



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

It is now less than 4 months to the next Round Table in Prato. This year we have joined with the Ageing SIRG and are running a joint Roundtable on October 17th and October 18th immediately prior to the Rome IASSID Europe Conference. The Venue is the same as that for the 2007 Roundtable a picturesque and historic city in the midst of Tuscany just a 2 hour train journey from Rome and 15 minutes from Florence. You can access the brochure at the IASSID website (www.iassid.org) immediately below the registration details for Europe or click on the attachment to this newsletter. The theme for this year's conference is "Active Ageing for People with Intellectual Disability". We have brought together people from the health and social aspect of ageing with Heleen Evenhuis and her team making a substantial contribution. Time is running out so please hurry and register. We have included a poster session so we can share information on our various activities.

Over the coming year our secretary Henny van Schrojenstein Lantman-de Valk will be installed as a Professor at *st Radboud UMCN* (University Medical Centre Nijmegen). This has been a well earned appointment and symbolises the leading role taken by our Dutch colleagues in the health aspects of intellectual disability. I am looking forward to celebrating this great occasion with her and our Dutch colleagues in Nijmegen prior to the Roundtable in Prato.

To be continued on page 2

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.

Presidents report part II

Originally the Health SIRG had planned for the 2011 Round table to be in South America. The original plan was dependent on IASSID plans for a regional conference in Brazil but it appeared that this will not eventuate. The Roundtable in Kingston provided a number of opportunities for both David O'Hara and myself to link up with medical colleagues in the US. There appears to be resurgence in interest in developing international links and the executive committee feels that it would be a great opportunity to build on this. We have agreed to work on developing a program in the US and have asked David O'Hara to continue his discussions with some of his compatriots and to bring together a program for us to consider.

Bob Davis, Chairperson IASSID Health SIRG

Upcoming events

IASSID SIRG Health Issues Roundtable

October 17-18 , 2010

Prato, Italy

3rd IASSID-Europe Congress

October 20-22, 2010

Rome, Italy

www.iassid.org

Preliminary announcements:

IASSID SIRG Health Issues Roundtable

May 23-25, 2011

Washington DC, USA.

IASSID regional conference

South America

2+3 September 2011

Sao Paolo, Brasil

Festschrift for Emeritus Professor Trevor R Parmenter

What is intelligence? What is intellectual disability?

Is Intellectual Disability Intellectual? The interactive cognitive, social & emotional dimensions of intelligence.

Keynote address: Professor Roy Brown

Saturday, 14th August 2010

Kolling Building, Royal North Shore Hospital,
Sydney, Australia

<http://www.cds.med.usyd.edu.au>

NEWS 2010

2009 was a good year for JIDR with a further increase in our impact factor to 1.85 which is an upward trend and the highest for the mainstream journals in our field. In addition, the number of downloads continue to increase and are now approximately 250,000 over a year. We have continued to publish 12 editions a year, two of which last year were Mental Health editions (edited by Anna Cooper), another included the abstracts for the Society for the Study of Behavioural Phenotypes (SSBP) meeting held in Cambridge in October (edited by Chris Oliver), and the final edition for the year 2009 included a special section devoted to the topic of *Resilience*. This special section was edited by Malin Olsson, Jan Blacher and Eric Emerson.

For 2010 and beyond we have three special editions in preparation. The first on 'Working memory and executive functioning in people with intellectual disabilities' edited by Cesare Cornoldi, Claudia Maehler and Lucy Henry was published over two editions as we had many good papers submitted. Future special editions include 'Family quality of life' edited by Ralph Kober and Mian Wang; and 'Challenges of residential and community care' edited by Trevor Parmenter and Roy Brown. Other possibilities for special editions are also being explored. In addition we published a special peer-reviewed supplement, funded from a conference grant, the papers for which were based on presentations given at an invited 'Counterpoint' conference initiated and hosted by Professor Jennifer Clegg from the University of Nottingham, UK.

Our publishing strategy continues to be to attract and to publish papers of a high academic standard that are reporting new data which advances knowledge in our field. We also aim, through the publication of annotations, to provide authoritative reviews and through our hypothesis section to provide space for new ideas and innovative thinking.. We will also publish the occasional position paper or 'research to practice' paper.

In the longer term the aim is to ensure that JIDR becomes an increasingly well recognised and highly respected academic journal that clinicians and academics will submit to as a first choice in the knowledge that their paper will be widely read, well cited, and inform practice. For this to be the case we need your support. I would encourage all of you to sign up for e-mail content alerts (this can be done through the JIDR web-site) and to support the Journal as much as possible through submissions, citations of papers published in JIDR, and through downloads. In achieving this aim we particularly value are links to international bodies such as IASSID and to the health SIRG.

Tony Holland

Editor in Chief JIDR

Preliminary announcement

Roundtable 2011 Washington Dc, US

David O' Hara recently presented in the steering committee the plans for the IASSID Health SIRG meeting in 2011. This will be a joint meeting with AUCD (American Association of University Centers on Disabilities), AADMD (American Academy of Developmental Medicine and Dentistry) and DDNA (Developmental Disabilities Nurses Association). Co sponsor will also be the CDC (the Centers for Disease Control and Prevention) who would bring several other US government agencies to the meeting.

The first focus is on Health Surveillance: this meeting would be the third time CDC has sponsored a meeting on this topic and they now have a strong international and US level of interest and participation in this issue. For this next meeting the focus would be on the issues of operationally defining intellectual disabilities for surveillance purposes and conducting a review of available sources of health data for people with ID. If you are interested in reading the results of the work of the first two meetings a report is available at

<http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/Meeting-Summary-5-2010.pdf>

(also see spin-off Kingston later in this newsletter.

The second focus would be on the need for, and models of, specialized health provider (primarily medicine, dentistry and nursing) training for the delivery of appropriate health care to individuals with intellectual disabilities. This collaborative meeting would provide an opportunity to look at models of specialized training that exist outside the US and see what kind of a consensus statement might be possible from an exploration and analysis of existing training models as well as an analysis of why there is a need for such specialized training.

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
Kingston, Canada (2009)

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.

Specialist Public Health Observatory for Intellectual Disability established in England

In response to concerns about the health inequalities faced by people with intellectual and developmental disabilities, the English government have announced the development of a specialist Public Health Observatory (PHO) to improve the availability and use of information on the health and well-being of people with intellectual disabilities. The specialist PHO will be hosted by the North East PHO (part of the network of regional generic PHOs) and Co-Directed by Professor Eric Emerson (Lancaster University) and Professor Gyles Glover (Durham University). The work of the PHO will cover such issues as developing robust national and local estimates of prevalence and need, investigating the effectiveness of annual health checks for people with intellectual disabilities, improving the identification of people with intellectual disabilities in health information systems and mapping the adjustments made within primary care services in response to the specific needs of people with intellectual disabilities.

Research Priorities for 'Better Health, Better Lives'

IASSID have been asked by the World Health Organization Europe to draft a paper on research priorities to accompany the proposed *European Declaration on Children and Young People with Intellectual Disabilities and their Families (Better Health, Better Lives)*. For each of the 10 priority areas we have very briefly summarised the state of existing evidence that would support action in relation to the area and identified three priorities for further research. It is expected that the Declaration will be signed and launched in November.

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Spin-off from Roundtable 2009 Kingston, Canada

The last Roundtable in Kingston, Canada in September 2009 seems to have an impressive spin-off: An article from Helene Ouellette and her team, with contributions of lots of participants is accepted in JIPPD, to be published later this year: "*Using a Knowledge Translation Lens to Develop International Collaborations to Improve the Health of Individuals with Intellectual Disabilities*" Renee Proulx and Loise Potvin went to Geneva to The 20th IUHPE World Conferences on Health Promotion following their Kingston work. A manuscript on Health promotion, based on the activities in the Kingston workshop is in progress.

A paper on health care organisations by Henny van Schrojenstein Lantman et al. is also nearly submittable.

The CDC held a meeting on the last day of the Kinston meeting, which resulted in a "white paper" that can be found on http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/209537-A_IDmeeting%20short%20version12-14-09.pdf. This gets a follow up in May 2011 in Washington.

Henny Van Schrojenstein Lantman-de Valk will be installed as professor in intellectual disability medicine on the 14th of October 2010 at St Radboud University Medical Centre in Nijmegen, the Netherlands . The title of her oration is: “Normal and accessible, on our way to adequate health care for people with intellectual disabilities in the community”.

News from the steering committee

Mark Scheepers, who has been the treasurer of the Health SIRG for several years has given over his post to David O’ Hara. The board thanks Mark gratefully for all his work in the last years.

The next AGM is planned during the Prato meeting in October .



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**Contributions to the next newsletter,
to be published in spring 2011
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