

IASSID NEWSLETTER

February, 2010



International Association
for the Scientific Study
of Intellectual Disabilities

Greetings from the President

Submitted by:

Glynis Murphy, IASSID President

IASSID members have been busy since the last newsletter, as you will see.

2nd Asia-Pacific Conference 2009

There was an excellent Asia-Pacific conference in Singapore in June 2009, masterminded by Keith McVilly and his colleagues (Balbir Singh, Kristin Kumar, Libby Cohen and Kenneth Poon). Over 400 delegates attended from over 36 countries. Roy Brown and his colleagues in IASSID Academy organised a series of successful workshops. Two ministers from the Singapore Government came to parts of the conference and I thought they were both very impressive – well-informed and extremely committed to improvements for people with intellectual disabilities. An Asia Pacific Roundtable at the conference began to plan further work in the Region and has some exciting new plans that will be brought to Council in Rome 2010.

The third Asia Pacific conference will be held in Tokyo in July 2013, so we look forward to IASSID's first visit to Japan.

3rd IASSID-Europe Conference 2010

The 3rd IASSID-Europe conference planning is well advanced. The conference will be held from October 20th-22nd in Rome. The preliminary programme and list of plenary speakers are already up on the website www.iassid.org to get all the details. The conference planning committee includes Giorgio Albertini and Fabrizio Fea in Rome, as well as Matt Janicki, David Felce and Patricia Walsh, so we are very grateful for all their hard work. Abstracts will be published in a special issue of the Journal of Applied Research in

Intellectual Disabilities.

World Congress Halifax 2012

As IASSID members are probably aware, the next World Congress will be held in Halifax, Canada, from 9th-14th July 2012. David Felce, Hélène Ouellette Kuntz, Vianne Timmons and myself recently met up in Halifax to start the serious planning. The conference venue and hotels are all of excellent quality and the people of Halifax were very welcoming. When we visited the weather was cold and wet but it will be different in the summer! The city and locality offer numerous attractions including the nearby ocean, beaches and the fascinating Pier 21 where millions of immigrants entered Canada

Web-site

Neil Ross has valiantly kept our website www.iassid.org going for many years, spending a vast amount of his time on it. However, we feel it needs a bit of up-dating now, especially in relation to the way that the system operates for paying members dues and the way SIRG members are logged. Neil Ross has been working with Phil Davidson and Hélène Ouellette Kuntz to re-design the website, with some technical advice. The new website went live in January; more functionalities will be added in the coming year.

2010

Meanwhile, we wish all IASSID members a happy and prosperous new year and we hope they enjoy the latest news from IASSID. Don't forget to renew your membership and we will see you all in Rome!



Glynis Murphy

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Rome 2010 Conference!

Submitted by:
Matthew Janicki

Plenary Speakers

Dr. Tony Holland - *University of Cambridge, UK* - Biological vulnerabilities and environmental risks: the integration of different perspectives when determining need.

Dr. W. Ted Brown - *New York State Institute for Basic Research in Developmental Disabilities, USA* - Recent progress in understanding the genetics of intellectual disabilities.

Prof. Toyojiro Matsuishi - *Kurume University, Japan* - Innovations in child health and intellectual disabilities.

Dr. Manfred Pretis - *SINN, Austria* - Meeting the needs of parents with early childhood intervention.

Dr. Luis Salvador - Carulla - *Psicosoc Scientific Association, Spain* - Functioning in persons with ID and mental health problems.

Dr. Maurizio Elia - *Oasi Institute for Research on Mental Retardation and Brain Aging, Italy* - Epilepsy and intellectual disabilities: a multidisciplinary approach.

Prof. Anna Firkowska-Mankiewicz - *The Institute of Philosophy and Sociology, Poland* - Adult careers: Does childhood IQ predict outcome?

Prof. Richard Hastings - *Bangor University, UK* - Families as systems: Recent research strategies.

Dr. Claudio Babiloni - *University of Foggia, Italy* - EEG and intellectual disabilities.

Dr. Alberto Pieranlini - *IRCCS San Raffaele Pisana, Italy* - Neuroimaging in intellectual disabilities.

Prof. Miguel-Angel Verdugo-Alonso - *University of Salamanca, Spain* - Measuring and using quality of life data.

Prof. Bea Maes - *Catholic University of Leuven, Belgium* - Key issues in supporting persons with profound intellectual and multiple disabilities.

The 3rd conference of IASSID-Europe will be held in Rome, Italy from **October 20 to 23, 2010**. The conference planning committee is busy organizing the event and has issued the call for papers (see Call for Papers, below).

Preceding the conference will be two days of intensive workshops being organized by the IASSID Academy on Education, Teaching and Research (on October 18 & 19). Some workshops have already been commissioned, and others are pending. Anyone interested in submitting a proposal for an Academy-sponsored workshop should get in touch with Prof. Roy Brown [roybrown@telus.net], the head of the Academy. Also, immediately following the conference will be a one-day special seminar for families and agency personnel sponsored by the San Raffaele IRCCS in Rome.

Preliminary Program

The conference preliminary program is available via the IASSID website and involves four plenary presentations each day and numerous symposia and free paper sessions, as well as posters, offered daily.

Conference Venues

The conference main venue is the Grand Hotel Palazzo Carpegna [www.grandhotelpalazzocarpegna.it] and the secondary

venue is the Torre Rossa Park Hotel [www.torrossaparkhotel.it], both located in Rome. Conference symposia and paper sessions will be held in both hotels, although all of the Plenaries will be held in the Grand Hotel Palazzo Carpegna. Arrangements have been made for special conference lodging rates at both of these hotels. Delegates will be able to make their own hotel reservations either at these two hotels or any other hotel in Rome. Hotel registration information for the Grand Hotel Palazzo Carpegna and the Torre Rossa Park Hotel is available at www.iassid.org. Both hotels are easily accessed via the Cornelia Metro stop on the Red Line. Special arrangements will be in place to aid registrants with mobility difficulties to move between the two hotels.

Registration

The IASSID is offering a sizable discount on the conference rate for IASSID members and an "early bird" registration rate will be available up until March 31st. Members are encouraged to register early as the overall registration number for the conference will be limited by the hotels' amenities.

For more information on the conference, check the IASSID website or contact the Conference Secretariat at [iassid_rome-congress@alice.it].

Call for Papers

All interested members who may be submitting a paper or poster proposal should note the deadline for the submission of abstracts: March 15, 2010.

For this conference, IASSID has contracted with an abstract management firm and abstracts will only be accepted via its on-line process. To access the abstract submission information, check at www.iassid.org.

All abstracts will appear in a special issue of the *Journal of Applied Research in Intellectual Disabilities*.

Submitted by:
Hélène Ouellette-Kuntz

September 8,9 and 10, Queen's University in Kingston, Canada, was host to the Health Issues Special Interest Research Group.

The event brought together researchers, clinicians, policy-makers, self-advocates (persons with intellectual disabilities) and students from as far away as Japan, New Zealand and Australia as well as several European countries, the United States and five Canadian provinces.

The goal of the meeting was to foster international collaboration to improve the health of individuals with intellectual disabilities. Workshops were organized around four themes: epilepsy, obesity, health promotion and healthcare delivery. A keynote address on the Canadian Institute of Health Research's (CIHR) Knowledge To Action Framework by Professor Margaret Harrison, School of Nursing, Queen's University, inspired the workshop groups to consider not only how to conduct research in collaboration but also how to collaborate in knowledge transfer.

The participants have developed workplans for ongoing collaboration, including the development of inventories of health promotion materials and programs adapted to the needs of persons with intellectual disabilities, and testing a tool to ensure those who have seizure disorders obtain optimal care.

The Roundtable was made possible thanks to a CIHR meeting grant as well as support from the Public Health Agency of Canada, the US Center for Disease Control and Prevention, the US-based Association of University Centers on Disability, the Quebec Chapter of the American Association on Intellectual and Developmental Disabilities, the St-Amant Research Center (Manitoba), the Community Network of Specialized Care – Eastern Region (Ontario), the Canadian Association for Research and Education in Intellectual Disabilities, the Centre for Addiction and Mental Health (Ontario), and Queen's University (Office of Research Services, Faculty

of Health Sciences and the Developmental Disabilities Program).

The Chair of the Planning Committee for the Roundtable, Hélène Ouellette-Kuntz (Associate Professor, Dept. of Community Health & Epidemiology, Queen's University), also helped organized a special working meeting of the US Center for Disease Control and Prevention on health surveillance among persons with developmental disabilities immediately following the Roundtable. The group of approximately 24 (mainly Americans) included 4 Canadians: Prof Ouellette-Kuntz and representatives from the Manitoba Center on Health Policy, the Ontario Ministry of Community and Social Services, and the Public Health Agency of Canada. The 24 hour session resulted in a draft document outlining how best to design a system for ongoing, systematic collection, analysis, and interpretation of health-related data to support effective planning, implementation, and evaluation of public health practice to reduce health disparities faced by individuals with intellectual disabilities.

International Collaboration to Improve the Health of Individuals with Intellectual Disabilities continued at Queen's for the next two weeks as the Special Interest Group Chair, Professor Robert Davis from Monash University extended his stay. As a visiting scholar, Dr. Davis gave various lectures and met with students, faculty, clinicians and local service providers.

HEALTH ISSUES SIRG Steering Committee

Chairperson:

Prof. Bob Davis (Australia)

Secretary:

Henny van Schrojenstein Lantman-de Valk (Netherlands)

Members:

Mike Kerr (UK)
Nick Lennox (AU)
David O'Hara (US)
Hélène Ouellette-Kuntz (CA)
Marijke Meijer (NL)
Heleen Evenhuis (NL)
Mark Scheepers (UK)
Monica Björkman (SE)
Leslie Rubin (US)



Back Row: Jonathon Perry, David O'Hara, Mike Kerr, Bob Davis, Jim Blair. **Front Row:** Hélène Ouellette-Kuntz, Marijke Meijer, Henny van Schrojenstein Lantman-de Valk, Jackie Small, Paula Jean Manners, Reneé Proulx

JIDR Update

Submitted by:
Tony Holland, Editor-in-Chief

Our publishing strategy continues primarily 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.

Book reviews are also there to help guide readers of JIDR as to what books they might wish to read – I am grateful to Shoumitro Deb and Kathy Lowe for their work organising these reviews.

We will also publish the occasional position paper or 'research to practice' paper. This section will include position papers produced, for example, by the Special Interest Research Groups (SIRGs) of the International Association for the Scientific Study of Intellectual Disabilities (IASSID), and best practice guidance developed by expert groups.

Our close link to IASSID is very important to the Journal and, through the owners of the Journal (Mencap), IASSID continues to receive financial support for their international meetings.

This brief article is to bring you up-to-date with what has been happening with JIDR and our plans for 2010. This past year has been 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 230,000 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. I am very grateful to the editors of these special editions and to Chris Oliver, Anna Cooper and Jan Blacher in general for the very significant support they give to the Journal and to me personally.

I would also like to acknowledge and thank those of you who have submitted papers to JIDR and have reviewed papers on behalf of JIDR. Throughout 2009 we received papers covering a very broad range of topics of relevance to the field of intellectual disabilities and those of you reviewing papers continue to provide very insightful and valuable comment.

For 2010 and beyond we have three special editions in preparation. These are entitled 'Working memory and executive functioning in people with intellectual disabilities' edited by Cesare Cornoldi, Claudia Maehler and Lucy Henry; '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 – suggestions are always welcome. In addition there will be a special supplement during the year, the papers for which are based on presentations given at an invited 'Counterpoint' conference initiated and hosted by Professor Jennifer Clegg from the University of Nottingham, UK. The cost of this special supplement is funded separately from the regular JIDR budget and covered through the sponsorship provided for the conference. The supplement is being published under the Editorship of Jennifer Clegg with papers being peer reviewed in the normal way. These special supplements were an occasional feature under the editorship of Bill Fraser but this is the first since I have been editor. In this case the supplement brings together some very novel and innovative papers addressing conceptual and service related issues.

In the longer term the aim is to ensure that JIDR becomes an increasingly well recognised and highly respected academic journal that 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.

Finally I would like to thank Sue Hampton-Matthews for her invaluable administrative support and wish you all the best for 2010.

JIDR

Journal of Intellectual Disability Research

Published on behalf of mencap and in association with IASSID

Submitted by:
Christine Bigby

Following on from our successful representation at the IASSID International Congress in Cape Town 2008, the Aging SIRG and its members have contributed to several major achievements over the last year.

We are pleased to report that the two state of science papers on aging in people with intellectual disabilities are now available on the IASSID website. The paper produced by Andre Strydom and colleagues on Dementia and the paper produced by Meindert Haveman and colleagues on Physical Health Risks, encapsulate the best currently available international evidence on the topic areas. These papers were the launch pad for symposia at the Cape Town Congress 2008 and were furthered at our recent Roundtable, held in Edinburgh in September 2009.

Furthermore, the Aging SIRG contributed to several symposia at the Asia-Pacific Congress in 2009. Prof Matt Janicki was a keynote at this conference and there were awareness-raising activities around aging in Japan afterwards. There was also a workshop in India that was well attended.

We are also pleased to announce that a special edition on aging issues, edited by Chris Bigby and Meindert Haveman, to be published in JPPID, is due out in March 2010.

The Aging SIRG's 17th International Roundtable was held in Edinburgh in September 2009. The Roundtable was arranged around a series of discussion sessions that aimed to build on and extend key colloquia from the IASSID World Congress in Cape Town 2008. The intention was to offer opportunities to explore some new issues, update and develop key papers and guidance for the SIRG, specifically in the following areas:

- Families and social relationships
- Physical health risks

- Death and dying
- Syndrome-specific aging
- Aging in Down Syndrome: Morbidity, Mortality and Implications for Service Provision
- Revisiting the Edinburgh Principles (strategies for service provision and design).

Over 40 individuals attended from across the globe and we were fortunate enough to also be in a position to offer six bursaries to support the attendance of new upcoming researchers. A number of the attendees were new to the Aging SIRG. Indeed, our membership has grown from a reported 88 in 2008 to 93 in 2009 (IASSID membership figures).

With regards to our future plans, as a group the Aging SIRG is committed to international knowledge exchange. Ongoing discussions around international evidence repositories that should be supported by the informatics arms of IASSID has energised a number of our members. This has been furthered with discussions with other SIRGs around knowledge exchange sessions that could be offered at the Rome Congress in October 2010. Furthermore, our 18th Roundtable is being planned as a joint venture with the Health SIRG. It will be held in Prato, Italy (2 hours from Rome) on 18- 19 October 2010 just prior to the European IASSID conference in Rome. Finally, we are pleased to announce that the Death & Dying Affinity Group have now formally merged with the Aging SIRG, which will add considerable strength to our group. We invite all members and other interested researchers to submit proposals for symposia on aging issues for the European IASSID conference in Rome and attend our Roundtable just prior in the delightful town of Prato at the Monash University Conference Centre.

IASSID Council

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- Joint VP for Asia/Pacific Region
- SIRG coordination
- By-laws and awards

Robert Davis, Australia

- Joint VP for Asia/Pacific Region
- SIRG coordination
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Jan Blacher, USA

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- Publications

Giorgio Albertini, Italy

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Ivan Brown: QoL

Bob Davis: Health

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Jim Mansell: CP&P

David McConnell: Parenting

Hans Reinders: Ethics

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Gwynnyth Llewellyn: Australia

Liliana Mayo: Peru

Germain Weber: Austria

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Tony Holland: JIDR Editor

Matt Janicki: JPPID Editor

Neil Ross: Web Editor

Asia-Pacific Conference Report

Submitted by:
Keith McVilly

About the Newsletter

Past issues of the IASSID Newsletter are available online:

http://seocura.org/IASSID/Updates_News.html

If you have ideas for future articles or items for the IASSID Newsletter, please contact H el ene Ouellette-Kuntz, IASSID Secretary, at: helene.kuntz@queensu.ca

In June 2009 at Singapore, IASSID hosted its second Asia-Pacific Conference. The theme selected for the conference was "*Creating Possibilities for an Inclusive Society*". The conference was a resounding success. There were nearly 400 delegates in attendance, representing 36 countries (despite the world economic crisis and the international influenza outbreak – which sadly contributed to many last minute cancellations). Together, delegates contributed nearly 200 papers, presented across up to 9 parallel streams each day, and an additional 25 poster presentations.

Across two days of the Singapore conference, we conducted an Asia – Pacific focused *Research to Practice Round Table Symposium*. Delegates contributed to vibrant discussion which will inform IASSID's on-going activities in the Asia-Pacific region. Follow-up work from the Research to Practice symposium will distil a number of project proposals for the region, which we hope IASSID, in partnership with other national and international organisations, will be able to support across the next few years.

Many thanks go to Dr Balbir Singh and Ms Kristin Kumar as Chair and Secretary respectively of the Singapore Local Organising Committee, and the many members of that committee. Particular thanks to Professor Libby Cohen and Dr Kenneth Poon of the Singapore National Institute of Education for chairing the Scientific Programme Committee, and the many IASSID members who contributed to the peer review process. Professor Roy Brown, Chair of the IASSID

Academy, was also integral to the organisation of the conference, especially in organising a rich and diverse curriculum of pre and post-conference workshops. In addition to workshops at Singapore, there were also IASSID Academy workshops in Malaysia and Hong Kong. Mention must also be made of the vital contribution of Professor Lisa Wang, without whose efforts IASSID would not have such an active role in the Asia-Pacific region.

The next Asia-Pacific conference of IASSID will be hosted by the Japanese Association for the Study of Intellectual Disabilities (JASDD), at **Tokyo, 4th to 6th July 2013**. We very much look forward to working with Dr. Hitoshi Hara, President of JASDD, and his many dedicated committee members who have already progressed much of the planning for the conference. Further information is soon to be posted to the IASSID website.

Associate Professor Robert Davis of Monash University, our Co-VP for IASSID in the Asia-Pacific, and I are very much hoping that with the growth of IASSID's engagement with the Asia-Pacific region, many of our SIRGs, traditionally based in Europe and the United States of America, will seek to host events in the Asia-Pacific region, including via the use of on-line technologies. To assist with this, the IASSID Executive is currently up-grading the IASSID website to include web conferencing facilities. The IASSID Academy too will have an important role to play in the dissemination of research findings and their application in policy and practice throughout Asia-Pacific.

Special thanks for their contribution to the Singapore conference go to our Key Note Speakers

Prof. Rune J. Simeonsson, University of North Carolina, USA;

Assoc. Prof. Levan Lim, National Institute of Education, Singapore;

Prof. Shigeru Suemitsu, Kawasaki University of Medical Welfare, Japan;

Prof. Glynis Murphy, University of Kent, UK;

Prof. Matthew Janicki, University of Illinois at Chicago, USA;

Dr. Monica Cuskelly, University of Queensland, Australia;

Dr. Henny van Schrojenstein Lantman-de Valk, Maastricht University, The Netherlands.

An Update from the IASSID Academy on Education, Teaching and Research: It's Been a Good Year!

Submitted by:
Roy I. Brown

Over the past year, the Academy has had the opportunity to organize or support a series of stand-alone workshops and courses in a number of different countries -- as well as take the responsibility for all of the pre-and post-academic workshops held in conjunction with the 2nd IASSID Asia-Pacific Conference held in Singapore in June.

Stand-alone Workshops and Courses

Our stand-alone workshops and courses covered a wide range of topics and were directed toward a range of community stakeholders. For example, these included "*Promoting Social Relationships and Friendship*" in Singapore, and "*Introduction to the Basics of Aging and Intellectual Disabilities*" Visakhapatnam, India under the auspice of Andhra University. Both workshops were highly successful; in fact the workshop in India led to the organization of a local older parents' advocacy association. The Academy also sponsored a complex of multi-day workshops in Malaysia co-sponsored by the Yayasan Sultan Idris Shah Community Based Rehabilitation Centre. Some 100 local workers attended. The experiences with the Academy's Malaysian venture lead to an interesting article written by Dr. Angela Hassiotis which is posted on the Academy's page on the IASSID website. Further, the Academy was instrumental in supporting a series of lectures and consultation sessions around aging and intellectual disabilities in conjunction with the Hong Kong Social Services Council which involved several IASSID members. Some 70 people attended this two-day session. Toward the end of 2009, the Academy helped organize an extensive and collaborative series of workshops that were held in Beijing, China, which drew over 200 participants. At the same venue, there was a consultation session on inclusive practices.

Pre- and Post-IASSID Regional Conference Workshops and Courses

The Academy was responsible for organizing, vetting, and overseeing all of the pre-and post-conference workshops that were offered in conjunction with the 2nd IASSID Asia-Pacific Conference held in Singapore.

These covered topics such as '*numeracy and literacy*', '*issues of puberty and females with disability*', '*assessment of risk and manageability for individuals with intellectual disabilities who offend*', '*individual and family quality of life*', and '*behavioral manifestations in complex developmental disabilities of dual diagnosis and autism*'. The workshops were offered through consultation with a number of local Singaporean associations, including the Social Services Training Institute, the NCSS Academy, the Down's Syndrome Association of Singapore and the Autism Association. Two other workshops on '*language and communication*' were supported by the Academy through the Society for the Physically Disabled. Overall, some 200 persons took advantage of the workshops or courses.

Next Steps

The Academy's planning activities are always carried out in collaborations with local agencies and community organisations – they are the crucial actors in assessing the local needs for translational education. Most of these events also involve small discussion groups to help promote learning and applications to local circumstances. When necessary, translations are arranged and materials are produced in the local language as well as English. In most instances, the audiences include front line practitioners, a range of professionals, parents, local organisers, advocates, and policymakers.

The Academy evaluates all its workshops using both quantitative and qualitative components. All workshops to date have been well received and the evaluations have been positive. Often numerous requests are received asking for further involvement. The Academy is pleased that many SIRG members have been involved with the development and implementation of the workshops and looks forward to more such cooperative endeavours.

The planning for 2010 has already begun and exciting things are in the works. Preliminary planning has taken place for a number of stand-alone workshops, include new ones in Amsterdam, The Netherlands;

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Roy Brown-Chair

Quality of Life Special Interest Research Group (QOL SIRG) Summary for 2009

Submitted by:
Fiona Rillotta

Quality of Life SIRG— Current and impending publications

- Quality of Life and disability book (international),
- Family Quality of Life book (Slovenia),
- a special issue of the JIDR on: Challenges of Residential and Community Care,
- a special issue of the JIDR on: Family Quality of Life.

Members have also published several other papers associated with quality of life during the year in refereed journals, including a special issue of JPPID in March 2009 on Quality of life and its applications.

The Quality of Life Special Interest Research Group (QOL SIRG) is a growing dynamic group of over 130 members. Our executive consists of 10 international colleagues, who come from various backgrounds. In 2009, along with our annual business meeting held in Singapore in conjunction with the IASSID Asia-Pacific Conference, we also ran a special disability meeting to maintain our connection with the International Society for Quality of Life Studies (ISQOLS) at their conference in Florence, Italy in July.

At the IASSID Asia-Pacific Conference we had a 'stream' of Quality of Life symposia moderated by our current co-chair, Ivan Brown and past chair, Roy Brown. These sessions, including presentations associated with the multi-national Family Quality of Life project currently underway in 19 countries, were well attended by researchers, practitioners and families, and they generated many interesting discussions.

Furthermore, the QOL SIRG contributed, along with other SIRG s, to IASSID Academy Workshops in Singapore and Malaysia in 2009. These workshops were extremely well attended and participants expressed

much appreciation. We were also represented in a meeting of Chairpersons from three IASSID SIRGs (QOL, Aging, and Comparative Policy and Practice) to discuss potential collaborations/ joint projects.

We are also developing an electronically accessible list of Quality of Life and Disability products, including recent key publications or instruments produced by our QOL SIRG members. The meeting for disability and quality of life researchers held at the ISQOLS conference and facilitated by the QOL SIRG enabled us to ensure that we have a core group of people who can contribute a "disability stream" of presentations at future ISQOLS conferences. One of the main discussions was associated with siblings of family members with a disability – a relatively new area that requires further research. There was a consensus that it is important to re-visit and focus on this area of research at our 2010 QOL SIRG meeting, inline with our current Family Quality of Life research.

Planning is currently underway for our next meeting in Rome in October 2010 in conjunction with the 3rd IASSID-Europe Conference.

Down syndrome Special Interest research Group Annual Report

Submitted by:
Rhonda Faragher - Secretary/Treasurer, Roy Brown- Chair

This year has been one of progress for the Down SIRG. The Down Affinity group has moved to SIRG status as originally agreed under the IASSID/DSI Agreement, an event much anticipated and appreciated by its members. The membership involves 27 registered colleagues from IASSID and an additional number from Down Syndrome International. Many members belong to both organizations.

Two meetings of the SIRG have been held during the year: one in June in Singapore at the IASSID Asia regional conference where 20 members attended, and a second in August at the DSI International Conference in Dublin where 44 individuals attended.

Items of note are: -

- 1) The setting up of a Scientific Advisory Board within DSI,
- 2) A call for papers for the Down syndrome Quarterly. A pleasing number of responses have now been received, and we anticipate 2 issues during 2010.
- 3) The development of a Wiki (a 2.0 technology that allows members to contribute to a web page that each member is able to input. <http://dsaffinitygroup.wetpaint.com/>)
- 4) An invitation to members to become involved in responding to the

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Australian Inquiry into Immigration treatment of Disability, <http://www.minister.immi.gov.au/media/media-releases/2009/ce09039.htm> an issue which is highly relevant to families with children who have Down syndrome or other intellectual and developmental disabilities. Full details of the minutes from the two meetings and the submission to the meeting in Edinburgh can be obtained from the Secretary, Rhonda Faragher, whose email is: Rhonda.Faragher@acu.edu.au, or on the wiki: <http://dsaffinitygroup.wetpaint.com>

5) The Down Syndrome SIRG, on invitation, forwarded a series of research issues relating to the field of Down syndrome and aging for the October IASSID Aging SIRG meeting in Edinburgh where we were represented by Karen Watchman. Details of the submission can be had from Karen Watchman karenwatchman@hotmail.com who collated the responses from members and represented us in Edinburgh. Members have been encouraged to submit proposals for papers and symposia to the IASSID Conference in Rome. See IASSID website for details)

An Update from the IASSID Academy on Education, Teaching and Research

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Thessalonica, Greece; and Skopje, Macedonia. Others are being considered in Asia and Central America.

As the Academy is responsible for the pre-conference workshop program at the

3rd IASSID Europe Conference this October in Rome, Italy, planning has begun in designing an interesting array of courses, both in Italian and English. The full list of course offerings will soon be posted on the Academy's webpage at www.IASSID.org.

Congratulations to Dr. Henny Van Schroyen-Lantman de Valk, who was appointed professor of medicine for persons with intellectual disabilities at the Faculty of Medical Sciences, Radboud University, Nijmegen, the Netherlands in November, 2009. Henny will direct a new program related to the health Care of persons with ID. We wish her well.

Australasian Society for the Study of Intellectual Disability (ASSID)

Submitted by:
Keith McVilly

At Hobart, Tasmania in November ASSID conducted its 44th annual conference, with the theme "Power and Passion; Progress through Partnership". The conference was convened by Craig Jones and Daryleen Wiggins, with nearly 500 delegates in attendance at the Wrest Point Casino.

Looking Ahead: ASSID invites IASSID SIRGs to submit symposia and special interest stream proposals for ASSID conferences, and is happy to assist in arranging facilities for SIRG meetings to be held in conjunction with ASSID conferences. For those planning ahead for a trip 'down under', the 2010 Australasian conference is to be held at Brisbane, in Queensland – 29th September to 1st October. For full details refer to the ASSID website or contact

Dr. Madonna Tucker:
Madonna.tucker@uq.edu.au.

And for those planning ahead to 2011, the ASSID conference will be at Adelaide in South Australia – contact Richard O'Loughlin: richardoloughlin@bigpond.com. Also, each year ASSID hosts a national conference dedicated to the interests of direct support staff. The Direct Support Worker Conference is hosted by the Victorian regional association of ASSID and is conducted at Melbourne, usually in November. Full details are on the ASSID website.

During the recent Australasian conference at Hobart, the ASSID Board for 2009/10 was elected: President – Mr Richard O'Loughlin (South Australia); Vice President – Dr Angus Buchanan (Western Australia);

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ASSID 44th Annual Conference Keynote Speakers

Dr Gary W LaVigna

Clinical Director of the Institute for Applied Behaviour Analysis in Los Angeles, California
 "Service Quality: How to measure it and how to get it"

Ms Beverley Funnell

Manager, Disability Bureau, Department of Premier and Cabinet, Tasmania
 "Partners in the Dance – But Who's Leading?"

Mr Robert Martin

National Self Advocacy Advisor, IHC National Self Advocacy Team, New Zealand
 "The Boy Who Kicked the Ball on the Roof"

Mr David Wareing

Occupational Therapist and Ethnomethodologist, Tasmania
 "The Moral Order of Supported Care - Who shot the donkey?"

Ms Denise Leembruggen

Immediate Past Vice President of the Association of Children with a Disability, Victoria
 "Community Partnerships That WORK!"

Teresa Iacono

Assoc. Professor, Senior Research Fellow and Deputy Director of the Centre for Developmental Disabilities Health Victoria
 "Partners on the Research Journey – An Ethics Perspective"

Many of the papers from the conference are available on the ASSID website: www.assid.org.au (go to the dedicated "Conference Papers" page).

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Treasurer – Mr Craig Jones (Tasmania); Registrar – Dr Olive Webb (New Zealand); and Secretary – Ms Darryleen Wiggins (Tasmania). Associate Professor Keith McVilly (Victoria) continues as the ASSID representative to IASSID.

Journal of Intellectual and Developmental Disability:

Associate Professor Ian Dempsey of the University of Newcastle, Aus. (Ian.Dempsey@newcastle.edu.au) and Professor Sue Balandin of Molde University, Norway (Susan.Balandin@hiMolde.no) are the current co-editors of ASSID's peer reviewed scientific journal, the *Journal of Intellectual & Developmental Disability* (JIDD). JIDD welcomes submissions from researchers from around the world. JIDD has comprehensive abstract / indexing coverage, including MEDLINE. In addition to research papers, JIDD also publishes Data Briefs, Opinions & Perspectives and Book Reviews. The Book Review Editor is Rachel Mayes of the University of Sydney (R.Mayes@usyd.edu.au). Rachel welcomes submissions of recent academic and practitioner-focused publications for review.

IASSID Members can subscribe to JIDD at a special discounted subscription rate. You can subscribe via the publisher, Informa, by using the link on the IASSID website (on the 'Books / Journals' page).

Awards

Annual JIDD Australasian Research Publication Prize, 2009:

Kate Davis and Susana Gavidia-Payne, RMIT University, Melbourne—*The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities* – JIDD Vol. 34 (2), pp. 153-162.

E - mail: susana.gavidia-payne@rmit.edu.au

Annual JIDD Journal Editor's International Research Publication Prize, 2009: Kathleen Fisher, Michael Green, Frederick Orkin and Vernon Chinchilli Drexel University, Philadelphia & Pennsylvania State

University—*A content analysis from a US state-wide survey of memorable health-care decisions for individuals with intellectual disability* – JIDD Vol. 34 (3), pp. 258-265.

E-mail: kmf43@drexel.edu.

Annual ASSID Research Grant, 2009:

Paul Ramcharan, Christine Bigby, and Patsie Frawley RMIT University, LaTrobe University & LaTrobe University "Developing a Research tool for Inclusive Research around Self Advocacy History" Email: (c.bigby@latrobe.edu.au)

& Julie Wilmoit University of Melbourne "Perceptions and Planning of Individual Planning Documents" (<http://www.ssps.unimelb.edu.au/>).

Intellectual Disability Australasia:

Ms Sue Peden of Western Australia Disability Services Commission (sue.peden@dsc.wa.gov.au) continues as Editor of the ASSID quarterly magazine, *Intellectual Disability Australasia* (IDA). Sue would welcome manuscripts for publication in IDA from service providers overseas, particularly detailing service achievements and examples of good practice. IDA also regularly publishes plain language summaries of research articles. These are co-ordinated by Ms. Sheridan Forster: sheridan.forster@med.monash.edu.au.

A major issue of current concern in Australia and New Zealand is the issue of restrictive practices in disability services (e.g., chemical restraint, physical restraint, seclusion and social restraint such as the use of intimidation and threatening consequences). Australia and New Zealand are now signatories to the United Nations Convention on the Rights of Persons with Disability, and we are undergoing major legislative and policy reforms across our two countries. ASSID has hosted several national forums on this topic and is formulating a position statement. ASSID is eager to work with IASSID on advancing debate and research on these issues, for which purposes it will contribute to the current work of the IASSID Mental Health & Behaviour SIRG.