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*Tools for the  
Primary Care of People with  
Developmental Disabilities*

**2011**

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➤ *Peer-reviewed*

➤ *Evidence-based*

➤ *User-friendly*

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For updates and to access the tools provided in this booklet please use the link below:  
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Comment sheets are provided at the end of the document and at [www.mumshealth.com](http://www.mumshealth.com).

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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

We would like to acknowledge the sponsors of the DD Primary Care Initiative: Ontario Ministry of Community and Social Services, Ontario Ministry of Health and Long-Term Care, Surrey Place Centre, and Surrey Place Centre Charitable Foundation. Their shared financial support of this initiative since 2005 has made the development and printing of these tools possible.

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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.