDD in Ontario
2. Describe primary care use of adults with IDD
3. Evaluate how good primary care provided to adults with IDD is using a set of indicators

Example of Guideline recommendations

- Perform an annual comprehensive preventive care assessment including physical examination
 - and use guidelines and tools adapted for adults with DD

Data Linkage

MERGED cohort

n=65,000

**Health
Admin
Data**

Data taken from:
Hospital stays
Visits to Doctors'
offices
Emergency
department visits

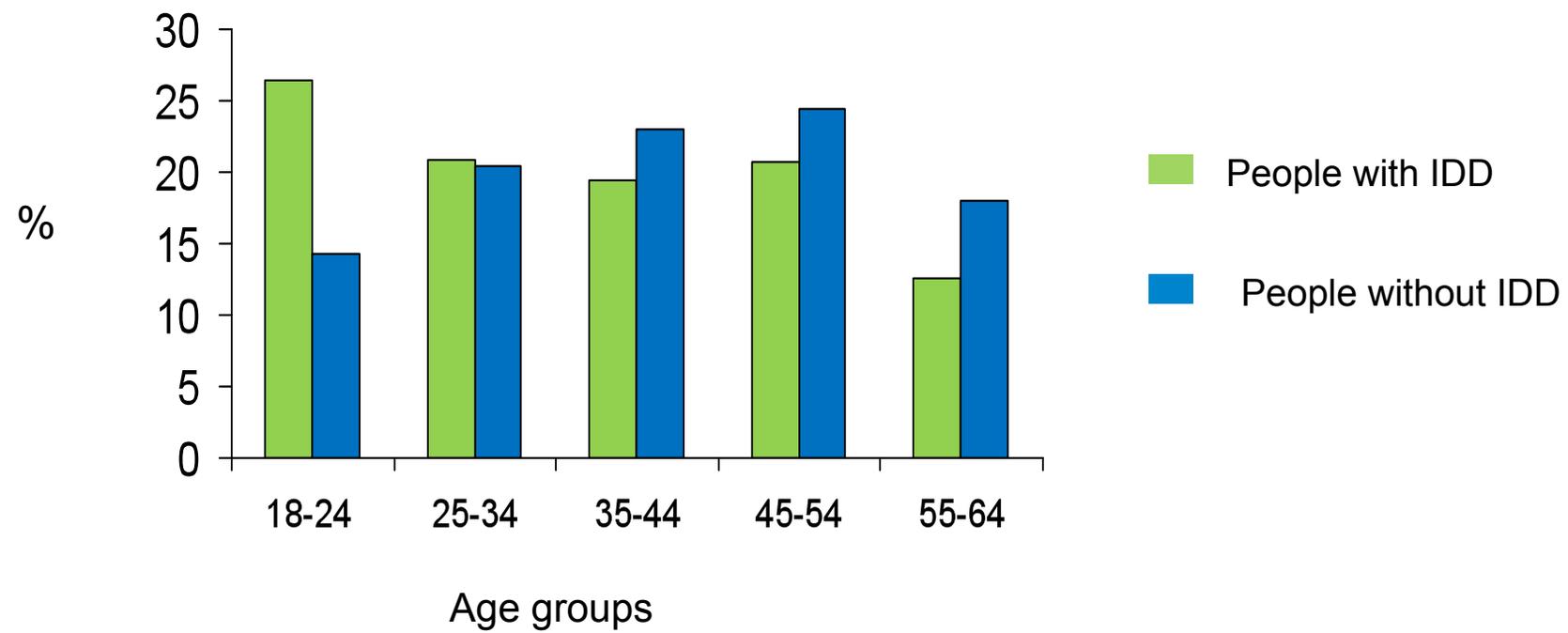
n=44,000

Data taken from:
MCSS Ontario
Disability Support
Program

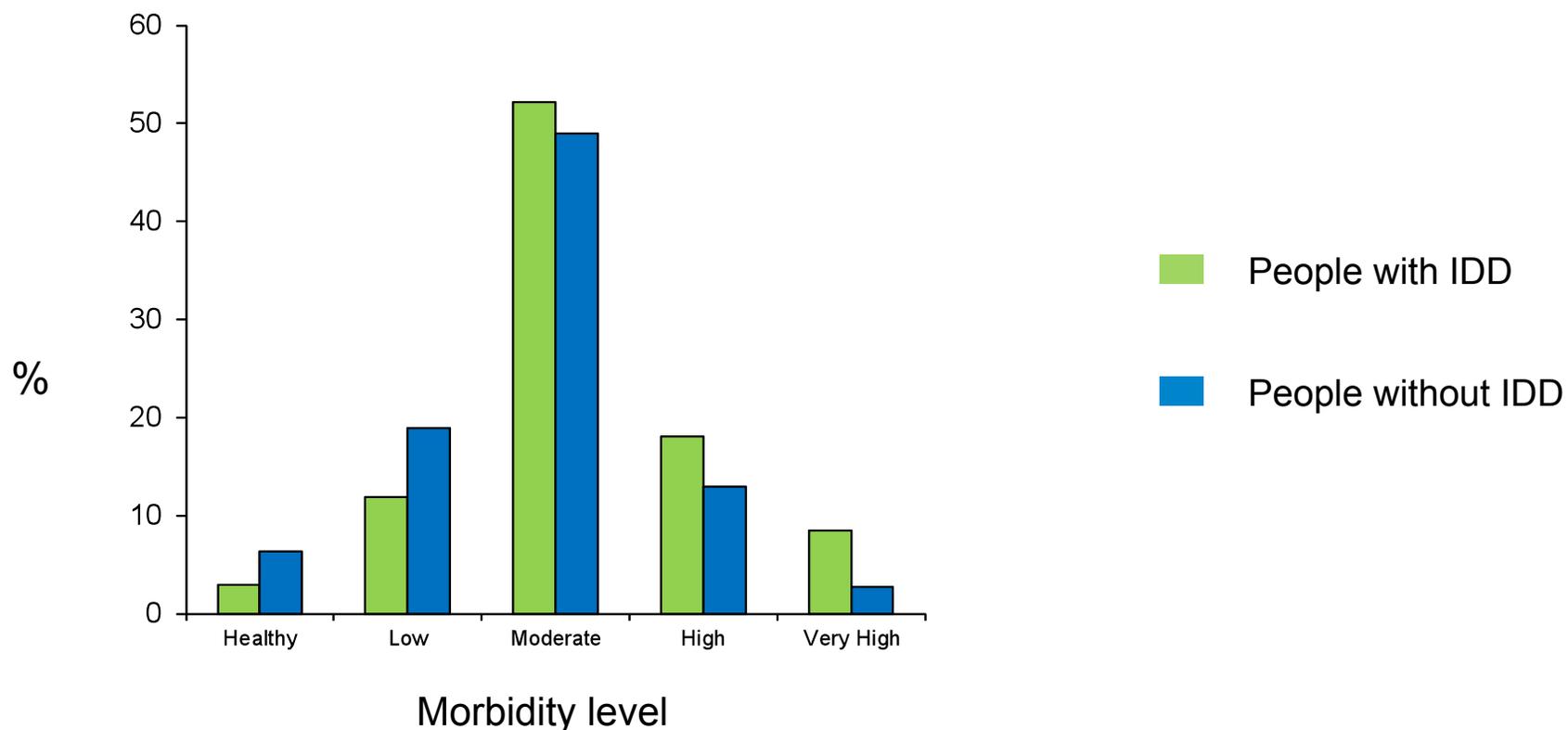
**Community
and Social
Services
Data**

N=39,000

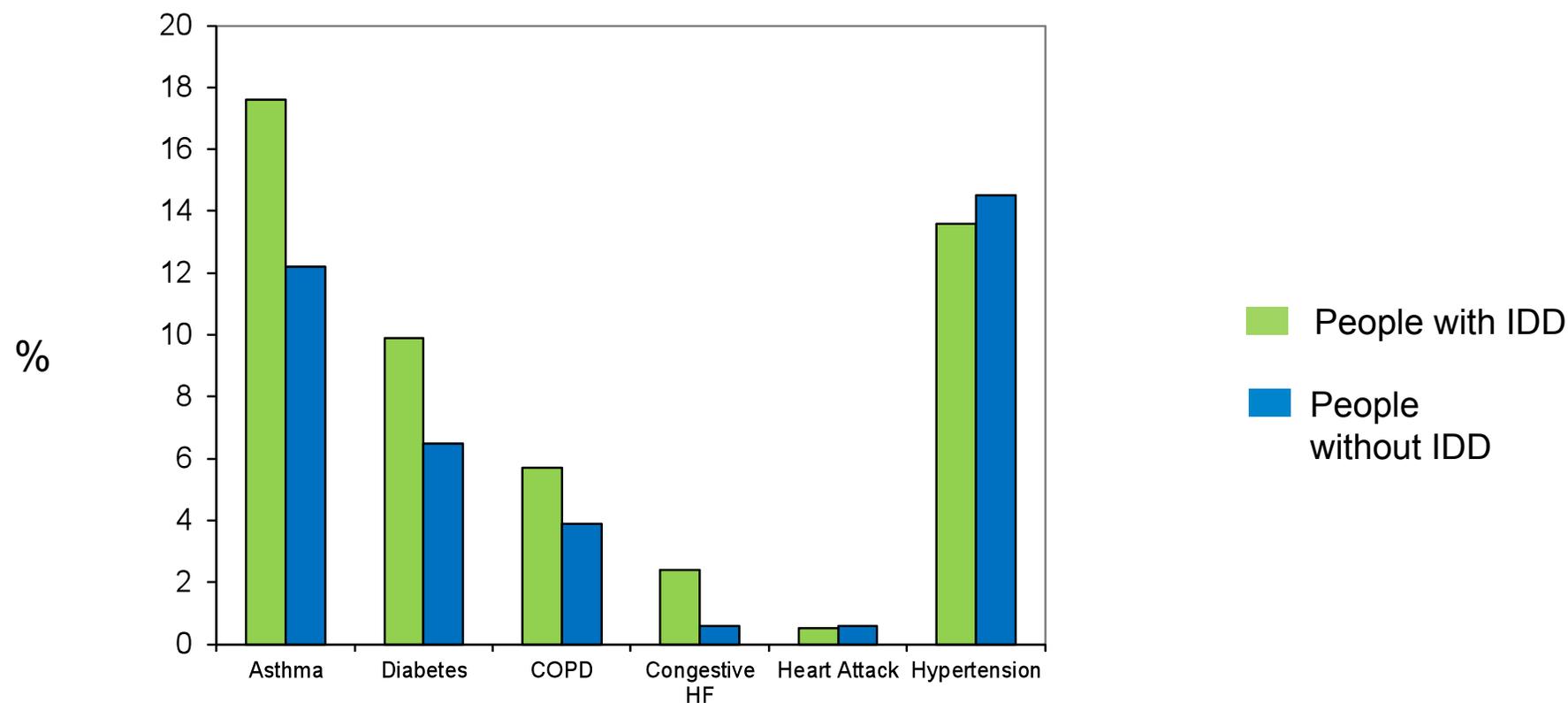
Comparison of Healthcare Users in Ontario with and without IDD: Age Distribution



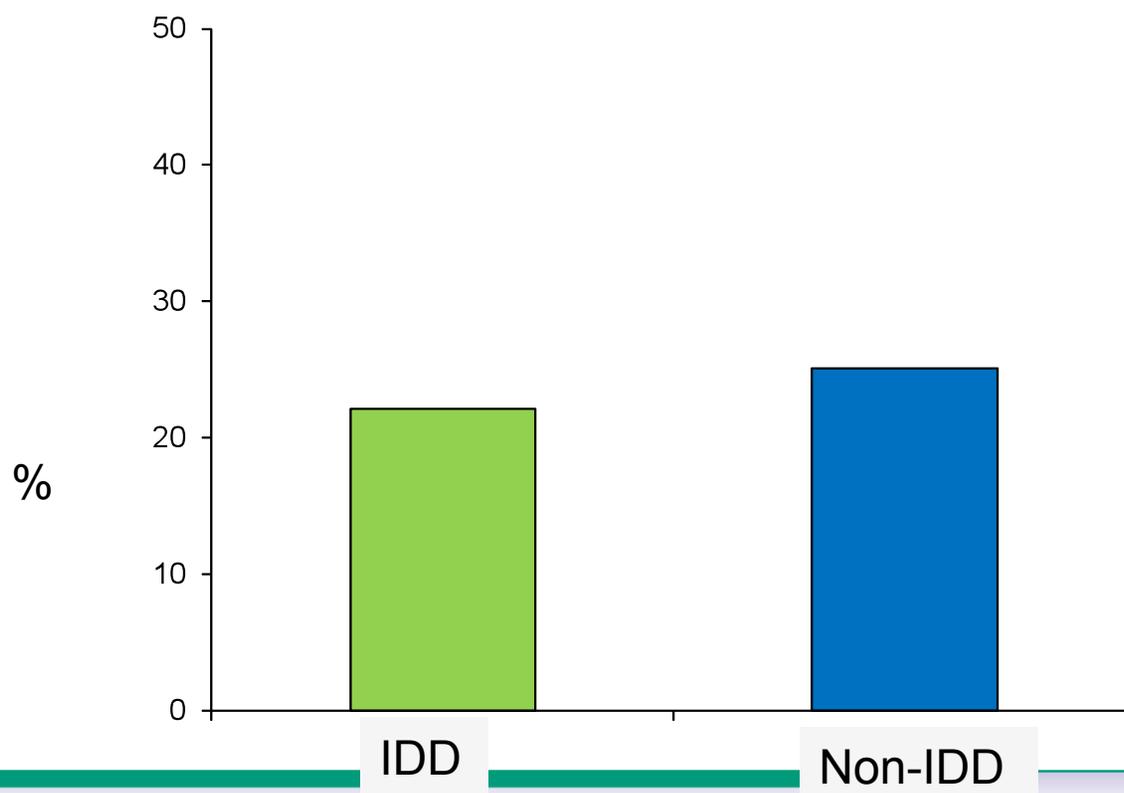
Comparison of Healthcare Users in Ontario with and without IDD: Morbidity



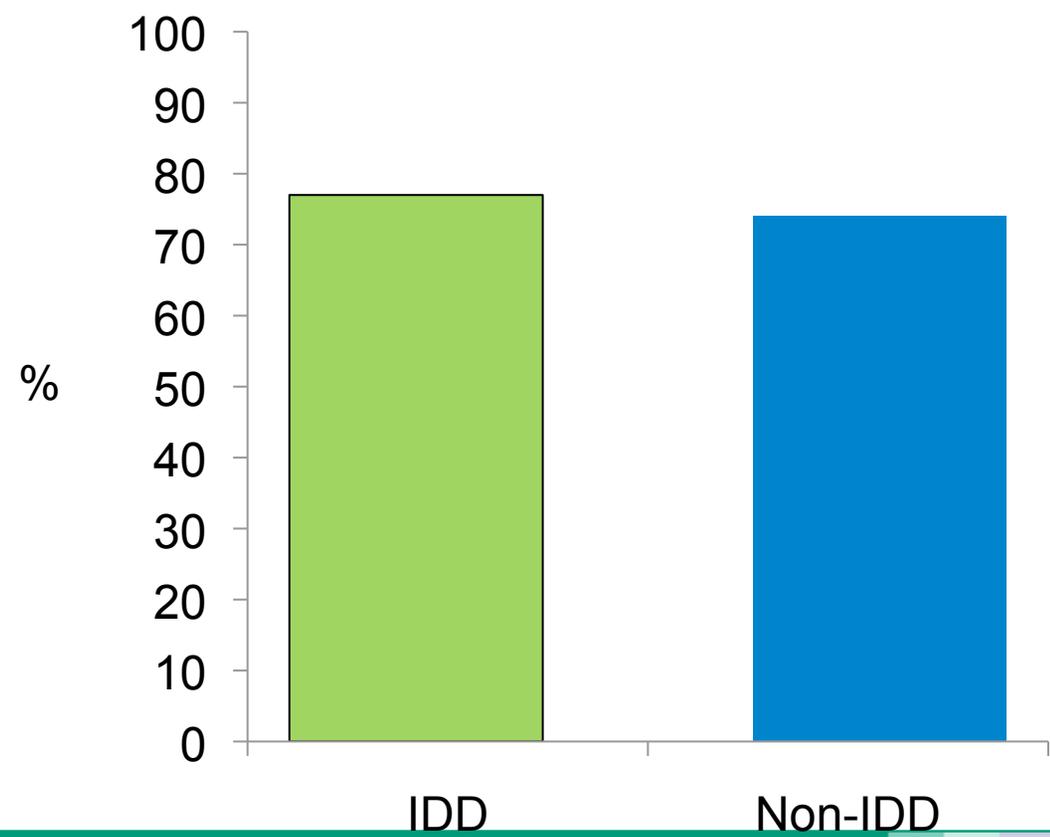
Comparison of Healthcare Users in Ontario with and without IDD: Rates of Chronic Conditions



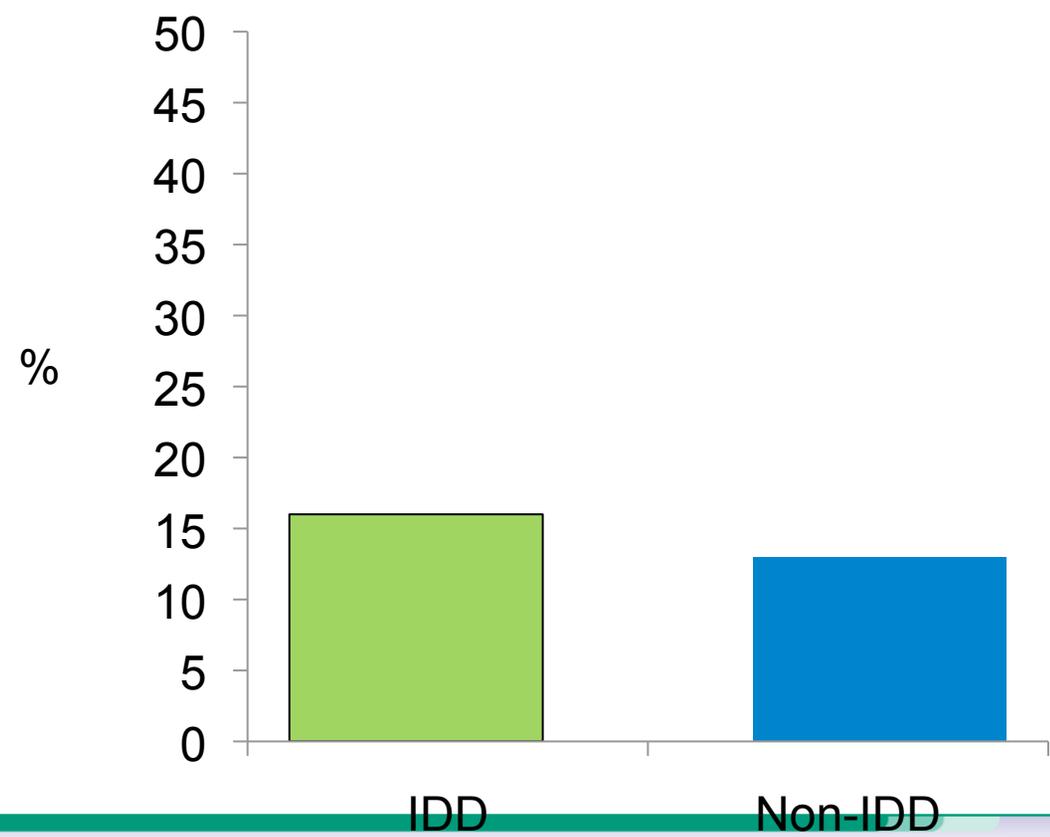
Proportion of Healthcare Users in Ontario with and without IDD: Rates of Comprehensive Health Check



Proportion of Healthcare Users in Ontario with and without IDD: Visit to primary care physician



Proportion of Healthcare Users in Ontario with and without IDD: Receiving care from FP in FHT



Implications for Policy and Practice



- HCARDD provides vital information for planning and evaluation of health and social services for adults with IDD
- Has developed a methodology for evaluating the guidelines
- Providing baseline information to assess impact
- Future research can look at population level results for all persons receiving services from Family Health Teams



Background

CANADIAN CONSENSUS GUIDELINES AND TOOLS



Primary care of adults with developmental disabilities

Canadian consensus guidelines

William F. Sullivan MD CCFP PhD **Joseph M. Berg** MB BCh MSc FRCPSych FCCMG **Elsbeth Bradley** PhD MB BS FRCPC FRCPSych
Tom Cheetham MD CCFP **Richard Denton** MD CCFP FCFP FRRMS **John Heng** MA **Brian Hennen** MA MD CCFP
David Joyce MD CCFP **Maureen Kelly** RN MPA **Marika Korossy** **Yona Lunsky** PhD CPsych **Shirley McMillan** RN MN CDDN



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Consensus Guidelines (2006, 2011)

- 4-day **colloquium** involving 50 primary care providers and consultants with expertise and experience in IDD
- Comprehensive **bibliography** on IDD and health care issues
- 6 commissioned **synthesis papers** reviewing bibliography and proposing specific guidelines
- **Group discussions**



Consensus Guidelines (2006, 2011)

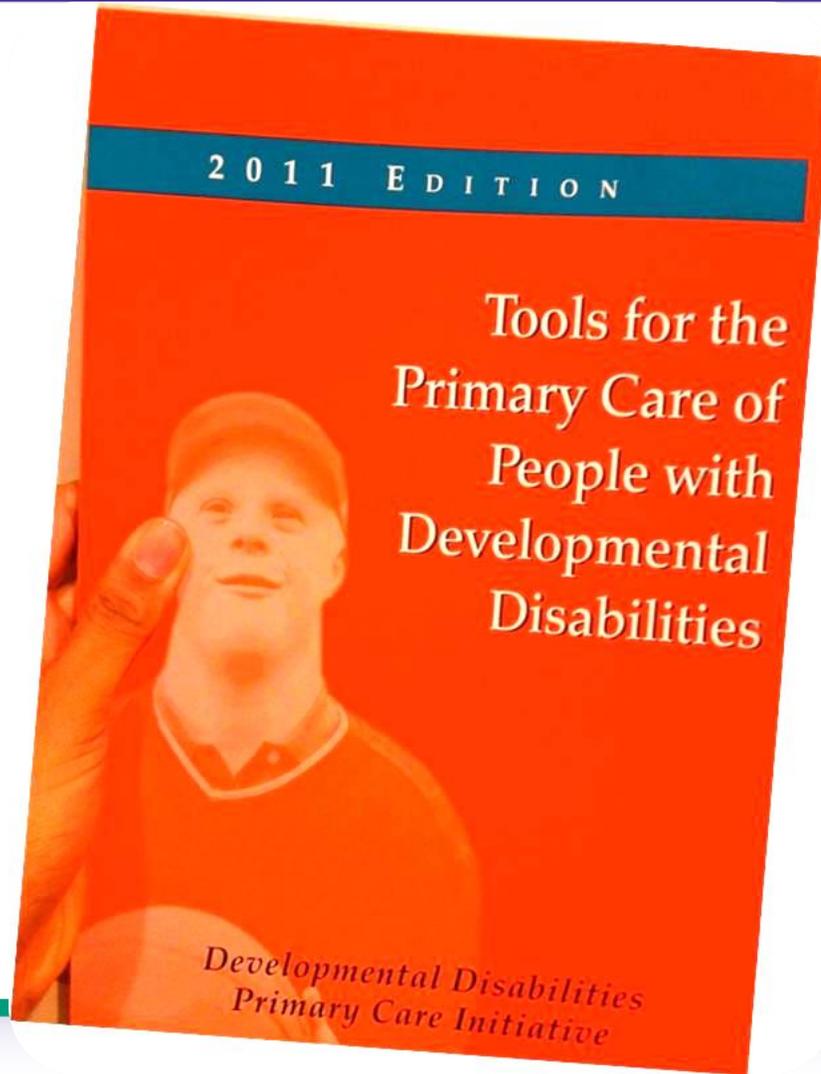
- **Criteria for selecting and prioritizing guidelines** from the POMONA project (2004)
- **Criteria for assigning strength of supporting evidence**
 - **Level I** = at least one properly conducted RCT, systematic review, or meta-analysis;
 - **Level II** = other comparison trials, non-randomized, cohort, case-control;
 - **Level III** = expert opinion
- **Ethical principles**
- **Feasibility** of implementing the guidelines

Consensus Guidelines (2006, 2011)

- Publication and distribution (40,000 paper copies of guidelines & tools to primary care providers, nurses, and family medicine training programs in Canada)
- Translation into French
- Website



Tools (2011) to implement Guidelines



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Tools

- Electronic versions available on the web:

www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx

- Paper copies available from MUMS Guidelines:

www.mumshealth.com



Tools

- **General Issues**, e.g.,
 - Genetic Assessment
 - Adaptive Functioning
 - Psychological Assessment
 - Informed Consent
- **Physical Health Issues**, e.g.,
 1. **Cumulative Patient Profile**
 2. **Preventive Care Checklists**
 3. **Health Watch Tables**
- **Behavioral and Mental Health Issues**, e.g.,
 - Understanding Behavioral Problems and Emotional Concerns
 - Auditing Psychotropic Medications
 - Essential Information for the Emergency Department
 - Guidance about Emergencies for Caregivers
 - Crisis Prevention and Management Plan

DISCUSSION



BREAK

Start at 2:50 pm – Thank you



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Implementation

CAREGIVER HEALTH ASSESSMENT, CPP, AND PCC



Overview

- Caregiver Health Assessment
- Cumulative Patient Profile (CPP) for adults with developmental disabilities (DD)
- Preventative Care Checklist (PCC)
 - For adult females with DD
 - For adult males with DD



Caregiver Health Assessment Tool *DRAFT*

- To collect a comprehensive history (over time)
- Identifies communication & health needs
- Facilitates collaboration
- References:
 - CHAP (Lennox 2005) & Health Assessment Program (Massachusetts dept. of Mental Retardation 2007)
 - Tools for Primary Care of People with DD (2011)



Caregiver Health Assessment Tool

- Contact Info - SDM
- **Part 1:** Background Info
 - Family History
 - Health Indicators
- **Part 2:** Head to Toe
- **Part 3:** Other Info
- Health Care Providers & Specialists
- **Appendix:** Annual Health Review Summary
- **Appendix:** Doctor's Appointment

CAREGIVER HEALTH ASSESSMENT FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Person's Name: _____		Address: _____	
Likes to be called: _____		City: _____ Postal Code: _____	
Date of Birth: ___/___/___		Telephone Number: _____	
How to Fill Out and Use This Form			
This health information helps the caregiver to know more about the person with a developmental disability and their health problems. This information can also be helpful to the family physician or primary care provider.			
This health information is strictly confidential to this person and their care providers. PLEASE – KEEP IT CONFIDENTIAL!!!			
<ul style="list-style-type: none"> • The person with the developmental disability should complete this form with the help of family members, caregivers, and medical records. Get as much information as possible. • Fill it out as well as you can – OK to check "Don't Know" • The form can be used at Intake, and at Team Meetings. It can be revised as needed when changes occur. 			
CONTACT INFORMATION			
CONTACT	NAME and ADDRESS	CONTACT INFORMATION (Telephone #'s: Home, Work, Cell, Email)	
Current Living Arrangement <input type="checkbox"/> Family <input type="checkbox"/> Group home <input type="checkbox"/> Foster home <input type="checkbox"/> Independent <input type="checkbox"/> Other			
<input type="checkbox"/> Substitute Decision Maker or <input type="checkbox"/> Power of Attorney for Personal Care			
Next of Kin Relationship: _____			
Family/ Significant Others/ Children			
Lead Agency			
PART I. BACKGROUND INFORMATION			
Person's Developmental Disability – (If Autism Spectrum Disorder - ASD diagnosed, please include) Known cause or syndrome? _____ Unknown			
Ever had a Genetic assessment? <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Yes Date: ___/___/___ Copy on file? <input type="checkbox"/> No <input type="checkbox"/> Yes Comments: _____			
Ever had a Psychological assessment: <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Yes → Date: ___/___/___ Copy on file? <input type="checkbox"/> No <input type="checkbox"/> Yes Comments: _____			



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Caregiver Health Assessment Tool

- **Part 1:** Family Medical History to highlight possible risk factors
- Health Indicators
 - Social History
 - Sleep
 - Pain
 - MedicAlert
- **Part 2:** Physical Health (Head to Toe Review), Behaviour & Mental Health

PART II: HEAD TO TOE REVIEW	YES	NO	DON'T KNOW	CHANGE – past yr.
<i>If you are unsure of the answer please check "Don't Know" rather than guessing.</i>				
1. EYES, EARS, & TEETH / MOUTH / THROAT Does this person				
EYES: LAST EYE DOCTOR APPOINTMENT: ___/___/___ RESULT: _____ <ul style="list-style-type: none"> • Wear glasses? • Have any signs of vision problems? <ul style="list-style-type: none"> • Ever have redness or drainage from their eyes? • Squint or rub their eyes? • Other: _____ 	ⓐ	ⓐ	ⓐ	ⓐ
EARS: LAST HEARING TEST APPOINTMENT: ___/___/___ RESULT: _____ <ul style="list-style-type: none"> • Wear a hearing aid? • Have any signs of hearing problems? • Ever have earwax problems? • Other ear problems (e.g., ear infections, drainage from ears) If yes, how often? _____ 	ⓐ	ⓐ	ⓐ	ⓐ
DENTAL: LAST DENTIST APPOINTMENT (dd/mm/yyyy): ___/___/___ RESULT: _____ <ul style="list-style-type: none"> • Have own teeth? • Have false teeth or partial dentures? • Have no teeth and no dentures? • Have problems with teeth? <ul style="list-style-type: none"> • Have toothaches? • Have gum problems? (e.g., swollen gums, or bleeding when brushing?) • Have poor oral hygiene? (brushing <2x/day, not flossing) • Have poor denture hygiene? • Refuse to go or hasn't been to the dentist regularly? • Need sedation for dental procedures? Last appointment: _____ 	ⓐ	ⓐ	ⓐ	ⓐ

Caregiver Health Assessment Tool

- Part 3: Other Important Health Info
- Appendices:
 - Annual Health Review Summary
 - Doctor's Appointment

14. MENTAL HEALTH: Does this person	YES	NO	Don't Know
<ul style="list-style-type: none"> • Have a diagnosed psychiatric disorder? <i>If yes, what kind?</i> <ul style="list-style-type: none"> <input type="checkbox"/> Mood (e.g., depression, bipolar) <input type="checkbox"/> Anxiety <input type="checkbox"/> Psychotic illness Comments: _____	🍏	🍏	🍏
<ul style="list-style-type: none"> • Has the person ever had a hospital admission for psychiatric reasons? <ul style="list-style-type: none"> • <i>If yes, when?</i> _____ • <i>For how long?</i> _____ • <i>How many times?</i> _____ Comments: _____	🍏	🍏	🍏

15. INFECTIOUS DISEASES		Universal Body Substance Precautions are essential for infection prevention	
<i>if known:</i>	MRSA: <input type="checkbox"/> +ve <input type="checkbox"/> -ve	Date of Diagnosis:	<input type="checkbox"/> Don't know
<i>if known:</i>	Hep B <input type="checkbox"/> +ve <input type="checkbox"/> -ve	Date of Diagnosis:	<input type="checkbox"/> Don't know
<i>if known:</i>	Hep C <input type="checkbox"/> +ve <input type="checkbox"/> -ve	Date of Diagnosis:	<input type="checkbox"/> Don't know
<i>if known:</i>	VRE <input type="checkbox"/> +ve <input type="checkbox"/> -ve	Date of Diagnosis:	<input type="checkbox"/> Don't know
<i>if known:</i>	HIV <input type="checkbox"/> +ve <input type="checkbox"/> -ve	Date of Diagnosis:	<input type="checkbox"/> Don't know
<i>if known:</i>	C. Difficile <input type="checkbox"/> +ve <input type="checkbox"/> -ve	Date of Diagnosis:	<input type="checkbox"/> Don't know
Other:		Date of Diagnosis:	

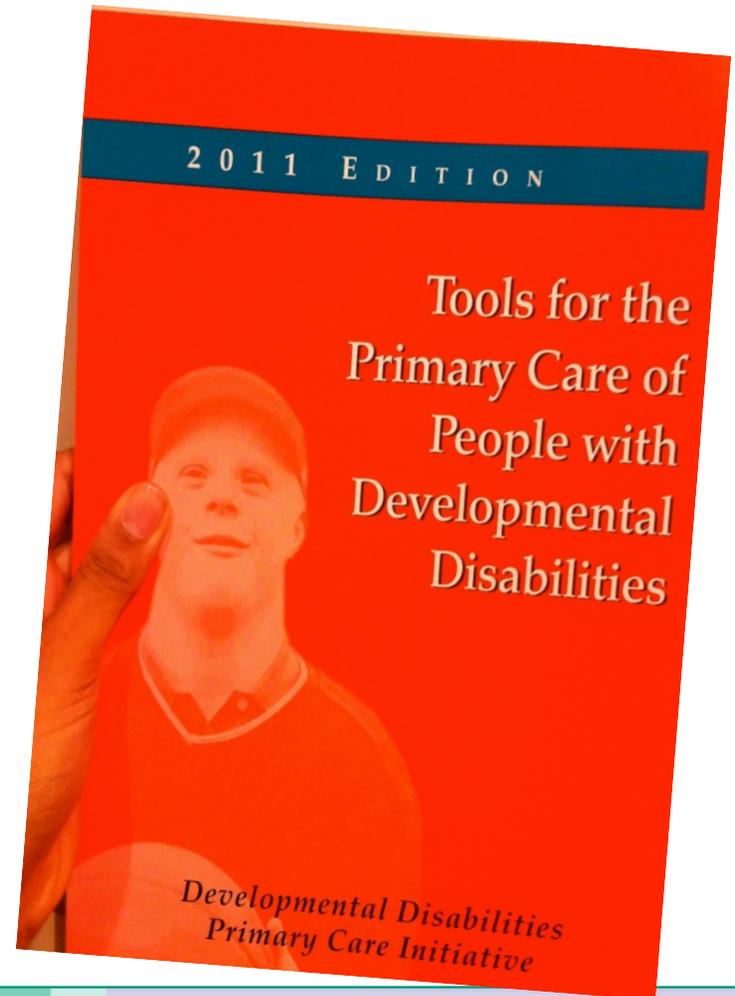
PART III: OTHER IMPORTANT HEALTH INFORMATION	YES	NO	Don't Know
<ul style="list-style-type: none"> • Has this person ever been <input type="checkbox"/> abused or <input type="checkbox"/> neglected? <ul style="list-style-type: none"> <input type="checkbox"/> sexual <input type="checkbox"/> physical <input type="checkbox"/> psychological Comments: _____	🍏	🍏	🍏
<ul style="list-style-type: none"> • Has this person ever had any operations (surgeries)? <ul style="list-style-type: none"> <i>If yes, please list type of surgery and year it happened, or patient's age when it happened.</i> Type of Surgery Year it was done <u>OR</u> Patient's Age when done	🍏	🍏	🍏
<ul style="list-style-type: none"> • Has this person ever been hospitalized, or seriously ill? <ul style="list-style-type: none"> <i>If yes, please list:</i> Hospitalization (and why) or serious illness When did this happen?	🍏	🍏	🍏



Primary Care Tools: CPP & PCC

Primary Care Tools available on Surrey Place Centre's website (enter "Primary Care" in Search box)

<http://www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx>



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Primary Care Initiative
Developmental Disabilities

CPP

CUMULATIVE PATIENT PROFILE

For adults with developmental disabilities (DD)

Adapted from template originally developed by the Department of Family and Community Medicine, Faculty of Medicine, University of Toronto, and Electronic Medical Record, DFCM, St. Michael's Hospital, Toronto

Name: _____ Gender: _____
(last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Prefers to be called: _____

Initial Assessment Completed:

____/____/____
dd mm yyyy

Consider annual review, and update sooner when changes occur, e.g., decision-making capacity

Etiology of DD: _____ Definite Probable Possible Unknown

Genetic assessment: No Yes Date: ____/____/____
dd mm yyyy

Report on file? No Yes: _____

Psychological assessment: No Yes Date: ____/____/____ Report on file? No Yes
dd mm yyyy

Level of adaptive functioning: Mild Moderate Severe Profound Unknown

Decision-Making Capacity: Capacity to consent may vary over time and with the type of decision. Assess when proposing interventions for which consent is required. [Guideline 7] See Informed Consent Tool

Capable Not capable Unsure

Substitute Decision Maker (SDM):

Name: _____ Contact Information: _____

Next of Kin (if not SDM):

Name: _____ Contact Information: _____

Others who may be helpful in decision making (e.g., Guardian, Power of Attorney for Personal Care, Office of the Public Guardian and Trustee, helpful agencies/support persons):

SPECIAL NEEDS AND COMMUNICATION

Usual Clinic Visit Routines: Prefers early day Prefers end of day Limit time in waiting room

Special positioning for exam Extra staffing needed May require sedation

Tolerates venipuncture? Yes No

Other: _____

Expressive Communication (method, devices):

Receptive Communication – prefers:

Pictures Simple explanations Written Sign language Other: _____

Triggers (e.g., trauma, noise, lighting, smells, colour, textures): _____

Response Behaviours:

How to help:

Usual Response to Medical Exam: Fully/partially cooperates Fearful Resistant Aggressive

Usual Response to Pain or Distress: Normal Unique (describe): _____

Cautions (e.g., aggression, pica, aspiration risk): – specify modifications, precautions

*Tools for the Primary Care of
People with DD, pages 30 - 33*

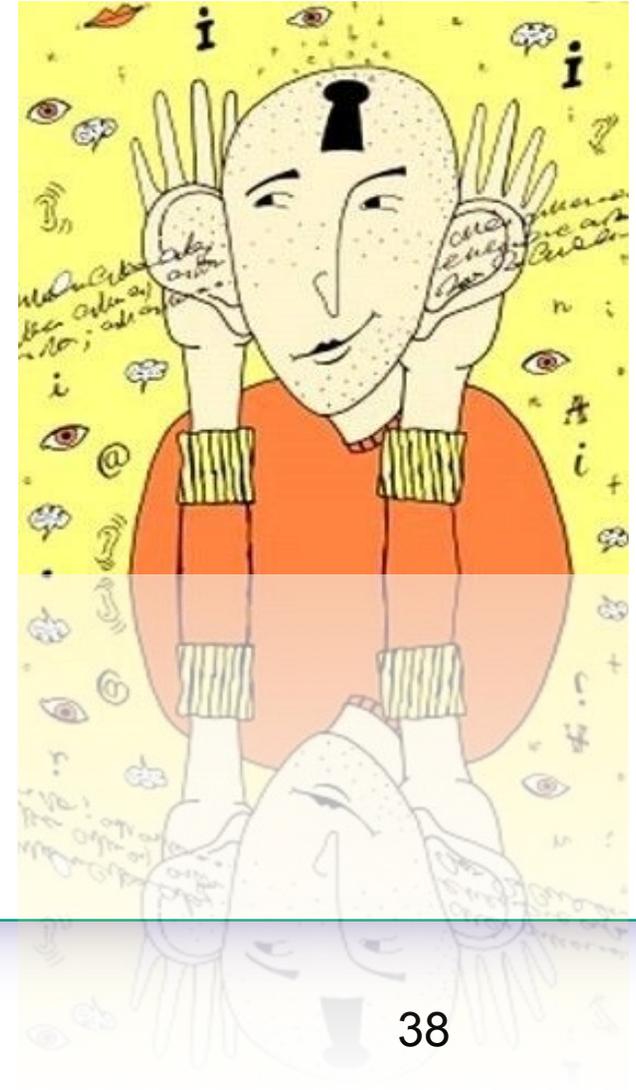


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Enabling Full Participation For People With*

CPP

Highlights

- Decision-Making Capacity
- Special Needs and Communication
- Problem List
- Current Medications & Record of Past Meds
- Allergies
- Immunizations
- Family & Past Health History
- Personal History
- Risks
- Reminders



PCC adult females



Tools for the Primary Care of People with DD, pages 35 - 36



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Preventive Care Checklist Form for adult females with a developmental disability (DD)



Original developed by: Dr. V. Dubey, Dr. R. Mathew, Dr. K. Iglar.
Adapted with permission by the DD Primary Care Initiative 2011

Please note:

- Bold** = Good evidence (Canadian Task Force on Preventive Health Care)
- Italics** = Fair evidence (Canadian Task Force on Preventive Health Care)
- Plain text** = Guidelines (other Canadian sources)
- Highlighted** = Differences with respect to DD – refer to Explanations sheet.

Name: _____ (last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Date of Visit: _____

Etiology of DD, if known:

Capacity to consent:

- Capable Guardian Substitute Decision Maker
- Power of Attorney Public Guardian & Trustee

Advance Care Planning Needs:

Living Situation:

- Family Group home Foster home Independent
- Other: _____

Update Cumulative Patient Profile Medications

- Family History Communication
- Hospitalizations/Procedures Allergies

Current Concerns

Lifestyle/Habits

- Diet: Fat/Cholesterol Smoking: _____
- Fibre Alcohol: _____
- Calcium Illicit Drugs: _____
- Sodium Sexual History: _____
- Exercise/Obesity: _____ Family Planning/ Contraception: _____
- Day Program/Work: _____
- Family: _____ Sleep: _____
- Relationships (recent changes?): _____

Functional Inquiry

	Normal	Remarks
HEENT:	<input type="checkbox"/>	
CVS:	<input type="checkbox"/>	
Resp:	<input type="checkbox"/>	
GI:	<input type="checkbox"/>	Screen: GERD, constipation, H.pylori
GU:	<input type="checkbox"/>	
Sexuality Issues:	<input type="checkbox"/>	
MSK/mobility:	<input type="checkbox"/>	
Fall assessment (if indicated):	<input type="checkbox"/>	
Derm:	<input type="checkbox"/>	
Neuro:	<input type="checkbox"/>	

	Normal	Remarks
Cognitive Changes:	<input type="checkbox"/>	
functional assessment (if indicated)		
dementia screen (if indicated)		
Behavioural Changes:	<input type="checkbox"/>	
difficult or challenging behaviours		
possible pain or distress		
possible abuse or neglect or exploitation (screen annually)	<input type="checkbox"/>	
Mental Health:	<input type="checkbox"/>	Depression screen <input type="checkbox"/> +ve <input type="checkbox"/> -ve
Constitutional Symptoms:	<input type="checkbox"/>	

Health Behaviours:

- folic acid (0.4-0.8 mg OD, for childbearing women)
- adverse nutritional habits
- dietary advice on fat/cholesterol (30-69 yrs)
- adequate calcium intake (1000-1500 mg/d)¹
- adequate vitamin D (400-1000 IU/d; 800-1000 IU/d > 50 yrs)
- regular, moderate physical activity
- weight loss counseling if overweight
- avoid sun exposure, use protective clothing
- safe sex practices/STI counseling

Alcohol Yes No

- case finding for problem drinking
- counseling for problem drinking

Smoking Yes No

- smoking cessation
- nicotine replacement therapy
- dietary advice on fruits and leafy green vegetables
- referral to validated smoking cessation program

Personal Safety

- noise control programs
- hearing protection
- seat belts
- bicycle helmets
- propensity to ingest noxious substances (pica)

Oral Hygiene (q6mths)

- regular dental care
- brushing/flossing teeth
- fluoride (toothpaste/supplement)
- tooth scaling and prophylaxis
- smoking cessation

EDUCATION / COUNSELING

PCC adult males



Tools for the Primary Care of People with DD, pages 37 - 38



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Preventive Care Checklist Form for adult males with a developmental disability (DD)

Original developed by: Dr. V. Dubay, Dr. R. Mathew, Dr. K. Iglar.
Adapted with permission by the DD Primary Care Initiative 2011

Please note:

- Bold** = Good evidence (Canadian Task Force on Preventive Health Care)
- Italics* = Fair evidence (Canadian Task Force on Preventive Health Care)
- Plain text = Guidelines (other Canadian sources)
- Highlighted = Differences with respect to DD - refer to Explanations sheet.

Name: _____ (last, first)

Address: _____

Tel. No: _____

DOB (dd/mm/yyyy): _____

Health Card Number: _____

Date of Visit: _____

Etiology of DD, if known:

Capacity to consent:

- Capable Guardian Substitute Decision Maker
- Power of Attorney Public Guardian & Trustee

Advance Care Planning Needs:

Living Situation:

- Family Group home Foster home Independent
- Other: _____

Update Cumulative Patient Profile

- Family History Medications
- Hospitalizations/Procedures Communication
- Allergies

Current Concerns

Lifestyle/Habits

- Diet: Fat /Cholesterol Fibre Calcium Sodium
- Smoking: _____
- Alcohol: _____
- Illicit Drugs: _____
- Exercise/Obesity: _____
- Sexual History: _____
- Family Planning/ Contraception: _____
- Day Program/Work: _____
- Family: _____
- Sleep: _____
- Relationships (recent changes?): _____

Functional Inquiry

	Normal	Remarks
HEENT:	<input type="checkbox"/>	
CVS:	<input type="checkbox"/>	
Resp:	<input type="checkbox"/>	
GI:	<input type="checkbox"/>	Screen: GERD, constipation, H.pylori
GU:	<input type="checkbox"/>	
Sexuality Issues:	<input type="checkbox"/>	
MSK/mobility:	<input type="checkbox"/>	
Fall assessment (if indicated):	<input type="checkbox"/>	
Derm:	<input type="checkbox"/>	
Neuro:	<input type="checkbox"/>	

Normal Remarks

Cognitive Changes:
functional assessment (if indicated)
dementia screen (if indicated)

Behavioural Changes:
difficult or challenging behaviours
possible pain or distress
possible abuse or neglect or exploitation (screen annually)

Mental Health: Depression screen +ve -ve

Constitutional Symptoms:

Health behaviours:

- adverse nutritional habits
- dietary advice on fat/cholesterol (30-69 yrs)
- adequate calcium intake (1000-1500 mg/d)?
- adequate vitamin D (400-1000 IU/d; 800-1000 IU/d > 50 yrs)
- regular, moderate physical activity
- weight loss counseling if overweight
- avoid sun exposure, use protective clothing
- safe sex practices/STI counselling

Alcohol Yes No

- case finding for problem drinking
- counseling for problem drinking

Smoking Yes No

- smoking cessation
- nicotine replacement therapy
- dietary advice on fruits and leafy green vegetables
- referral to validated smoking cessation program

Personal Safety

- noise control programs
- hearing protection
- seat belts
- bicycle helmets
- propensity to ingest noxious substances (pica)

Oral Hygiene (q6mths)

- regular dental care
- brushing/flossing teeth
- fluoride (toothpaste/supplement)
- tooth scaling and prophylaxis
- smoking cessation

EDUCATION / COUNSELING

Implementation

GUIDELINES AND TOOLS IN THE CONTEXT OF A FAMILY HEALTH TEAM



Implementing Guidelines and Tools

“Disparities in primary care exist ...”



Family Health Team

Goal:

Perform an annual comprehensive preventive care assessment



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Enabling Full Participation For People With Developmental Disabilities

Setting: Queen's Family Health Team



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Implementing Guidelines and Tools in FHT

Consensus	→	Team
Identify patients	→	Data support person
Point-of-care resources	→	Adapt Guidelines and Tools
Invite patients, update	→	Receptionists
Obtain past records	→	Medical records clerk
Appointments	→	NPs and MDs
Team meeting	→	+ RN, SW, pharm, dietician
Follow-up	→	NPs and MDs
Evaluation	→	Patient and caregivers



Consensus



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Point-of-care resources:

DD Health Review form in EMR

Health Review for adults with a developmental disability (DD) Original development by: Dr. V. Dubey, Dr. R. Mathew, Dr. K. Igar Adapted with permission by the DD Primary Care Initiative 2011 Further adaptation: Queen's Dept. of FM, 2012			
Please note: Bold = Good Evidence (Canadian Task Force on Preventative Health Care) Plain Text = Guidelines (other Canadian sources) Highlighted = Differences with respect to DD—refer to explanation sheets			
Caregiver's/Patient's self-reported History Tool reviewed		Copy scanned to EMR	No Yes
Etiology Of DD (1):		Definite Possible	Probable Unknown
Genetic Assessment (2):	No Yes Date:	Report on File?	No Yes
Psychological Assessment (3):	No Yes Date:	Report on File?	No Yes
Level of Adaptive Functioning (4):	Mild Moderate Severe	Profound Unknown	
Decision-Making Capacity (5): Capacity to consent may vary over time and with type of decision. Capable for some/all medical decisions Not capable for most/any medical decisions Unsure			
Update OSCAR Admin Page (6): Tick box if the following items have been updated in OSCAR Next of Kin (and Substitute Decision Maker, if not Next of Kin) Usual Clinic Routines Mobility Person/Agency to Contact regarding making appointments			
Update OSCAR CPP Fields (7): Disease Registry Social History Reminders Allergies Prescriptions Preventions and Immunizations Ongoing Concerns Medical History Family History			
Current Concerns: 			
Functional Inquiry:			
Normal Remarks	Normal Remarks		
Constitutional Symptoms: HEENT (8): CVS (9): Resp (10): GU: GI (11): Screen GERD, Constipation, H.pylori Sexuality Issues (12): MSK/Mobility (13): Fall Assessment (14): (if indicated) Derm: Neuro (15):	Cognitive Changes: Functional assessment (if indicated) (4) Dementia screen (if indicated) (16) Behavioural Changes: Difficult or challenging behaviours (17) Possible pain or distress (18) Possible abuse, neglect, or exploitation (screen annually) (19) Mental Health: Depression screen +ve -ve		

Resource page linked to items in the

DD Health Review form

Health Review for Adults with a Developmental Disability –Resource Sheet

INTRODUCTION:

This resource sheet contains brief explanations and suggestions to help you work through each of the sections of the Health Review form, along with the evidence and recommendations from the Consensus Guidelines that support them, and links to tools and other resources that can help you implement these guidelines.

The Guidelines and related recommendations for each section are from:

Sullivan WF, Berg JM, Bradley E, Cheatham T, Denton R, Heng J, Hennen B., Joyce D, Kelly M, Korossy M, Lunskey Y, McMillan S. 2011. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician*. 2011; 57:541-53. <http://www.cfp.ca/content/57/5/541.full.pdf+html>

After each recommendation the level of evidence supporting that recommendation is given in square parentheses.

Level I: At least 1 properly conducted randomized controlled trial, systematic review, or meta-analysis.

Level II: Other comparison trials, non-randomized, cohort, case control, or epidemiologic studies, and preferably more than 1 study.

Level III: Expert-opinion or consensus statements.

In the section marked "Tools," you will find links to relevant tools and forms created by the Developmental Disabilities Primary Care Initiative (also published in the "Orange Book" series: Developmental Disabilities Primary Care Initiative. *Tools for the Primary Care of People with Developmental Disabilities*. 1st ed. Toronto: MUMS Guideline Clearinghouse; 2011) which are available online at: <http://www.surreyplace.on.ca/Clinical-Programs/MedicalServices/Pages/PrimaryCare.aspx>

A Note on Communication during the Health Review:

- It will generally take more time to communicate and establish rapport with persons with DD.
- An assessment of language skills helps to choose the level of language to use.
- Many people with DD have stronger receptive (understanding) communication skills than expressive skills. Conversely, the person's expressive speech may sometimes give an impression of better comprehension than is actually the case. It is important to check the person's understanding.
- Involving caregivers who know the person well may help you to better understand his/her subjective experiences. However, continue to focus your communication efforts on the person rather than his/her caregiver.
- Behaviour is a form of communication.
- Distress signs and behaviours are unique to the individual and may not be specific to a particular cause.

The DDPCI tool **Communicating Effectively with People with Developmental Disabilities** provides suggestions for communicating with patients with DD and tips on establishing rapport, choosing appropriate language, listening and communicating without words:

<http://www.surreyplace.on.ca/Documents/Communicating%20Effectively%20with%20People%20with%20DD.pdf>

ETIOLOGY OF DD (1):

- Developmental disability has many possible causes, including chromosomal and genetic causes or environmental causes (i.e. Fetal Alcohol Spectrum Disorder, complications related to prematurity, birth trauma, accidents, poisoning, a lead, undernutrition, brain

Down Syndrome:

<http://www.surreyplace.on.ca/Documents/Down%20Syndrome.pdf>

Fragile X Syndrome:

<http://www.surreyplace.on.ca/Documents/Fragile%20X%20Syndrome.pdf>

Prader-Willi Syndrome:

<http://www.surreyplace.on.ca/Documents/Prader-Willi%20Syndrome.pdf>

Smith-Magenis Syndrome:

<http://www.surreyplace.on.ca/Documents/Smith-Magenis%20Syndrome.pdf>

22q11.2 Deletion Syndrome:

<http://www.surreyplace.on.ca/Documents/22q11.2del%20Syndrome.pdf>

Other Resources:

Peer-reviewed disease descriptions, "Gene Reviews," available at <http://www.ncbi.nlm.nih.gov/sites/GeneTests/>

GENETIC ASSESSMENT (2):

- Reasons to seek a genetic assessment include:
 - to inform medical and psychosocial management
 - to identify an etiology that might have health management consequences for other family members
 - to identify risk of recurrence within a family
 - to relieve parental guilt and provide reassurance by identifying a genetic cause

Guidelines:

Advances in genetic knowledge continue to enhance detection of etiology.

Recommendations:

Consider reassessment periodically if a previous assessment was inconclusive, according to the criteria of the genetics centre [III].

Tools:

Genetic Assessment: FAQs provides answers to questions related to making referrals to a genetic centre:

http://www.surreyplace.on.ca/Documents/Genetic%20Assessment_FAQ.pdf

Other Resources:

Contact information for **Genetic Centres in Canada** is available at: <https://cagc-accg.ca/>

PSYCHOLOGICAL ASSESSMENT (3):

- Reasons to consider referring an individual for psychological testing include:
 - Failure to cope well with current support system
 - Change from an earlier assessment
 - Future planning needs (i.e. vocational, housing, educational plans)
 - Before a psychiatric diagnosis
 - Significant unexplained change in behaviour
 - Specific diagnosis is needed for income support services (i.e. ODSP, disability tax credit)

Guidelines:

Invite patients to take part



Caregiver Health Assessment

CAREGIVER HEALTH ASSESSMENT FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Person's Name: _____	Address: _____
Likes to be called: _____	City: _____ Postal Code: _____
Date of Birth: ___/___/___	Telephone Number: _____

How to Fill Out and Use This Form

This health information helps the caregiver to know more about the person with a developmental disability and their health problems. This information can also be helpful to the family physician or primary care provider.

This health information is **strictly confidential** to this person and their care providers. **PLEASE – KEEP IT CONFIDENTIAL!!!**

- The person with the developmental disability should complete this form with the help of family members, caregivers, and medical records. Get as much information as possible.
- Fill it out as well as you can – OK to check "Don't Know"
- The form can be used at Intake, and at Team Meetings. It can be revised as needed when changes occur.

CONTACT INFORMATION

CONTACT	NAME and ADDRESS	CONTACT INFORMATION (Telephone #'s: Home, Work, Cell, Email)
Current Living Arrangement <input type="checkbox"/> Family <input type="checkbox"/> Group home <input type="checkbox"/> Foster home <input type="checkbox"/> Independent <input type="checkbox"/> Other		
<input type="checkbox"/> Substitute Decision Maker or <input type="checkbox"/> Power of Attorney for Personal Care		
Next of Kin Relationship: _____		
Family/ Significant Others/ Children		
Lead Agency		

PART I. BACKGROUND INFORMATION

Person's Developmental Disability – (If Autism Spectrum Disorder - ASD diagnosed, please include)

Known cause or syndrome? _____ Unknown

Ever had a Genetic assessment? No Unsure Yes Date: ___/___/___ Copy on file? No Yes

Comments: _____

Ever had a Psychological assessment: No Unsure Yes--> Date: ___/___/___ Copy on file? No Yes

Comments: _____



Living Your Potential - All Your Life
Enabling Full Participation For People With Developmental

Implementing Guidelines and Tools in FHT

Consensus	→	Team
Identify patients	→	Data support person
Point-of-care resources	→	Adapt Guidelines and Tools
Invite patients, update	→	Receptionists
Obtain past records	→	Medical records clerk
Appointments	→	NPs and MDs
Team meeting	→	+ RN, SW, pharm, dietician
Follow-up	→	NPs and MDs
Evaluation	→	Patient and caregivers



First appointment with NP

Second appointment with MD



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Case presentation at monthly Clinical Team Meeting



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Follow-up appointment



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Evaluation

- Patient and caregiver surveys
- Key indicators from chart review, e.g.,
 - % of FHT patients with DD, who
 - received a comprehensive health review
 - were reviewed at clinical team's monthly meeting
 - had follow-up visits



DISCUSSION

**How can the DD Guidelines and Tools
be most effectively implemented
in a Family Health Team?**



CONCLUSIONS
CONCLUSIONS

NEXT STEPS?
NEXT STEPS?



THANK YOU!

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