



International Association  
for the Scientific Study  
of Intellectual Disabilities

## Newsletter of the IASSID Special Interest Research Group on Health Issues

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## Chairmans Report Health Issues SIRG June 2011

The Health Issues SIRG has continued to engage its members with a full range of activities over the last year. Two Health Issues SIRGs have been held since the last AGM of IASSID. The executive committee meets regularly by Skype organized through Prof Henny Lantman's office and continues to communicate with its membership via newsletter.

### Joint Ageing & Health Issues Round Table 2010

This Roundtable was held at the Monash University Campus in Prato, Italy prior to the Rome IASSID Europe conference. Forty two delegates enjoyed a stimulating conference with a theme of Active Ageing that covered the social and health aspects of ageing. The organizing committee consisted of Prof Chris Bigby of La Trobe University and Assoc. Prof Bob Davis and Dr Jenny Torr of Monash University. The Roundtable was run in 4 half day sessions commencing with didactic presentations and various themes followed by discussion in break out groups. Prof Bigby and Dr Torr provided a broad view of the current status of the social and health of ageing. Prof Heleen Evenhuis and a team of her PhD students reported on their progress at looking at indicators for health problems in ageing People with ID. On the second day Professor Prof Mary McCarron presented on best practice models in Dementia Care and Dr Stuart Todd on End of Life Care. This was followed by Sharon Blandford providing The Service Provider Perspective and Prof Tamar Heller presenting on Knowledge Exchange.

### Membership

At the middle of 2010 the health SIRG currently had around 140 members of IASSID who have indicated an interest in the SIRG. I encourage members to continue to indicate their interest in the field and support IASSID as the world's peak body in research for people with intellectual disability

### 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.

## Health Frontier for Intellectual Disability 2011

This year's meeting organized through David O'Hara has been a joint meeting of the Health SIRG with AUCD (American Association of University Centers on Disabilities), AADMD (American Academy of Developmental Medicine and Dentistry) and DDNA (Developmental Disabilities Nurses Association). The meeting has provided an opportunity to interact with our American colleagues and to engage those involved in health surveillance from our various constituencies in discussions around health outcomes for people with intellectual disability. We extend our thanks to the co sponsor the CDC (the Centers for Disease Control and Prevention) and the other US government agencies attending the meeting. More details about this inspiring conference can be found on page III of this newsletter.

### Other Activities

The 2012 Roundtable will be within the program of the Halifax IASSID conference and the steering committee has indicated a preference to have a joint roundtable or seminar with the Policy and Practice SIRG. At this stage initial plans for the 2013 are for it to be held in Nijmegen, the Netherlands in September or October . The SIRG continues to circulate a newsletter edited by Dr Marijke Meijer

## Bob Davis, Chairperson IASSID Health SIRG



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## Upcoming events

### **IASSID world congress**

July 9 - July 14, 2012  
Halifax, Nova Scotia, CA

### **Future Directions for Ageing Well: A Roadmap for Ageing in Persons with Intellectual Disability**

September 7, 8, 2011, Dublin, Ireland

### **Challenging Behavior & Mental Health SIRG 2011 Round Table**

September 4-5, 2011, Manchester, UK

### **2011 Down Syndrome Round Table and AGM**

Sunday, 11th September, 2011 Portsmouth, UK

Also see: [www.iassid.org](http://www.iassid.org)

## Health Frontiers for Intellectual Disabilities

From May 23 to 26, 2011, the Health SIRG was a co-sponsor of a conference – “Health Frontiers for Intellectual Disabilities: Improving Surveillance, Professional Education, Services and Research” held in Washington, USA. Other sponsors included the U.S Administration on Developmental Disabilities, the Centers for Disease Control and Prevention, the National Institute on Disability Research and Rehabilitation, the Association of University Centers on Disability, the North Carolina Developmental Disabilities Planning Council, and the Wal-Mart Foundation - quite an unprecedented mix of support.

The conference addressed three key themes: the need for better health surveillance of people with intellectual disabilities; the need for specialized health professional training; and, the state of the science on lifespan health and function of adults with intellectual and developmental disabilities – translating research into practice. All the presentations from this conference can be found on the AUCD website at [http://www.aucd.org/template/event.cfm?event\\_id=2474&id=16](http://www.aucd.org/template/event.cfm?event_id=2474&id=16)

These themes reflected a continuity of engagement of the Health SIRG with issues identified in a 2002 report – “Closing the Gap” issued by the U.S. Surgeon General which explored the persistence of critical health disparities for people with intellectual disabilities. The Health SIRG has been a co-sponsor of two previous meetings called to address issues raised in this report. One in New York in 2003 issued a report – “An Agenda for Change” – based on the work of 5 expert panels convened at the meeting. A second meeting in Kingston, Ontario in 2009 led to various summary documents, again from the work of expert panels convened for the conference as well as the article “Using a knowledge translation lens to develop international collaborations to improve the health of individuals with intellectual disabilities.” These prior meetings were held with significant support from the first the US and then the Canadian and US governments.

Over 120 participants from 10 countries participated the Health Frontiers meeting and for the first time there was significant government representation from 4 other countries. This led to some interesting policy discussions as well as ideas for future international collaboration. With the quadrennial IASSID conference planned for Halifax, Nova Scotia, in July 2012, the opportunity for continued cross-country engagement with the health issues of individuals with intellectual disabilities is very strong.

## 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)  
Prato, Italy (2010)  
Bethesda, US (2011)

**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. Contributions to the next newsletter, to be published in december 2011, please send to the editor Marijke Meijer: [m.meijer@elg.umcn.nl](mailto:m.meijer@elg.umcn.nl)**



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## American effort to create national plan on dementia and ID

A national task group was recently formed in the United States to help develop a national strategy on addressing the growing challenges that dementia poses for people with intellectual disabilities and their families and providers. Stimulating this formation was the recently enacted National Alzheimer's Project Act (NAPA) which directs the federal government to develop a coherent and coordinated national strategy on dealing with Alzheimer's disease in the United States.

To complement this federal initiative and to address the myriad requests for more specific information and practice models for providing quality care for people with intellectual disabilities affected by dementia, the American Association on Intellectual and Developmental Disabilities (AAIDD), the American Academy of Developmental Medicine and Dentistry (AADMD), along with the Rehabilitation Research and Training Center on Aging and Developmental Disabilities-Lifespan Health and Function at the University of Illinois at Chicago, created the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). It is the intent of the National Task Group to feed into the NAPA effort and ensure that the concerns and needs of people with intellectual disabilities and their families, when affected by dementia, are considered as part of this national strategy.

The overall goal of the NTG is to review and update the technological and clinical practices used by agencies in delivering supports and services to adults with ID affected the various dementias and produce a document which will

- (1) suggest a workable screening instrument that will help substantiate suspicions of dementia-related decline
- (2) produce a new set of practice guidelines for post-determination health care and supports, and
- (3) examine and recommend models of community-based support and long term care of persons with ID affected by dementia.

The National Task Group convened in St. Paul, Minnesota, in June 2011, as part of the annual conference of the AAIDD. The NTG's all-day meeting lead to the production of draft document summarizing its work and addressing the three areas noted above. A draft of the overall National Task Group report is being circulated for broader input and comments and a final report, with recommendations, is targeted to be released in late 2011.

Information on the NTG and its draft report can be accessed at [www.aadmd.org/ntg](http://www.aadmd.org/ntg). The co-chairs of the NTG are Dr. Seth Keller, the president of the AADMD, and Dr. Matthew Janicki, of the University of Illinois at Chicago. They can be contacted at [sethkeller@aol.com](mailto:sethkeller@aol.com) and [mjanicki@uic.edu](mailto:mjanicki@uic.edu).

## Halifax IASSID World conference 2011

The Health SIRG has the intention to organize symposia about :

1. Health professional training
2. Physical causes of challenging behaviour
3. Psychotropic medication
4. Preventive health care
5. Research and policy
6. Health surveillance

Any other suggestions are welcome, please address to the secretary

## **Towards a gendered model of health: Why this is important for understanding the health of men with intellectual disabilities**

The evidence across most developed countries is that men have shorter life expectancy than women across most age cohorts before the age of 65. This has in part been explained by the way men adopt health-damaging behaviour, such as fast car driving, substance and alcohol abuse. Furthermore, men generally seek out health professional advice less than women and have a set of specific health conditions that are both biological and attributed to the way men behave in relation to their health. Men's tendency to accumulate fat around the waist in the middle years of life, for example, is a risk factor for other diseases and contributes to metabolic syndrome, such as high blood pressure, insulin resistance and cholesterol abnormalities all of which are associated with cardiovascular disease (CVD) and late onset diabetes.

It is now widely established that a series of specific health conditions occur more frequently within the intellectually disabled population when compared with the non-disabled population, such as epilepsy, CHD, Mental health, sensory problems and poor dental health. Men are not a homogeneous group and the term *masculinities* is used within social science literature to reflect the way men behave differently in relation to their health. Whilst the concept of masculinities has emerged within social sciences is useful when analysing men's health, there is little evidence about how different marginalised groups of men understand masculinity and its impact on their health.

This piece articulates that a more gendered approach to studies in the field of intellectual disability is required. Surveys that specifically examine this population need to drill down to implications of gender that applies equally to men and women for example X linked conditions, osteoporosis. Few studies have:

1. Explored how men with intellectual disability understand their own masculinity and health
2. Examined their involvement in the wider men's health movement
3. Identified whether this group of men adopt the same health damaging behaviours as non disabled men, or other marginalised groups of men.

This lack of research or awareness places men with intellectual disability at a double disadvantage, given their disability and male identity and puts this specific population at further risk of deteriorating health, undetected health conditions and marginalisation.

For further information:

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### **Recent Publications**

Janet Robertson ,Hazel Roberts, Eric Emerson  
Health Checks for People with Learning Disabilities: A Systematic Review of Evidence.  
Centre for Disability Research, School of Health & Medicine, Lancaster University  
Supported by the department of Health, UK.

## E learning health promotion

Laurence Taggart was awarded a grant for £96,000 in 2010 from the Research & Development Office, Belfast, Northern Ireland: this is an 18-month project. The aim of the project is to 'Promote the health of young people with intellectual and other developmental disabilities (aged 5-19 years) through a blended e-learning module designed for teachers, classroom support assistants, health staff, youth staff and parents'. The e-learning module with a supported CD-rom that includes resources will be accredited by the University of Ulster and should be available from Sept 2011 for participants to enroll. Further information will be made available along with module details early 2012.

### Recent publications:

Taggart, L. (2009): 'How are you today? Mental health, what does it mean to me? An information booklet for young people with learning disabilities. University of Ulster & Compass Advocacy Network.

Taggart, L. (2010): 'Me and my boobs? Breast cancer what does it mean to me? An information booklet for women with learning disabilities. University of Ulster & Compass Advocacy Network

Electronic copies of the booklets are available. Please email:

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## My Health Passport

Dr. Elizabeth Perkins, Research Assistant Professor and Health Coordinator at the Florida Center for Inclusive Communities, a University Center of Excellence in Developmental Disabilities at the University of South Florida, Tampa, USA, has developed My Health Passport - a document to be completed by an individual (and/or their caregiver), that describes important aspects about the person with IDD's special health care needs. My Health Passport was designed to be shared with Health Care Professional's in both clinics and hospital settings, particularly for inpatient treatment when the individual will interact with new HCP's - especially those who are not familiar in providing care to individuals with intellectual/developmental disabilities. My Health Passport was designed to provide a quick and ready reference, in an eye-catching format. English and Spanish versions are available for free download directly from the following website.

<http://flfcic.fmhi.usf.edu/projects/health.htm>

The passports are available as a typeable pdf - so the relevant information can be typed in before printing, or they can be printed then completed.

See also:

<http://cfs.cbcs.usf.edu/news-events/detail.cfm?id=685>

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### Recent publication

Perkins, E. A., & Moran, J. A. (2010). Aging adults with intellectual disabilities. *Journal of the American Medical Association*, 304(1), 91-92.