

## Developmental Disabilities Primary Care Initiative (DDPCI)

This initiative has brought together family physicians and other health care professionals who practice in a variety of clinical settings, with expertise in the care of adults with developmental disabilities (DD). Their names, areas of expertise, and place of practice are listed below.

Dr. William F. Sullivan (Chair)  
Family Medicine and Ethics  
Toronto, ON

Dr. Cynthia Forster-Gibson  
Family Medicine and Genetics  
Mississauga, ON

Maureen Kelly  
Nursing  
Toronto, ON

Dr. Joseph M. Berg  
Medical Genetics and Psychiatry  
Toronto, ON

John Heng  
Ethics  
London, ON

Marika Korossy  
Library Science  
Toronto, ON

Dr. Elspeth Bradley  
Psychiatry  
Toronto, ON

Dr. Brian Hennen  
Family Medicine  
Halifax, NS

Dr. Yona Lunskey  
Psychology  
Toronto, ON

Dr. Tom Cheetham  
Family Medicine  
Toronto, ON

Dr. David Joyce  
Family Medicine  
Vancouver, BC

## Scientific and Editorial Staff

William F. Sullivan, MD, PhD  
Laurie Dunn, MSc, BScPhm  
John Heng, MA  
David Joyce, MD

Maureen Kelly, BScN, MPA  
Marika Korossy, BA  
John Pilla, MSc, BScPhm

Jo-Anne Jackson, BA

## Copy Editor

## Expert Review Committee of Core Developmental Disabilities Primary Care Tools

Laura Arthurs  
Quest Society  
Rehabilitation  
Halifax, NS

Dr. Nicholas Lennox  
Director, Queensland Centre for  
Intellectual and Developmental  
Disabilities  
University of Queensland  
Brisbane, Australia

Ruth Northway  
Learning Disability Nursing  
University of Glamorgan  
Glyntaff, Wales, UK

Jane Bernal  
Developmental Neuropsychiatry  
Cornwall Partnership Trust  
Truro, Cornwall, UK

Dr. Andrew Levitas  
Psychiatry  
School of Osteopathic Medicine  
Stratford, NJ, USA

Hélène Ouellette-Kuntz  
Community Health &  
Epidemiology  
Queen's University  
Kingston, ON

J. Carolyn Graff  
College of Nursing  
University of Memphis  
Memphis, TN, USA

Dr. James Meuser  
Family Medicine  
University of Toronto  
Toronto, ON

Dr. Walter Rosser  
Family Medicine  
Queen's University  
Kingston, ON

Dr. Nick Kates  
Psychiatry  
McMaster University  
Hamilton, ON

## Working Groups and Contributors for Primary Care Tools

### Team Lead

### Team Members

#### General Issues in Primary Care

William F. Sullivan  
Family Medicine  
Toronto, ON

Tom Cheetham  
Cynthia Forster-Gibson  
Maureen Kelly

Elizabeth Grier  
Stephannie MacDonell  
Valerie Temple

#### Informed Consent

Greg Gillis  
Family Medicine  
London, ON

Maria Gitta  
John Heng  
Marika Korossy

Renata Leong  
William F. Sullivan  
Hugo Scher

#### Cumulative Patient Profile (CPP) and Medication Record

Tom Cheetham  
Family Medicine  
Toronto, ON

Deborah Champ  
Bruce McCreary  
William F. Sullivan  
Elizabeth Grier

Brian Hennen  
David Joyce  
Stephannie MacDonell

#### Preventive Care Checklist (PCC)

Brian Hennen  
Family Medicine  
Halifax, NS

Terry O'Driscoll  
Joseph M. Berg  
Wendell Block

Cynthia Forster-Gibson  
David Joyce  
William F. Sullivan

#### Health Watch Tables / Syndrome-Specific Charts

William F. Sullivan  
Family Medicine  
Toronto, ON

Joseph M. Berg  
Donna Cameron  
Cynthia Forster-Gibson

Maureen Kelly  
Alin Khodaverdian  
Marika Korossy

#### Behavioural and Mental Health Tools

Elsbeth Bradley  
Psychiatry  
Toronto, ON

Tom Cheetham  
Caroll Drummond  
Nancy Huntley  
Maureen Kelly  
Louise Kerr  
Marika Korossy

Yona Lunsky  
Stephannie MacDonell  
Shirley McMillan  
William F. Sullivan  
Margaretha Vanderwelden

#### Tools for Use by Caregivers to Assist with Coordination of Care

Leeping Tao  
Nurse Practitioner  
Toronto, ON

Richard Denton  
Emer Dudley  
Maureen Kelly  
Theresa Broda

Judith Ludlow  
Sandra Stemp  
Karen Cowan  
Nicole Martindale-Coke

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## Introduction

*Developmental disabilities (DD)* or *intellectual disabilities* are terms used synonymously in Canada (*learning disabilities* is used in the UK and the older term *mental retardation* in the USA). These terms refer to a range of conditions in which lifelong limitations in intellectual functioning and in conceptual, social, and practical skills (i.e., adaptive functioning) are noticeable before age 18 years. Estimates of the prevalence of people with DD vary between 1-3% of Canadians, and if one includes those with borderline DD, the prevalence is significantly greater. Most adults with DD reside in and receive health care in the community. The tools in this book were developed to assist primary care providers (general practitioners, family physicians, nurses, nurse practitioners) in caring for adults with DD by helping them to implement various recommendations in *Primary care of adults with developmental disabilities: Canadian consensus guidelines (DD Guidelines)*.

## Development Process

Participants in a DD Training Course, based on the DD Guidelines (150 participants over four years) identified challenges in implementing the recommendations of the Guidelines and recommended development of specific tools for this purpose. Several clinician-led Tools Working Groups were tasked with developing brief, practical, and evidence-informed tools to respond to these requests. Initially, six Tools Working Groups developed a set of tools that Training Course participants and faculty deemed to be priority issues. Draft versions of each tool were reviewed by two or more nationally and/or internationally acknowledged experts in relevant areas of DD medicine and, based on feedback received, the tools were finalized. Subsequently, additional tools have been developed to address practical matters related to implementing other recommendations in the DD Guidelines.

## Use of Developmental Disabilities Tools and Ongoing Development

The tools in this book are meant to complement DD Guideline recommendations. Those recommendations are framed by guiding principles that inform the DD Guidelines and related tools (i.e., dignity, inter-personal relationships, and justice considerations relevant to persons with DD). The tools are organized to correspond to the DD Guidelines sections: General Issues, Physical Health Issues, and Behavioural and Mental Health Issues. Within each section, tools are listed in the order in which they arise in the DD Guidelines. Not every guideline recommendation has a corresponding tool. Tools in this book have been developed for, and in most cases by, primary care providers with helpful input from related disciplines.

Other tools not included in this book were developed primarily for and by others who work with primary care providers. For example, the Caregiver Health Assessment was developed for and by caregivers who typically work in group homes. Such tools are meant to facilitate collaboration with primary care providers. These latter tools, along with the most recent versions of tools in this book, full references and new tools, are available at [www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx](http://www.surreyplace.on.ca/Clinical-Programs/Medical-Services/Pages/PrimaryCare.aspx).

We are aware of the need to update and revise these tools. We encourage readers to assist us by providing comments and suggestions regarding tools in this book and by recommending other tools they would like to see developed. This can be done by returning the completed comment page at the back of this book. We look forward to receiving your feedback and continuing support and participation.

## Acknowledgements

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A special thank you to those listed in the prior pages who have contributed so much to the development and review of these tools. Thank you also to parents of adults with DD, caregivers and in particular to persons with DD who have contributed generously in various ways to this project.

On behalf of all those who have contributed to this project, we hope that these tools will help, in some way, to improve the health and well-being of adults with DD, so that they may more fully take part in all aspects of life.

Sincerely,

William F. Sullivan, Maureen Kelly, Marika Korossy, and John Heng, Co-editors

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<sup>1</sup>Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, Hennen B, Joyce D, Kelly M, Korossy M, Lunskey Y, McMillan S. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Can Fam Physician* 2011;57:541-53.