An **Interdisciplinary Focused** One-Day Conference on Complex Health Issues in People with IDD

Persons with Intellectual Disabilities can have many neurological conditions. This leads to complexity and challenges for families, developmental services agencies, Primary Care Physicians and Specialists.

This one-day training program is designed for multi-disciplinary health care professionals from both Developmental Services and Health Care Sectors who support individuals with IDD. Cross sector collaboration is vital to help meet the complex needs for this population.

**Training includes the following areas:**
- Special Presentation: Seeing Beauty Beyond the Diagnosis, Positive Exposure
- The Relentless Pursuit of Perfection; Dr. Rick Rader
- Seizure Disorders-An International Perspective; Panel of Global Experts
- Aging, Panel of Global Experts
- Lunch & Learn Topics (Primary Care, Epilepsy, Cerebral Palsy, Aging, Psychiatric Issues & More..)
- 6 x Breakout Sessions:
  - Primary Care (2 x Sessions)
  - Behavioural Neurology
  - Dementia
  - Advocacy
  - Movement Disorders

**Who should attend:**
Multi-disciplinary health care professionals, home care, LTC, primary care, community care, Networks of Specialized Care, DS leads in Urgent response and Crisis, health care facilitators, leaders in agencies with a role in health care.

**Where:**
Chestnut Conference Centre
89 Chestnut Street, Toronto, ON M5G 1R1

**When:**
Wednesday, April 29, 2020
7:30 AM – 5:00 PM (Session Commences promptly at 8:30 AM)

**Cost:** $175.00 + HST ($197.75)
Fees are payable by credit card at time of registration processing. Includes Course, Continental Breakfast, refreshment breaks and lunch. No Cancellations/Refunds, however substitutions are permitted.

Program

7:30 AM - 8:30 AM
Registration and Breakfast

8:30 AM - 8:45 AM
Welcome Remarks

8:45 AM - 9:00 AM
SPECIAL PRESENTATION:
Seeing Beauty Beyond the Diagnosis
As a professional photographer whose foundation of work was in the high-fashion beauty industry, Rick Guidotti has seen some of the most beautiful people in the world through his lens. When his work then led him to discover more about how people with rare conditions and disabilities were portrayed, it was life changing. Rick’s review of medical textbooks with their dehumanizing images was especially disturbing. His mission to build awareness with health care professionals, medical students and publishers began.
Speaker: Rick Guidotti

10:15 AM - 12:00 PM
PLENARY SESSION PANEL:
Seizure Disorders-Common Health Conditions that Challenge Daily Life
Seizure disorders are the most common neurologic complication in people with intellectual and developmental disabilities. Seizures often continue to occur despite medical therapy and the treatment themselves can create their own difficulties with side effects that may include a worsening of underlying behavioral challenges. The speakers will review the importance of gathering pertinent personal information about the seizure events, quality of life measures and will also discuss a rational approach in which the “team” of care providers including the individual themselves need to be part of the care and decision-making process.
Facilitator: Dr. Shirley McMillan
Speakers: Dr. Seth Keller, Dr. Danielle Andrade & Dr. Christian Brandt

10:30 AM -10:45 AM
Morning Break

9:00 AM -10:00 AM
KEYNOTE:
The Relentless Pursuit of Perfection and How It Influences Our Response to Human Imperfection
We seek perfection in virtually every aspect of our lives; and our daily choices demonstrate it. This ongoing affinity has impacted on how we view, respond and treat impairments, imperfections and disability. We examine the intrinsic, hard wiring that has influenced the field of intellectual and developmental disabilities. Coming to grips with and accepting human exceptionality is the core of what drives people to and away from working with people with complex conditions. How do we mitigate the negative perceptions of “imperfect” people and overcome the survival instinct of avoiding people who are different, strange, unattractive and misunderstood? Perhaps it’s time to take a self-inventory of what drives some of us to supporting our cherished and stigmatized population
Speaker: Dr. Rick Rader

10:00 AM -10:15 AM
Morning Break

12:00 PM - 1:15 PM
LUNCH & LEARN (or Network)
8 Tables will be designated to allow attendees to have lunch with and discuss specific cases, issues with one/two of our distinguished faculty. Select your preference on the registration form - seating is limited to 8 or 9 per table, first-come, first-served. Note: You may choose to enjoy lunch and network with colleagues instead.

Table 1 Dementia
Dr. Seth Keller & Leslie Udell

Table 2 Epilepsy
Dr. Christian Brandt & Dr. Danielle Andrade

Table 3 Cerebral Palsy
Dr. Bhooma Aravamuthan

Table 4 Transition of Care
Dr. Miya Asato

Table 5 Aging and IDD
Kathy Service & Dr. Matthew Janicki

Table 6 Primary Care
Dr. Bill Sullivan & Dr. Dara Abels

Table 7 Psychiatric Issues in IDD
Dr. Anupam Thakur & Dr. Ben Margolis

Table 8 Quality of Life
Dr. Roy Brown & Dr. Ivan Brown
Program

1:30 PM – 2:30 PM
BREAKOUT SESSION 1 (Select one on the registration form)

A1 – You’ve Got This! Identifying and Addressing Challenge in Primary Care for People with IDD
Primary health care for people who have IDD and complex health needs can include predictable challenges across the lifespan. Some of these at the patient level include physical/sensory/communication accessibility, behavioral issues, adaptations to routine age-based screening, and monitoring and addressing health concerns that arise differently or more frequently in this population. Coordinating across disciplines and service systems takes extra time and knowledge, which is not always supported financially. Electronic Health Records can be helpful tools, or barriers to meaningful interaction with patients and their circles of support. Engaging the individual to participate in identifying goals of care and other health decision making often pulls in families or service agencies in unique ways. In this interactive session, we will address these and other challenges, offer some solutions we have found, and learn from each other about useful tricks of the trade. Come prepared to talk!
Moderator: Dr. Jessie Sanders
Speakers: Dr. Dara Abells, Dr. Steven Sulkes & Megan Henze

A2 – Assessment and Management of Behavioral Challenges in I/DD
Psychiatric and behavioral care for individuals with I/DD is lacking in guidelines, standardization and is not included in most psychiatric or neurologic residencies, in spite of the tremendous degree to which behavioral dysregulation presents challenges for this population, and in spite of the frequent use of psychotropic medications. We will present a framework for approaching neurobehavioral care along with both pharmacologic and nonpharmacologic approaches to managing some of the most common challenges in psychiatric I/DD care.
Moderator: Brandie Stevenson
Speakers: Dr. Anupam Thakur & Dr. Benjamin Margolis

A3 – Community Supports for Persons with ID Affected by Dementia
Persons aging with intellectual disability and affected by dementia face a number of challenges with respect to living arrangements, diagnostics, post-diagnostics supports, health care, and protection and advocacy. This session touches on these challenges and offers summative ideas and recommendations for best practices.
Moderator: Kathy Service
Speakers: Dr. Seth Keller, Leslie Udell & Dr. Matthew Janicki

2:45 PM – 3:45 PM
BREAKOUT SESSION 2 (Select one on the registration form)

B1 – Lasting Impressions: Patients with an Intellectual and Developmental Disability in a Primary Care Practice
A discussion of the challenges, strategies and creative problem solving in caring for people with intellectual and developmental disabilities in primary care through the perspective of a family physician, neurologist and family quality of life through the lifespan. The Developmental Disability Primary Care Project, an education and advocacy program in Ontario will be highlighted.
Moderator: Dr. Jessie Sanders
Speakers: Dr. Bill Sullivan, Dr. Roy Brown & Dr. Michael Sowell

B2 – Advocacy to Embrace Complexity
Individuals with IDD are often very complex in their presentations. These individuals as well experience their health care needs being unmet due to the complexities. This occurs through the lifespan. The panelists for this session will share their knowledge and experience as it relates to pediatrics, adults and a behavioural optometrist.
Moderator: Dr. Benjamin Margolis
Speakers: Dr. Miya Asato, Dr. Susan Abend & Dr. Su Danberg

B3 – Motor dysfunction and Spasticity: The Importance of Providing Care Throughout the Lifetime
Motor dysfunction including spasticity are very common physical challenges faced by many individuals with cerebral palsy and other types of intellectual and developmental disabilities. These difficulties often begin in childhood and persist throughout one's lifespan. The importance of continued vigilance to the changes that may occur when someone ages will be discussed as well as to what forms of therapy and care should be considered that will include the importance of targeting quality of life measures and the persons activity of daily living.
Moderator: Sandy Stemp
Speakers: Dr. Bhooma Aravamuthan & Angie Gonzales

3:50 PM – 4:50 PM
PLENARY SESSION PANEL:
Critical Issues in Aging and Intellectual Disability
Aging affects adults with intellectual disability mostly in the same way as it does in other adults. However, there are some dissimilarities and particular challenges. The panelists discuss some areas of particular concern and proffer suggestions for actions that can be undertaken to attend to the differences and ensure appropriate health management and quality of life in older age.
Moderator: Kathy Service
Speakers: Dr. Seth Keller, Dr. Matthew Janicki, Dr. Ben Margolis & Claire Staniforth

2:30 PM – 2:45 PM
Afternoon Break

4:50 PM – 5:00 PM
Closing Remarks
Faculty:

Susan L. Abend MD, FACP
Founder and Chief Executive Officer of The Right Care Now Project, Inc., a non-profit organization that develops strategies and technologies to improve health quality and safety for individuals with developmental and intellectual disabilities.

Dr. Danielle Andrade, MD, MSc, FRCPC
Medical Director, Epilepsy Program; Director, Epilepsy Genetics Program; Director, Transition Epilepsy Program, University Health Network, Toronto

Dr. Bhooma Aravamuthan, MD, DPhil
Assistant Professor, Neurology, Division of Child Neurology/Movement Disorders, Washington University School of Medicine in St. Louis

Dr. Dara Abells, MD CCFP MScCH
Family physician at Forest Hill Family Health Centre in Toronto, Ont, and the Integrated Services for Autism and Neurodevelopmental Disorders, and Lecturer in the Department of Family and Community Medicine at the University of Toronto.

Dr. Miya Asato, MD
Program Director, Neurodevelopmental Disabilities Residency Program, UPMC Children’s Hospital of Pittsburgh, Associate Director, Child Neurology Residency Program, UPMC Children’s Hospital of Pittsburgh, Professor, Pediatrics and Psychiatry, University of Pittsburgh School of Medicine

Dr. Christian Brandt, MD
Dr. Christian Brandt, MD, is a board-certified neurologist and epileptologist. He is Head of Department of General Epileptology at Bethel Epilepsy Centre in Bielefeld, Germany.

Dr. Roy Brown
Professor Emeritus, University of Calgary, Canada, and Emeritus Professor Flinders University, Australia. Currently Adjunct Professor, University of Victoria, BC, Canada.

Dr. Susan Danberg O.D., F.C.O.V.D.
Behavioral Optometrist in private practice and specializes in Visual Therapy and Rehab. She recently retired as a Global Clinical Advisor Special Health Program and was the Co-founder of Special Olympics Lions Clubs International Opening Eyes Program.

Angie Gonzales, RN, MN
Advanced Practice Nurse, in the Health Care Facilitator role for the Community Networks of Specialized Care Toronto Region at Surrey Place with Masters of Nursing Degree in Community Health at the University of Toronto. Angie is also part of ECHO Mental Health virtual training, and Griffin Centre Dual Diagnosis Certificate program.

Megan Henze, OT
Megan Henze is an occupational therapist with experience working with young people with disabilities as they transition into adulthood. In her current role at Surrey Place she is the clinical lead for a newly established Transitional Aged Youth clinic created in partnership with St. Michael’s Hospital (Toronto).

Dr. Matthew Janicki, Ph.D.
Matthew P. Janicki, Ph.D. is the co-chair of the US National Task Group on Intellectual Disabilities and Dementia Practices, as well as a research associate professor in the Department of Disability and Human Development at the University of Illinois at Chicago.

Dr. Seth Keller, MD
Co-Chair, National Task Group on Intellectual Disabilities and Dementia Practices; Chair, Special Interest Group Adult IDD, American Academy of Neurology; Past President, American Academy of Developmental Medicine and Dentistry
Faculty:

**Benjamin Margolis, MD**
Neurologist and psychiatrist providing neurobehavioral care to adults with developmental disabilities at Access: Supports for Living in Orange County, NY. He is board certified in both neurology and psychiatry, having completed the combined residency program in neurology and psychiatry at Brown University in Providence, RI.

**Dr. Shirley McMillan, RN, PhD**
Clinical Nurse Specialist in the Adult Program at Surrey Place Toronto

**Dr. Rick Rader, MD**
Medical Futurist and Director of Health Care, Orange Grove Center, Tennessee; Editor-in-Chief of Exceptional Parent Magazine

**Dr. Jessi Solomon Sanders, MD**
Jessi is a sixth year Neurodevelopmental Disabilities resident at Boston Children’s Hospital. Jessi’s career goals focus on caring for patients with special needs of all ages and improving healthcare systems to better meet the needs of aging individuals with intellectual and developmental disabilities (IDD).

**Kathy Service**
Health Care Consultant, Educator, and Advocate; Steering Committee Member of the National Task Group on Dementia and Intellectual Disabilities

**Dr. Michael Sowell, MD, FAHS**
Professor of Neurology, Associate in Pediatrics and Director of the University of Louisville Comprehensive Headache Program. Board-certified in Neurology with special qualification in child neurology and UCNS Headache Medicine Board-certified. He is a founding member of the section on Adults with Intellectual and Developmental Disabilities (IDD) of the American Academy of Neurology.

**Claire Staniforth, M.Ed.**
Claire Staniforth has more than 20 years’ experience working with people with IDD. Her most recent passion has been pursuing studies in Geriatrics and Palliative Care so that we can expand our clinical services for people with IDD who are ageing in Toronto. She is a provincial trainer for the NTG-Canadian consortium.

**Sandy Stemp**
Chief Operations Officer of Reena, a developmental services agency in Toronto and York region. A nurse by training with an interest and advocating for health care and IDD for over 30 years.

**Brandie Stevenson, M.A., C. Psych Associate**
Graduated with Masters of Forensic Psychology; Applied Forensic Services in 2008 and has worked in the field of clinical and forensic psychology since 1997 and is a registered member of the College of Psychologists. Brandie has been working as a private practitioner providing assessment and treatment for youth and adults with risky behaviours as well as those who have been victims of abuse. She is also co-owner of Safe Management Group’s Residential Treatment Services for individuals with high risk complex behavioural needs.

**Dr. Steven Sulkes**
Dr. Sulkes has served on the Board of the Association for University Centers on Disability, and the American Academy of Developmental Medicine and Dentistry, where he currently is President. His research and advocacy passions merge around improving health care delivery for people with intellectual and developmental disabilities.
Faculty:

Dr. Bill Sullivan, MD CCFP(COE) FCFP PhD
Associate Professor, Department of Family and Community Medicine, University of Toronto, Staff Physician, Medical Services, Surrey Place Centre and Family Practice Unit, St Michael’s Hospital, Director of the Developmental Disabilities Primary Care Program at Surrey Place Centre

Dr. Anupam Thakur,
Dr. Anupam Thakur is a psychiatrist in the Adult Neurodevelopmental Service at Centre for Addiction and Mental Health, Toronto and Surrey Place, Toronto. He is an Assistant Professor in Department of Psychiatry at University of Toronto (UoT).

Leslie Udell
Continuing Education instructor with Red River College, in the Therapeutic Recreation for Older Adults program and Teacher, Intro to Gerontology, Cognitive Impairments and Grief, Loss and Palliative Care. Leslie is a member of the NTG-Canadian Consortium and a Master Trainer for the NTG Canada-Dementia Capable Support of Adults with Intellectual Disabilities and Dementia course.

Questions?
Please direct any questions regarding registration for this workshop to:
Cliff Walsh Reena Learning & Development Registrar,
Email: cwalsh@reena.org | Phone: (905) 889-2690 x 2048

Special Photo Exhibit Installation...
...and meet the founder!

Rick Guidotti, an award winning photographer, worked in NYC, Milan, Paris and London for a variety of high profile clients including Yves St Laurent, Revlon and L’Oreal. His work has been published in newspapers, magazines and journals as diverse as GQ, People, the American Journal of Medical Genetics, The Lancet, Spirituality and Health, the Washington Post, Atlantic Monthly and LIFE Magazine. Rick founded POSITIVE EXPOSURE after a chance encounter in 1997 with a young lady living with albinism at a bus stop in New York City. As an artist, Rick was taken by her extraordinary beauty. In a quest for a better understanding of albinism, Rick sought out medical textbooks, where he was affronted by the dehumanizing images depicting disease, lacking all humanity. It was this experience which forced Rick to turn his lens from the more traditional ideas of beauty, to the beauty and richness of human diversity. Rick has since spent more than twenty years collaborating internationally with advocacy organizations/NGOs, medical schools, universities and other educational institutions to effect a sea-change in societal attitudes towards individuals living with genetic, physical, behavioral or intellectual difference.

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