

September 8-10, 2009
Kingston, Canada

I.C.I.D.

International Collaboration to
Improve the Health of
Individuals with Intellectual
Disabilities



IASSID HEALTH ISSUES SPECIAL INTEREST RESEARCH GROUP
2009 ROUNDTABLE

Invitation



International Association
for the Scientific Study
of Intellectual Disabilities

Queen's University and the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID) invite you to attend the 2009 IASSID Health Issues Special Interest Research Group Roundtable, entitled **International Collaboration to Improve the Health of Individuals with Intellectual Disabilities (I.C.I.D.)**.

Roundtable Objectives

This Roundtable will foster collaboration in the conduct of research and knowledge translation/mobilization around the world. The premise of the Roundtable is that we have much to learn from each other through collaborative and comparative endeavours. We can advance knowledge and knowledge transfer by joining forces when we design and conduct our research and when we seek to influence policy and practice.

Roundtable Details

The Roundtable will consist of five [workshops](#) in the following research priority areas:

- Epilepsy
- Obesity, nutrition, and lifestyle
- Sensory impairments
- Health promotion
- Healthcare delivery

These topics will be discussed, with the goal of generating international collaboration and opportunities to apply knowledge. Workshop leaders represent a wide variety of backgrounds and include researchers from Australia, the Netherlands, the United Kingdom, and the United States.

Who should attend?

Registration is open to all IASSID Health Issues SIRG members, to local policymakers and researchers, and to students. It is expected that 100 participants will attend. Space is limited, so [register](#) today to secure a spot in your preferred workshop.

CONTACT INFORMATION:

Hélène Ouellette-Kuntz
c/o SEO CURA in ID
191 Portsmouth Avenue
Kingston, ON, K7M 8A6
CANADA



Phone: 613-548-4417, ext. 1198
Fax: 613-548-8135
Email: oulette@queensu.ca

Roundtable Planning Committee

Hélène Ouellette-Kuntz (Chair), Epidemiologist, Queen's University (Kingston, Canada)
Deborah Elliott, Psychiatrist, Queen's University (Kingston, Canada)
Marijke Meijer, Physician for People with ID, Ipse de Bruggen (Maastricht, the Netherlands)
Diane Morin, Psychologist, Université du Québec à Montréal (Montréal, Canada)
David O'Hara, Social Worker and Chief Operating Officer of the Westchester Institute for Human Development (Valhalla, U.S.A.)



Mike Kerr is a clinical professor of psychological medicine at the University of Cardiff in Wales.

Jonathan Perry is Senior Officer at the Welsh Centre for Learning Disabilities at Cardiff University in Wales.

Jacqueline Small is a paediatrician in developmental disability at the Children's Hospital at Westmead in Australia.

Louise Baur is a professor of paediatrics and child health at the University of Sydney and is Director of Weight Management Services at the Children's Hospital at Westmead in Australia.

Eric Emerson is a professor of disability and health research in the School of Health & Medicine at Lancaster University in the United Kingdom.

Keynote speaker

Margaret Harrison (RN PhD) is an academic nurse at Queen's University in Kingston, Ontario, Canada. She is a founding member of ADAPTE, an international collaboration to promote the adaptation of existing guidelines for local use, and has been actively engaged in implementation science and research.

Keynote Address

Margaret Harrison (co-author of *Lost in Translation: Time for a Map?* and Director of the Queen's University [Joanna Briggs Collaboration](#)) will orient the Roundtable participants to the Canadian Institutes of Health Research's Integrated Knowledge Translation approach and a Knowledge to Action framework. Knowledge translation describes the movement of research among researchers, policymakers, and service providers for the purpose of improving the health of the population, developing more effective services and products, and strengthening the healthcare system.

Workshops

Workshop A: Epilepsy

The Identification and Reduction of Disability in Adults Who Have Epilepsy and Intellectual Disability

Lead: Mike Kerr with Jonathan Perry

This workshop will focus on exploring how to identify needs in individuals with epilepsy and ID. In addition to gaining an understanding of the disability caused by epilepsy in a person with an ID, this workshop aims to design a draft screening tool to identify treatment gaps. Participants will develop an action plan for rolling out a pilot project of this tool in individual countries. This workshop is intended to be educational to participants and to establish the groundwork for future research collaboration.

Workshop B: Obesity, Nutrition, and Lifestyle

Obesity in Children and Adults with Intellectual Disability

Lead: Jacqueline Small with Louise Baur & Eric Emerson

The goal of this workshop is to share information on the measurement, definition, and determinants of overweight and obesity in individuals with ID in an effort to undertake international comparison, especially population-based prevalence. Workshop participants will discuss existing and proposed interventions for weight management in individuals with ID in the context of current policies related to healthy living, including nutrition and physical activity, in each country. Outcomes of workshop deliberations will be sent to key organizations in an effort to develop links with networks of obesity researchers, practitioners, and policy-makers.

Background materials Prior to the Roundtable, background documents for each workshop topic will be posted on the Roundtable website. Posting the documents in advance will allow the workshop leaders to solicit comments or reactions from invitees regarding the comprehensiveness of the materials and ensure that invitees are adequately prepared for the work to be undertaken at the Roundtable. Once your registration form and fee have been received, you will be sent the link to the Roundtable website and the pass code to access the documents.



Heleen Evenhuis is a physician in intellectual disability at Erasmus University in the Netherlands.

Renée Proulx is a psychologist practicing in Québec, Canada.

Bob Davis is a general practitioner and an associate professor at Monash University in Australia.

David O'Hara is a social worker and the Chief Operating Officer of the Westchester Institute for Human Development in the United States.

Henny van Schrojenstein Lantman de Valk is a physician in intellectual disability at Maastricht University in the Netherlands.

Marijke Meijer is a physician in intellectual disability at Ipse de Bruggen (a local service provider) in the Netherlands.

Paula Jean Manners is a trainee clinical psychologist at the Centre for Applied Social & Psychological Development at Canterbury Christ Church University in the United Kingdom.

Jim Blair is a senior lecturer in learning disabilities at Kingston University in the United Kingdom.

Workshop C: Sensory Impairments

Visual Impairment and Blindness in People with Intellectual Disabilities: Improvement of Identification, Diagnosis, and Treatment Around the World

Lead: Heleen Evenhuis

The objective of this workshop is to formulate a model for identifying and treating visual impairments and blindness in children and adults with ID which is applicable in different healthcare systems. Workshop participants will identify organizational barriers to implementing such a model and will identify conditions for successful implementation. The workshop will result in preparations for small-scale improvement projects and training of service provider staff in project management.

Workshop D: Health Promotion

Adapting Health Promotion Materials and Approaches for Individuals with Intellectual Disabilities

Lead: Renée Proulx with Bob Davis & David O'Hara

The goal of this workshop is to facilitate the design of an international research protocol related to understanding how best to enhance access to health promotion for people with ID. Workshop participants will identify key health promotion priorities for people with an ID, review information on health promotion programs and materials for this group, and explore options for refining, disseminating, and evaluating these materials collaboratively.

Workshop E: Healthcare Delivery

Healthcare Management for Individuals with Intellectual Disabilities: Policy and Practice

Lead: Henny van Schrojenstein Lantman de Valk with Marijke Meijer, Paula Jean Manners, & Jim Blair

The purpose of this workshop is to establish international research cooperation in refining and implementing evidence-based health management programs for persons with ID. The workshop will focus on a discussion of the state of the science on evidence-based policies and practices in health screening, specialized consultative, and comprehensive health care service models. Participants will engage in comparative policy and practice analysis and leave the workshop with a better understanding of the potential for knowledge translation and mobilization activities in many countries.

Outcomes of the Roundtable Each workshop will result in a draft plan for further international work, including identification of potential sources of funding. Working groups will be established for preparing international research proposals on the topics. In addition, a report of the Roundtable will be submitted to the key sponsors and to the *Journal of Policy and Practice in Intellectual Disabilities* for publication.



The 2009 Roundtable will take place in the beautiful city of Kingston, Ontario, Canada. Located at the confluence of the St. Lawrence River, the Rideau Canal Waterway, and Lake Ontario, Kingston boasts a wealth of historic landmarks, including Fort Henry, a UNESCO World Heritage site. Kingston is also known for its waterfront location, historic museums, and fine dining.

(See Tourism Kingston at <http://tourism.kingstoncanada.com/en/>)

Roundtable Location

The Roundtable will take place at the Donald Gordon Conference Centre, just minutes away from the Queen's University campus and downtown Kingston (421 Union Street). If you require overnight accommodation, please check the appropriate option on the [attached form](#). You will receive an email verifying your Roundtable registration (and accommodation) upon receipt of your payment. If you have any questions, please email Aileen Diment at dimenta@queensu.ca.



Roundtable Agenda

Our Roundtable offers a full agenda of collaborative workshops and plenary discussions. Special guests include Margaret Harrison from the Queen's University Joanna Briggs Collaboration. In addition, expert workshop leaders will help to make this conference well worth your time.

Monday, September 7th, 2009

Evening arrival and check-in at the [Donald Gordon Conference Centre](#). Pick up workshop materials.

Tuesday, September 8th, 2009 (Day 1)

Day 1 begins with a welcome from guest speaker Margaret Harrison, followed by introduction to workshop topics by our workshop leaders. After lunch, participants will break out into workshop groups to begin discussion of background materials relevant to their workshop research area.

Wednesday, September 9th, 2009 (Day2)

Day 2 will begin with plenary roundtable discussion and group feedback regarding ideas generated from Day 1's separate workshop discussions. The afternoon will be spent developing collaborative research ideas and will finish with a delicious banquet at Kingston's own 19th Century British Military Fortress, Fort Henry.

Thursday, September 10th, 2009 (Day3)

Day 3 will also begin with a plenary roundtable discussion of ideas generated from workshop collaborations. Research protocol ideas will be presented to all invitees in order to gather feedback. Workshop groups will develop task lists for ongoing collaboration. The final luncheon will involve an address from the Planning Committee regarding follow-up activities.

To Register

Registration is first come, first served. To register, please complete the [attached form](#). Registration forms must be received before April 30, 2009, in order to receive early bird rates. Please note that overseas participants may apply for travel bursaries up to \$500 CAD. To be considered, registrants must include a letter indicating their need and the benefits of their participation in the Roundtable. Students may apply for both travel bursaries and registration fee waivers. To be considered, students must include a letter indicating their need and the benefits of their participation in the Roundtable.



International Collaboration to Improve the Health of Individuals with Intellectual Disabilities

Registration Form

All invitees must use this form. All registrations are handled on a **first come first served** basis (Maximum 100 participants).

Print out and fax or email a completed and signed copy of this form to:

Hélène Ouellette-Kuntz, c/o SEO CURA in ID, 191 Portsmouth Avenue, Kingston, Ontario, K7M 8A6, Canada; FAX: 613-548-8135.

EARLY BIRD DEADLINE: April 30, 2009

Name: _____ Institution: _____

Researcher Student Policymaker Service provider Other (_____)

Address: _____

City: _____ State/Province: _____

Zip/Postal code: _____ Country: _____

Phone (including country code): _____ Fax (including country code): _____

Email address: _____

Workshop (please indicate preference from 1 to 5, with 1 being most preferred workshop)

_____ Workshop A _____ Workshop B _____ Workshop C _____ Workshop D _____ Workshop E

Registration fee

Early Registration (before April 30)

- IASSID member with accommodation at the Donald Gordon Conference Centre* \$700 CAD
- IASSID member without accommodation \$375 CAD
- Non-IASSID member with accommodation at the Donald Gordon Conference Centre* \$825 CAD
- Non-IASSID member without accommodation \$500 CAD

Late Registration (after April 30)

- IASSID member with accommodation at the Donald Gordon Conference Centre* \$750 CAD
- IASSID member without accommodation \$425 CAD
- Non-IASSID member with accommodation at the Donald Gordon Conference Centre* \$875 CAD
- Non-IASSID member without accommodation \$550 CAD

Travel Bursary for Overseas Participants: (Check if applied and attach letter)**

Travel Bursary for Student: (Check if applied and attach letter)**

Registration Waiver for Student: (Check if applied and attach letter)**

*Includes overnight accommodation on September 7, 8, and 9; daily (September 8-10) breakfast, lunch, and coffee breaks; reception on September 8; and banquet on September 9. **There are only 50 rooms available at the Donald Gordon Centre for registrants. Confirmation of accommodation will be emailed to you upon receipt of payment.**

**Registrants who apply for bursaries and waivers must first pay full amount as indicated by the above registration rates. Notice of bursary or waiver status will be sent to registrants after the early bird registration deadline.

Payment Method (please check one)

Cheque (payable to Queen's University) MasterCard Visa American Express

Credit card number

_____/_____
Expiry date Total Amount (CAD)

Cardholder's signature (please sign for validation)

Name on Card