



International Association
for the Scientific Study
of Intellectual Disabilities

Newsletter of the IASSID Special Interest Research Group on Health Issues

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Presidents Report

Over the last few weeks we have had Henny Lantman visiting our centre. Henny's visit reminds me of the importance of our relationship through the SIRG. We have so many common goals and share a passion for our patients with intellectual disability. Many of the issues we face are much the same. In particular the challenge of engaging with the generic health system, the particular diagnostic and management difficulties of our population and challenge of advocating for the health issues of this population with governments and our medical colleagues. It also helps to work through strategies together. Henny and I have taken the opportunity to reflect on the future direction of the SIRG.

I attended the IASSID council as the Health SIRGH representative in Singapore. IASSID as an organisation has undergone a change in outlook over the last 8 years. Under David Felce's leadership and more recently Glynis Murphy IASSID is now a financially viable organisation with genuine international agenda. The South African Conference ended up making a profit in the end so this position looks set to continue. IASSID has asked for an independent review of the academies with a view to have a more integrated approach that may well include the SIRGs. IASSID faces a challenge of representing a broad range of professional and social interests in intellectual disability. In the past members of SIRGs were asked to pay a premium for activities in those SIRGs, now the cost of this is covered through funding proportional to the expressed interest of the membership. This expression of interest is communicated when paying IASSID subscription fees generating a data base which the treasurer uses to distribute funds. Unfortunately it would appear this data base needs to be upgraded. Linked to this is a need to redevelop the website and to consider the development of a secretariat.

Plans for Kingston are well in train and from my perspective this will have a significant impact on the way we approach health issues. We need to consider 2010 where we plan to join with the Ageing SIRG in Prato Tuscany with a theme of healthy ageing prior to the IASSID Europe conference in Rome. We will also need to consider the venue for 2011.

Bob Davis

Mission

The mission of the Special interest Research Group on Health is to promote physical health of people with an intellectual disability. This is done by formulating priorities for health care, research and training and by sharing ideas and results. The SIRG organizes annual roundtables in varying countries around specific themes.

History of roundtables

Leiden, the Netherlands (1998)
Manchester, England (1999)
Seattle, US (2000) IASSID World Congress
Gothenburg, Sweden (2001)
Dublin, Ireland (2002)
Westchester, NY, US(2003)
Montpellier, France (2004) IASSID World Congress
Melbourne, Victoria, AU,(2005)
Combined Roundtable of the Health Issues and Mental Health SIRGs of IASSID.
Maastricht, Netherlands (2006)
European IASSID Congress
Prato, Italy (2007)
Cape Town , RSA, (2008) IASSID World Congress

Other upcoming events

SIRGAID Roundtable 2009
SIRGAID Roundtable in Edinburgh, Scotland on 23 - 25 September 2009.

<http://www.crf.ac.uk/events/iasid.htm>

International Congress of Best Practice in Intellectual Disability Medicine. Bristol UK
13- 14 May 2010

www.bridge2010.org

7th European Congress of the European Association of Mental Health in Intellectual Disability (EAMHID) "Promoting mental health for people with intellectual disability".
3/4/5 September 2009

Amsterdam, Holland

<http://www.amsterdamcongress2009.org/>

3rd IASSID-Europe Congress
October 20-22, 2010
Rome, Italy

www.iasid.org

Roundtable 2009 Kingston, Canada

The 2009 IASSID Health Issues Special Interest Research Group Roundtable will be held in Kingston, Ontario, Canada from September 8 to 10. Since our last meeting in Prato, Italy, a Planning Committee including myself, David O'Hara, Marijke Meijer, Diane Morin and Deborah Elliott have been preparing this event including securing funding. In addition to the funds provided by the SIRG to start planning the Roundtable, financial support has to date been received from the Canadian Institutes of Health Research, the US Center for Disease Control and Prevention, Queen's University, the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities, the Association of University Centers on Disabilities, the Ontario Community Networks of Specialized Care – East Region, the AAIDD-Quebec chapter, and St-Amant Research Center.

The theme of the Roundtable is International Collaboration to Improve the Health of Individuals with Intellectual Disabilities (I.C.I.D.). Participants will join one of five concurrent workshops in the following research priority areas:

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

These topics will be discussed, with the goal of generating international research collaboration and opportunities to apply knowledge. The workshops are being organized by a number of SIRG members including Mike Kerr, Jonathan Perry, Jacqueline Small, Eric Emerson, Heleen Evenhuis, Henny Lantman, Marijke Meijer, Paula Jean Manners, Jim Blair, Renée Proulx, David O'Hara and Bob Davis. Non-ID researchers experts in the priority areas will also be contributing to the workshops.

For more information and to register, go to <http://www.iasid.org/pdf/health.pdf> or <http://seocura.org/> or contact me at helene.kuntz@queensu.ca.

Looking forward to welcoming many of you to beautiful Kingston!

Hélène Ouellette-Kuntz,

Chair of the Roundtable Planning Committee

Report from down under: the first half of my stay.

Just a brief note on my experiences so far down under .

My sabbatical leave brought me to Melbourne, where Bob Davis and his colleagues are excellent hosts. It is another world here, especially when coming from a hot summer in the Netherlands and arriving in a rainy winter climate here. Short days, early darkness. But fantastic people everywhere.

At CDDHV, I sat in at clinics with several of the physicians, saw mainly patients with severe challenging behaviour (nowadays called behaviour of concern here), the coping of dedicated families and staff, the problems of untrained staff and how to manage that all as a good doctor. There are a lot of similarities between what is happening here and what I see in my country.

I met several of the PhD students, working on issues such as determinants of challenging behaviour, behavioural characteristics in Down syndrome, communication with people with severe and profound multiple disabilities etc. In general, there is a lot of research going on here. The evidence base is being shaped.

Fortunately, this week, the 4th years' undergraduate medical students had a half day on intellectual disability in their general practice module. They do have quite intensive teaching on ID here, mainly in year 1 and year 4. With beautiful teaching materials, including videos. This morning there was a lecture, and after the lecture the students were split up in groups of 6-8 in which they had to meet people with intellectual disabilities. After getting to know each other, they got fact sheets from the teacher, and had to explain to the tutoring person with ID about health problems such as dandruff, gastroenteritis, diabetes, asthma and more. That was hard, to explain all the stuff they just had learned in complex language to reduce to the essentials and explain to the persons with ID. They all enjoyed it. I saw the evaluation forms afterwards with excited and positive remarks from the students. The tutors with ID are prepared and trained for this role, they are paid for doing this and receive a realistic salary for doing so.

I visited Sydney, invited by Seeta Durvasula, I met various people at RRCS, North Shore and Concord Hospital. We had a symposium there on updates in ID with a large attendance from various disciplines. Next week I will be off to Brisbane for a few days, to meet Nick Lennox and his people at QCIDD.

I feel that we all should create more of these opportunities to visit each others' working places. It is very inspiring and brings you new ideas to further the work.

To be continued.

I do look forward to meeting many of you in Kingston in September.

Henny Lantman

Contributions to the next newsletter,
to be published in fall 2009:

Please send to:

marijke.meijer@hag.unimaas.nl

This newsletter is a medium
to share ideas, to report on
activities publications and
other important matters
related to health issues of
people with intellectual
disabilities.

Pomona project

People with intellectual disabilities make up about 1% of the population of Europe. As trends toward community life advance, they have become more visible and more likely to access generic health systems. Yet evidence suggests that there are striking disparities between the health of this group and that of the general population. Increased longevity means that adults in this group expect to live longer lives and thus to encounter age-related risks for various health conditions. Evidence suggests, too, that information about the health of persons in this segment of the population is not routinely surveyed in European health information systems, further impeding reliable, comparable data.

The *Pomona II* project, 'Health Indicators for People with Intellectual Disability: Using an Indicator Set' was a public health project funded by the European Commission from May 2005-April 2008. The Project co-ordinator was Patricia Noonan Walsh, NDA Professor of Disability Studies and the Project Manager was Dr Christine Linehan, UCD, Dublin.

A set of 18 health indicators for people with intellectual disabilities that had previously been developed (*Pomona I*, 2002-2004) was operationalized in a survey instrument. This was translated into thirteen languages and field-tested. Health data were collected on behalf of more than 1200 participants within the fourteen participating European countries (Walsh 2008).

More information, including the *Final Report*, is available on the website:

www.pomonaproject.org

The Pomona project team consisted of:

Ireland: Professor Patricia Noonan Walsh (Principal Investigator), University College Dublin

Austria: Prof Dr Germain Weber, University Of Vienna

Belgium: Prof Dr. Geert van Hove, Universiteit Gent

Finland: Dr. Tuomo Maatta, Social Welfare/Service Centre of Kuusankoski, The Joint Municipal Authority For Specialised Health Care And Social Welfare In Kainuu

France: Dr. Bernard Azéma, C.R.E.A.I. Languedoc Roussillon Formerly Professor Charles Aussilloux, Service Medicine Psychologique Enfants Adolescents PEYRE

Germany : Prof.dr.Meindert Haveman, University Dortmund

Italy: Dr. Serafino Buono, Irccs Associazione Oasi Maria Ss.

Lithuania: Dr. Arunas Germanavicius, Vilnius University

The Netherlands: Dr HMJ van Schroyen Lantman-de Valk, Care and Public Health Research Institute

Norway: Dr. Jan Tossebro, Norwegian University Of Science And Technology

Romania: Dr. Alexandra Carmen Căra, Sc Medfam Apolo Srl

Slovenia: Dr. Daša Moravec Berger, Institute of Public Health of the Republic of Slovenia

Spain: Prof Luis Salvador, Asociación Española Para El Estudio Científico Del Retraso Mental (AEECRM)

United Kingdom: Prof Mike Kerr, Cardiff University

Patricia Walsh

on behalf of the *Pomona* Group (2008). Applying an Indicator Set to Survey the Health of People With Intellectual Disabilities in Europe. *Journal of Policy and Practice in Intellectual Disabilities* 5, 211-213.

Recently published literature from Health SIRG members:

Drum, C., G. Krahn, and H. Bersani. Disability and Public Health. Washington, D.C.: American Public Health Association and American Association of Intellectual and Developmental Disabilities (2009). Available at www.aphabookstore.org

Kerr M, Scheepers M, Arvio M, Beavis J, Brandt C, Brown S, et al. Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *J Intellect Disabil Res.* 2009 Jun 12.

Lifshitz H, Merrick J, Morad M. Health status and ADL functioning of older persons with intellectual disability: community residence versus residential care centers. *Research in developmental disabilities.* 2008 Jul-Aug;29(4):301-15.

Strydom. Report on the state of Science on Dementia in People with Intellectual disabilities. IASSID special interest group on Ageing an Intellectual disabilities. 2009. [http://www.iassid.org/pdf/dementia_iassid_report_fin\[1\].pdf](http://www.iassid.org/pdf/dementia_iassid_report_fin[1].pdf)

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Willis, D. S., Satgé, D. & Sullivan, S. G. (2008). Breast cancer surveillance in women with intellectual disabilities. *International Journal of Human Development*, 7(4), 407-413.

Willis, D. S., Kennedy, C.M. & Kilbride, L. (2008). Breast cancer screening in women with learning disabilities: current knowledge and considerations. *British Journal of Learning Disabilities*, 36 (3), 171–184.