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4th Edition

DEVELOPMENTAL DISABILITIES

IN ONTARIO

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Ivan BROWN
Maire PERCY

EDITORS

DEVELOPMENTAL
DISABILITIES in Ontario

DEVELOPMENTAL DISABILITIES IN ONTARIO, FOURTH EDITION

DRAFT

DEVELOPMENTAL DISABILITIES IN ONTARIO

Fourth Edition

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The photo in Chapter 2 of what came to be called Huronia Regional Centre is in the public domain and is reprinted here, with permission, from the website of the Ontario Ministry of Children, Community and Social Services.

DRAFT

To the many people who came before us – those with disabilities, their families, their supporters, and their many allies – who often struggled in a world where acceptance and tolerance were not always to be found, but whose persistent efforts helped pave the way for better recognition and inclusion today.

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Foreword

To be added

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About the Editors

Ivan Brown, B.A., B.A. (Hons.), B. Ed., M. Ed., Ph.D.

Ivan has worked in, and contributed to, the field of disabilities for the past 38 years. He began his career as an elementary school teacher for 8 years before taking a position with what is now Community Living Toronto, where he worked as a vocational counsellor, a community support worker, and an APSW while completing his graduate studies in counselling psychology (M.Ed.) and special education (Ph.D.). In 1991, he took a position as Research Associate with the Centre for Health Promotion, Department of Public Health Sciences, University of Toronto, where he managed a number of large research projects. Several of these addressed quality of life of children with disabilities, adults with developmental disabilities, seniors, and adolescents. He held appointments during the 1990s as Assistant Professor in the Departments of Occupational Therapy and Public Health Sciences, both at the University of Toronto, and taught both in the graduate health promotion program in the Department of Public Health Sciences and in the School of Early Childhood Education at Ryerson University in Toronto, which has a special focus on young children with special needs. From 2001-2010, Ivan held the position of Manager of the Centre of Excellence for Child Welfare, a national body for research and policy development in child welfare, to which he brought the essential disability focus. The Centre was housed within the graduate Faculty of Social Work at the University of Toronto. Research in disability has been a critical part of his career, with a strong recent focus on international family quality of life. Since 2009, Ivan has taught Toronto-based masters level students as an Adjunct Professor for Brock University's Department of Applied Disability Studies.

Ivan has a strong history of community involvement in disability, serving on numerous government and community agency committees and boards, participating in research projects, and acting in leadership roles with several professional organizations. In particular, he was a longstanding member of the Board of Directors of the Ontario Association on Developmental Disabilities and served as the Board's Chair for a 2-year period. In 2001, he was awarded this association's Directors' Award of Excellence. He was the founding editor of the *Journal on Developmental Disabilities* in 1992, served as Editor-in-Chief for many years, and is still a member of the Chief Editorial Board. In addition, he is on the Editorial Boards of several Canadian and international journals. Ivan has been a fellow of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) since 2000, and is currently the Vice-President of IASSIDD for Education and Policy, Director of IASSIDD's Academy, and an active international speaker and workshop leader of IASSID's Academy on Education, Teaching, and Research. He was also a long-standing member of the American Association on Intellectual and Developmental Disabilities.

Ivan has contributed substantially to the Canadian and international literature, particularly in the areas of quality of life and intellectual disabilities. He has 15 books to his credit (including the three previous editions of *Developmental Disabilities in Ontario*), and more than 150 peer-reviewed journal articles and book chapters, as well as numerous other articles, editorials, reviews, booklets, scales, and manuals. He has made 130 presentations at academic conferences in the past 20 years, and several keynote speeches.

Ivan continues to be personally involved in disability issues, through active community work and consultation, teaching, and sharing the lives of many friends with disabilities. He holds a strong belief that including disability as part of our daily life activities is an enriching experience for us all.

Maire Percy, B.Sc. (Hons.), M.A., A.R.C.T., Ph.D.

Maire is Professor Emeritus of Physiology and Obstetrics & Gynaecology at the University of Toronto. From 1989-2011, she directed the Neurogenetics Laboratory at Surrey Place Centre. She holds a bachelor's degree in physiology and biochemistry, a master's degree in medical biophysics, and a doctoral degree in biochemistry all from the University of Toronto; in addition, she is an Associate of the Royal Conservatory of Music of Toronto (A.R.C.T.). She did postdoctoral training as a Medical Research Council Fellow in immunology at the Agricultural Research Council Institute of Animal Physiology, Babraham, United Kingdom, and in immunology and genetics at the Hospital for Sick Children in Toronto. As a National Health Research Scholar (Health Canada), Maire entered the field of developmental disabilities by serendipity after a chance meeting with Dr. Arthur Dalton, then Director of Behaviour Research at Surrey Place Centre. He recognized the potential of her multidisciplinary background and enthusiasm for research and suggested a collaborative project, for which he found the funding, to study the involvement of oxidative stress in the development of dementia in older persons with Down syndrome. The rest is history.

Research in dementia soon took precedence for her. In 1989, she was invited to join the Department of Biomedical Services and Research at Surrey Place Centre, under the direction of Joseph M. Berg, eminent clinical geneticist and psychiatrist. Maire's knowledge and expertise in the field of developmental disabilities continued to expand as the result of her research, and also by osmosis as the result of interacting with colleagues at Surrey Place Centre (especially Dr. Vera Markovic and Marika Korossy) and other activities that included: chairing/co-chairing the Research Ethics Board at Surrey Place Centre; co-founding the Research Special Interest Group of the Ontario Association on Developmental Disabilities (OADD) and the Fragile X Research Foundation of Canada; chairing the Publication Committee of the OADD; and being a member of the Chief Editorial Board of the *Journal on Developmental Disabilities* and an associate editor of the *International Journal of Developmental Disabilities*. A dedicated teacher, Maire developed a graduate course called Neuroscience of the Developmental Disabilities, which provided the inspiration and much background material for the first edition of *Developmental Disabilities in Ontario* that came to life with Ivan Brown. Author of more than 250 published papers, book chapters and conference presentations, reviewer of publications and grants for numerous scientific journals and granting agencies, and co-editor of three previous versions of *Developmental Disabilities in Ontario* and two editions of the sister book published by Paul H. Brookes Publishing Co., Maire is internationally known for her work on risk factors in serious human diseases and as a passionate mentor of students.

Honours include the OADD Award for Excellence in Research (2004), the OADD Award of Excellence (2011), and the June Callwood Award for outstanding contributions in support of people with developmental disabilities and autism spectrum disorder (2012). Maire continues to publish about risk factors for dementia with colleagues, and to conduct later life learning courses in the community. The mother of Carol (Professor of English, University of Toronto), she shares her home with husband John (Professor Emeritus of Astronomy, University of Toronto), and Elf the cat.

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Rosemary A. Condillac, B.A., M.A., Ph.D., C.Psych., BCBA-D

Rosemary Condillac has worked in the field of developmental disabilities for over 30 years, in a variety of roles including direct care staff, behaviour consultant, psychologist, researcher and professor. As a scientist-practitioner, she has dedicated her career to providing evidence-based supports and services focused on improving the lives of children, youth, adults, and seniors (with a range of developmental and mental health issues) and their families. She is an Associate Professor in the Department of Applied Disability Studies at Brock University, where she teaches graduate courses in clinical ethics, skills, and professionalism. Her research interests include positive-based interventions for individuals with severe challenging behaviour, parent and caregiver training, improving direct-care staff well-being and client engagement, and post-secondary experiences of students with Autism Spectrum Disorders.

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Wai Lun Alan Fung is a medical specialist board-certified in Psychiatry; Behavioral Neurology & Neuropsychiatry; and Sleep Medicine. He serves as the Physician Lead of the Mount Sinai Hospital Wellness Centre, University of Toronto Faculty of Medicine. He also served two terms (2014-2020) as Chair of the North York General Hospital Research Ethics Board. He is a Research Professor at Tyndale University in Toronto, and is a faculty member of the University of Toronto. He completed his B.Sc. and M.D. degrees, as well as residency training in psychiatry, all at the University of Toronto. He also completed an M.Phil. in psychiatric epidemiology at the University of Cambridge, United Kingdom, as well as a Research Doctorate (Sc.D.) in neuropsychiatric genetic epidemiology at Harvard University. He is a Fellow of the Royal College of Physicians of Canada as well as of the American Psychiatric Association. His clinical and scholarly interests include neuropsychiatry and genetics; cultural and spiritual/religious dimensions of mental health and care; global mental health; interprofessional collaborations and education. He was a Co-Editor of *A Comprehensive Guide to Intellectual and Developmental Disabilities*, 2nd edition, and co-led the development of the first set of professionally-endorsed guidelines for managing adults with 22q11.2 deletion syndrome.

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Barry Isaacs is Director of Research, Evaluation and Education at Surrey Place in Toronto. He has been working in the developmental services sectors for 27 years. He has a B.A. (major in Psychology, minor in Philosophy), an M.A. in Psychology and a Ph. D. in Psychology from York University. He specializes in the evaluation of health and social services provided to people with developmental disabilities and their families. In this work, he places an emphasis on incorporating strong stakeholder engagement and integrated knowledge translation approaches. His specific research interests include quality of life for people with developmental disabilities and their families, homelessness and developmental disabilities, and individualized funding models and implementation.

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Tina has her B.A. (Hons.) in Psychology and Women's Studies from York University. Currently, she works as an Addiction Counsellor at an addiction treatment centre located in an Ontario hospital. Prior to this, Tina worked for the Centre of Excellence for Child Welfare (CECW), Factor-Inwentash Faculty of Social Work, University of Toronto, and at the Disability Support Unit, Centre for Health Promotion, University of Toronto. In these roles, she has worked on the editorial staff of numerous publications related to both Child Welfare and Developmental Disabilities, including: *Developmental Disabilities in Ontario, 2nd edition*, *Journal on Developmental Disabilities*, *CECW Research in Briefs*, *Putting a Human Face on Child Welfare: Voices from the Prairies*, and numerous other reports and applied printed documents. Tina is the proud mother of two boys, one of whom has been diagnosed with both ASD and a Learning Disability.

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Juanito has a degree of Bachelor of Science in Agricultural Education (BSAEd.), with a major in Agronomy. He completed the academic requirements in Master of Arts in Education (Educational Management) program from the University of Northern Philippines. Before he migrated to Canada, he was a high school teacher at Candon National High School where he taught Agriculture and Health and Physical Education. After emigrating to Canada in 1990, he was a Billing Production Co-ordinator at one of the biggest cellular networks in Canada. He became certified with the Ontario College of Teachers (OCT) in 2006, and he began the following year as elementary teacher at the Dufferin-Peel Catholic District School Board (DPCDSB). Currently, he is a Teacher-Librarian at St. Brigid School in Brampton, where he teaches Special Education, Arts, Music, Health, and Physical Education. He also acted as an assistant to the editors in the preparation of *Developmental Disabilities in Ontario, 3rd edition* in 2011. Juanito was raised in a family that included a brother with a developmental disability.

Proofreaders

A final step in the preparation of this book's chapters was a careful proofreading by at least two people for each of the 50 chapters. Our proofreaders have backgrounds in disability studies, education, psychology, and related fields. Almost all have professional or family experience with developmental and learning disabilities. The editorial staff and the publisher are very grateful to the following people for their valuable volunteer proofreading:

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Kelly MacDougall, has been active in self-advocacy for many years. She believes that self-advocates have a right to be heard, to make their own decisions, and to have opportunities to learn and grow. For this to happen, self-advocacy needs access to resources and supports.

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Chapter 9: Introduction to Early Development: A Multidisciplinary Perspective

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Chapter 10: Genetics: How It Works and How It Affects Developmental Disabilities

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Chapter 13: Factors Causing or Contributing to Developmental Disabilities

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Chapter 14: Down Syndrome: Characteristics and Health Issues

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Chapter 15: Fragile X Syndrome

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Chapter 17: 22Q11.2 DELETION SYNDROME

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Chapter 20: Other Syndromes and Conditions Associated with Developmental Disability

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Chapter 23: Introduction to Services and to Ontario's Developmental Disability Service System

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For many years, we have worked closely with the Ontario Association on Developmental Disabilities (OADD) on the production and distribution of this book, and we are extremely happy to have their involvement continue in the distribution of this fourth edition of *Developmental Disabilities in Ontario*. We particularly appreciate the strong sense of cooperation and unwavering faith in us as editors from the OADD Board of Directors, and the immense support from their Executive Officer, Jennifer Shaw.

On behalf of the other authors and the publisher, we offer fond remembrance of Dr. Jeanette Holden, and Dr. Tom Cheetham, who passed away before the completion of this book. Both authors made strong and important contributions to all previous editions, and their work continues to be represented in this volume in slightly amended form. Jeanette and Tom will be sincerely missed, both as professionals in our field and as vibrant individuals.

We would like to recognize our institutions and employers for providing numerous types of in-kind supports to the editors and authors of this text. Not least of these contributions is the wide range of opportunities and experiences that institutions and employers have offered our authors over the years to add to their knowledge and to enrich their professional experience. That knowledge and experience is shared with the readers of this volume. A number of authors have included case examples in their chapters to illustrate their material more clearly for the reader. Some of these are composite examples drawn from the broad experiences of the authors' professional work.

Finally, on behalf of all the members of the editorial team, the editors thank those with whom we have lived and worked during the book production for their patience and understanding.

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The editors and publisher of *Developmental Disabilities in Ontario*, fourth edition, are particularly grateful to Paul H. Brookes Publishing Company in Baltimore for their ongoing strong cooperation. Through an agreement with Brookes, material from previous editions of *Developmental Disabilities in Ontario* was updated, expanded, and adapted for an international and broader readership by Ivan Brown and Maire Percy to produce Brookes' 2007 book *A Comprehensive Guide to Intellectual & Developmental Disabilities*. This same agreement was the foundation for a second edition of this book, published in 2017 with Michael Wehmeyer, Ivan Brown, Maire Percy, Karrie Shogren, and Alan Fung as editors.

In turn, Brookes has agreed to share material in editions of *A Comprehensive Guide to Intellectual & Developmental Disabilities* to be updated and adapted for use in the *Developmental Disabilities in Ontario* series. This special relationship is highly beneficial to both publishers, and we very much appreciate Brookes' helpfulness and strong spirit of cooperation in this matter.

A Comprehensive Guide to Intellectual & Developmental Disabilities (2nd ed.), is available from www.brookespublishing.com/

Introduction

We are very pleased to bring you *Developmental Disabilities in Ontario*, Fourth Edition. Our first edition, published in 1999, was the first text that provided broad and multi-disciplinary information about developmental disabilities and, at the same time, was specifically for people who live and work in Ontario. The second edition, published in 2003, updated the information in the first edition, and added several new chapters. The third edition, in 2011, updated and reorganized that information, and added five new chapters to provide additional information that was not previously included. This fourth edition continues the series with updated information and additional chapters. It also includes several new authors.

Developmental Disabilities in Ontario, Fourth Edition, is intended to appeal to a broad range of people in Ontario. Students in Ontario colleges and universities use it as a comprehensive text with specific reference to Ontario to guide their learning. We consider this to be particularly important, since these students are the future professionals and community leaders in the field of developmental disabilities. This book is also intended for use by people who directly support people with developmental disabilities, educators, health care workers, social workers, academics, policy makers, government leaders, those concerned with legal and ethical issues, and many others. Perhaps most important, the book provides one way for family members to learn about a broad range of issues and new knowledge in the field of developmental disabilities. At a time when many families want to have a stronger voice in determining support for their family members with disabilities, such information is needed. Finally, it is our hope that the material contained between these covers will help the general public to understand developmental disability better, and to include people with developmental disabilities of all ages in Ontario society.

This book has attempted to capture core research and practical knowledge in the developmental disabilities field and to present it in a format for learning and for day-to-day use. The main goal of the book is to promote sharing of information, experience, solutions, and insights in order to help people with developmental disabilities, their families, and their other supporters improve their quality of life.

We have assembled *Developmental Disabilities in Ontario*, Fourth Edition, for three additional reasons. First, interest in the book arose from our collective experiences as researchers and teachers, and from networking through our activities with the Ontario Association on Developmental Disabilities (OADD) — an organization whose mandate is to promote the education of professionals in the field — and OADD's Research Special Interest Group. We realized that service providers of all disciplines, service recipients, students, educators, researchers, policy makers, and others would benefit from a book that presented core and practical information from a multi-disciplinary perspective. There is a tremendous amount of information in the developmental disabilities field. Because the field is changing so quickly, and because most people do not have a broad understanding of all the issues in the field, much valuable information is not readily accessible to people who need it when they need it. Second, there is a large body of

informal knowledge based on the extensive experiences of clinicians, educators, and researchers that has not been brought together before. Finally, new philosophical and policy directions in developmental services have emerged in recent years, and good responses to these require solid knowledge of the field.

The term developmental disabilities requires elaboration (see also Chapter 1). In its broad sense, the term refers to disabilities that are related to development. To a great extent, though, the term developmental disabilities as it is commonly used in Ontario and elsewhere grew out of, and replaced, the terms mental retardation, mental handicap, and developmental handicap, which had become outdated by the mid 1980s. The term intellectual disability is used in many countries of the world, and is increasingly being used in Ontario as an equivalent term to developmental disability. In this book, we have continued to use the term developmental disability, because that is the term used in the major policy documents that influence the field in Ontario. It is also in keeping with the name of the only provincial professional organization in our field, the Ontario Association on Developmental Disabilities.

The field of developmental disabilities in Ontario is, in many ways, not substantially different from that of other parts of Canada or other countries. Thus, much of the information in this book will be very useful indeed to people in other jurisdictions. Still, people live within cultural and political environments that often have considerable influence upon their lives. People with developmental disabilities who live in Ontario are influenced by the customs, the values, the laws, the natural and human resources, and the many other characteristics that comprise the Ontario environment.

One of the primary intents of this book is to capture as much as possible of the Ontario environment that influences the lives of people with developmental disabilities. In doing so, our aim is to place the lives of such people — and the field of developmental disabilities itself — within its environment, and to explore, as much as we can, the interrelationship among people, the field, and the environment. Every chapter contains references to resources that are available in Ontario — a list of "where to start" when confronted with a question about developmental disabilities. This provides a way for new parents, family members, students, adults supporting people with disabilities, professionals in education and health care, and many others to connect with other people and supports right here in Ontario.

We have tried to capture a great deal of the complexity in the broad field of developmental disabilities in the chapters that comprise this edition of *Developmental Disabilities in Ontario*. In doing so, we have not been able to include every aspect of life of people with developmental disabilities, nor have we been able to raise every issue or perspective that is of importance to people with developmental disabilities, their families, and those who support them in the many ways they do. We have brought to you, though, a comprehensive set of chapters under one cover about developmental disabilities. We have endeavoured to place the material of each of these chapters within the Ontario context, and it is this unique feature of which we are most proud.

One of the interesting by-products of producing this book has been the opportunity for interaction among a wide variety of people whose lives are affected by developmental disabilities, including family members, professionals, policy makers, researchers, and those who provide numerous types of

supports. A very large team of experts, almost all of whom live and work in Ontario, contributed to this book. This represents a vast amount of knowledge from professionals whose life work includes sharing and connecting with others.

In producing *Developmental Disabilities in Ontario*, Fourth Edition, we are very pleased to continue to collaborate with the Ontario Association on Developmental Disabilities, which will assist in the ordering and distribution of the book. OADD, an organization of people who pursue careers in the field of developmental disabilities in Ontario, was formed in 1989. Both of us have been strong supporters of OADD for many years, and have acted in leadership roles on its Board of Directors and its Research Special Interest Group. Since one of the principal goals of OADD is to promote learning opportunities for people who work in the field of developmental disabilities, this book very much supports its mandate.

In presenting to you the 50 chapters of *Developmental Disabilities in Ontario*, Fourth Edition, it is our hope that they will be informative and helpful to you in your understanding of developmental disabilities in Ontario, and that the contents of this book will encourage you to network with others in the developmental disabilities field.

Ivan Brown
Maire Percy
Editors

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