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## Update on IASSID World Congress 2008

August 25 to 30<sup>th</sup> - Cape Town, South Africa

submitted by :

Glynis Murphy, IASSID President-Elect and David Felce, IASSID President

Planning for the World Congress is advancing apace. David Felce and Glynis Murphy visited the venue in Cape Town (CTICC, the Cape Town International Conference Centre) and met with the conference management centre and the Local Organising Committee at the end of last August. The visit was timed to be on the same dates as the conference will be, so as to check on the weather at that time of year (it was good, mostly sunny).

Posters and postcards advertising the conference have been sent out to IASSID council members (please let [g.h.murphy@kent.ac.uk](mailto:g.h.murphy@kent.ac.uk) know if you would like either of these). A number of journals have also advertised the conference for us and more adverts will be rolling out over the next year.

The themes for the conference will include: ageing and lifespan; biological and biobehavioural issues; challenging behaviour; cognition and communication; education; employment; empowerment, rights and ethics; families and parenting; mental health; physical health; populations, policy and service systems; profound and multiple disability; quality of life. Plenary speakers are being finalised now and will include a mixture of speakers from the African region and from elsewhere.

We hope for the first time at a IASSID World Congress, there will be pre- or post-conference workshops. Roy Brown and colleagues are working on the planning of these.

Finally, you will be interested to know that the IASSID council agreed to support some research into intellectual disabilities in Africa. We hope the results of the research will be

The timetable during the conference will be like that for previous World Congresses, with plenary speakers, parallel sessions for papers, and posters. The first day will start in the late afternoon of the 25<sup>th</sup> August 2008 and will include plenary speakers and an opening reception. Then days 2, 3, 4, 5 will look like this, with 16 parallel sessions and posters:

9:00 - 9:40	<b>Plenary</b>	
9:45 - 10:45	Parallel sessions 1-16	Posters
10:45-11:00	Tea/Coffee	
11:00 - 12:00	Parallel sessions 17-32	Posters
12:00 - 13:00	Parallel sessions 33-48	
13:00 - 14:30	Lunch	
14:30 - 15:15	<b>Plenary</b>	
15:15 - 16:15	Parallel sessions 49-64	Posters
16:15 - 16:30	Tea / Coffee	
16:30 - 17:30	Parallel sessions 65-80	Posters

The final day will include plenary sessions only and will be especially focused on research of relevance to South Africa. It will be open to local people, who may not have been able to attend the rest of the conference, as well as IASSID Congress delegates.

presented at the World Congress. We have so far had 9 applications for research funds from countries as diverse as Nigeria, Rwanda and South Africa. IASSID has agreed to fund 3 projects directly and 3 other projects are recommended for funding. IASSID is approaching other bodies for support for these projects.

#### **IASSID Executive:**

##### President

Prof. David Felce

##### President-Elect

Prof. Glynis Murphy

##### Secretary

Dr. Vianne Timmons

##### Treasurer

Dr. Matthew P. Janicki

##### Past-President

Dr. Neil Ross

##### Vice-President (Program Committee & Liaison with Sub-Committee)

Dr. Patricia Noonan Walsh

##### Vice-President (Membership Committee & SIRG Coordination)

Dr. Henny M.J. Schroyen  
Lantman de Valk

##### Vice-President (Constitutional Affairs)

Mr. Stephen Kealy

##### Vice-President (Publications Committee & SIRG Coordination)

Dr. Anthony Holland

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#### **IASSID Membership**

by M. Janicki

IASSID membership is a valuable asset and many organizations, universities and foundations, as well as individuals around the world belong. In 2007, IASSID membership includes subscriptions to two premier journals in the field of intellectual disabilities, the *Journal of Intellectual Disability Research* (JIDR) and the *Journal of Policy and Practice in Intellectual Disabilities* (JPPID). IASSID membership also entitles members to special rates for IASSID books published by Blackwell Publishing and Roundtree Publishing, as well as to reduced registration fees to IASSID's various 2007 meetings, such as the upcoming IASSID-Sudamerica Congress (September 4-6 in Santiago de Chile, Chile), the Health Issues SIRG Roundtable (May 21-23 in Prato, Italy), the Aging SIRG Roundtable (May 31-June 1 in Oslo, Norway), the Quality of Life SIRG Roundtable, and the Comparative Policy & Practice SIRG (Nov 16-17 in Prague, Czech Republic). This year, IASSID opened up membership in an unlimited number of SIRGs as part of the regular membership. Individual memberships for 2007 are US\$170 with both journals and \$120 without JIDR. Members resident in developing market economy nations are eligible for special rates. Reduced membership rates for pensioners and students are also available.

Continued IASSID membership will also provides advantages with registration for the 2008 IASSID World Congress to be held in Cape Town, South Africa in August 2008. Members can obtain more information on these benefits, and peruse the other membership options on our website ([www.iassid.org](http://www.iassid.org)). Members may also correspond with the IASSID membership office via email at [iassidoffice@aol.com](mailto:iassidoffice@aol.com).

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#### **Agreement of Mutual Understanding Signed**

by R. Brown

An agreement of mutual understanding and support has been signed between the international Association for the Scientific Study of Intellectual Disability and Down Syndrome International (DSI) following input and study by the boards of both associations. The agreement provides for co-operation between the two organizations with the understanding that either organization can raise issues to change or improve the agreement. It is a reciprocal and supportive agreement which allows members of both organizations to share information, to attend their international meetings at member rates, and gives member access to Journals at same member rates. It also provides opportunities, through invitation, for senior representatives or their appointees to attend meetings of each others organization, which will facilitate joint planning around international events such as conferences. IASSID has authorized developing a special interest research group (SIRG) in Down syndrome, which would compliment the SIRGs it already sponsors. It is hoped that

**IASSID COUNCIL**

- Giorgio Albertini
- Monica Björkman
- Jan Blacher
- Philip Davidson
- Robert Davis
- Ilana Duvdevany
- Fabrizio Fea
- Richard Hastings
- Tamar Heller
- Sheila Hollins
- Ulla Jacobson
- George Jessien
- Mike Kerr
- Joel Levy
- Maria del Carmen Malbran
- Keith McVilly
- H el ene Ouellette-Kuntz
- Hans Reinders
- Franck Sturtz
- Shigeru Suemitsu
- Miguel Verdugo
- Carla Vlaskamp
- Lisa Wang

DSI will participate in this, thus furthering scientific development. A meeting to discuss this was held in Vancouver at the DSI conference last August 2006. It is through such developments we anticipate that the study and support for people with Down syndrome and their families will be enhanced. Also, representatives of DSI will participate in the IASSID-Sudamerica conference in Santiago, Chile this September 4-6.

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**Evidence-Based Practice & Policy in Intellectual Disabilities**


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Many countries are increasingly moving towards a model of 'evidence-based' policy and practice for developing supports for people with intellectual disabilities. As a result, there are increasing demands on managers, professionals and advocates to: (1) understand the nature of 'evidence'; (2) critically appraise its value; and (3) contribute to the development of a robust evidence-base that can make a real difference in enhancing the life experiences of children and adults with intellectual disabilities.

In order to better equip managers, professionals and advocate to address these challenges the Institute for Health Research at Lancaster University in the UK has developed a new series of innovative modular on-line distance-based postgraduate programmes of study. The programmes are innovative in cutting across fields of study with a core grounding in the nature of evidence leading to more specialised enquiry in either intellectual disabilities, public health, disability studies or end of life care. They also allow students to exit the programme at various levels (Post-graduate Certificate, Post-graduate Diploma, Masters by Research). Further details are available at: <http://www.lancs.ac.uk/fass/ihr/courses/online/intro.htm>

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**50 YEARS OF THE JOURNAL OF INTELLECTUAL DISABILITY RESEARCH (JIDR)**

*by T. Holland*

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The Journal of Intellectual Disability Research (JIDR) celebrated its 50<sup>th</sup> birthday in 2006 with a party held during the IASSID Europe conference in Maastricht. IASSID and JIDR have a strong and enduring relationship and, as the present Editor, I thought this Newsletter would be an appropriate place for reflecting on this relationship and for saying something about the future of JIDR in the next 50 years!

The links between the JIDR and IASSID take several forms. First, the Journal is available to individual members of IASSID at cost price. Secondly, JIDR publishes the abstracts for the IASSID International Conferences. Thirdly, there has been a strong tradition of the Special Interests Research Groups (SIRGs) initiating and taking an editorial lead in the publication of special editions of the Journal, the most recent of these being on family issues. Finally, with the support of the Journal publishers, Blackwells and the UK Charity, Mencap, (joint owners) free editions of the Journal are sent to various parts of the world where access to publications in the field of intellectual disability are not readily available. From the proceeds of the Journal, Mencap also supports studentships to attend the international meetings. In 2008, and for a further two international conferences, Mencap will also meet the costs of the abstract edition of the Journal. Thus, there is a fruitful and mutually beneficial relationship.

***In 2006, of the major journals in intellectual disabilities, we had the most citations and during that year JIDR articles were downloaded over 144,000 times – a growth of 27% from the previous year***

## Stevens-Shapiro Memorial Fellowship

This Fellowship has been established as a tribute to the memory of Harvey Stevens, co-founder and the first President of IASSMD (now IASSID) and the late Alexander Shapiro, co-founder and second President. The name of the Association recently changed to become the IASSID.

The IASSID Fellowship has been established to encourage research in intellectual disabilities internationally.

These fellowships are open to young researchers under 30 years of age, who are actively involved in the field of intellectual disabilities.

Information on the Fellowships is available from:

Stephen Kealy,  
Moore Abbey,  
Monasterevan,  
Co. Kildare,  
Republic of Ireland.

Tel: + 353 45 525327 / 529455.

Fax: + 353 45 529029.

Email: [Stephen.Kealy@scjms.ie](mailto:Stephen.Kealy@scjms.ie)

The profile of research and of scientific publications in intellectual disability is strong and growing. We are pleased to be part of this and aim to remain as the foremost international Journal publishing research in intellectual disability. There are four specific areas of development that are highlighted in this newsletter. First, we remain committed to publishing a full range of high quality papers from the perspectives of different disciplines, whether theoretical or applied, and both quantitative or qualitative in design. The subject matter for JIDR is deliberately wide as the field of intellectual disability spans very different disciplines that both individually and collaboratively contribute to understanding, to the development of new approaches, and to policy and practice. As much of academic study becomes narrower in its focus, the need to support interdisciplinary research and provide the opportunity to reflect on different perspectives becomes even more important.

Secondly, particularly given our relationship with IASSID, we will continue to promote the journal as truly international, both in terms of the different countries of those who submit papers and the readership. In 2006 we have published papers from 11 countries and our known readership includes subscribers from 27 countries. The availability of subsidised access to JIDR through having individual membership of IASSID and of free editions of JIDR to some centres, together with 'open access' for some papers, are all part of our strategy for expanding our international presence in an area of study that is often of low priority. Through these policies we aim to ensure that those papers published will be read by an international readership. We aim to include high quality research undertaken in different cultures and often under very different social and economic circumstances. In addition, to ensure that research findings are disseminated to a wider audience we have established a JIDR web site where lay summaries of the papers are available ([www.ldrg.org.uk/jidr](http://www.ldrg.org.uk/jidr)).

Thirdly, two years ago we took the decision to expand the number of editions of JIDR from 8 to 12 a year. This was not without its risks. However, our submissions have increased and with these other developments we have more than enough copy of high standard. At the time this increase was driven primarily by the need to ensure that accepted papers were published relatively rapidly. However, we also had longer term considerations, specifically as to how we could best serve those undertaking research and those working in varied settings who wished to keep informed about research findings. The combination of expanding the number of editions and establishing 'on-line early' are two factors that have enabled us to improve our performance. Our aim is to make decisions about papers within three months of submission, and if accepted, to have them on-line or in-print within three months. We acknowledge the pressures that researchers are under in their countries and the need for them to have their work peer-reviewed, and, if accepted, then published and in the public domain, as rapidly as possible.

Fourthly, this increase in the number of editions has also enabled new developments and the continuation and/or expansion of previous ones. We aim to increase the number of invited annotations, including reviews that are both directly related to our field and others that will examine developments elsewhere that may be of relevance to intellectual disabilities. All annotations will be available free as 'open access'. Professor Chris Oliver is taking the lead on this. We also wish to support conceptual developments in the field of intellectual development through the 'Hypothesis' section. The Mental Health special issues have been highly successful and we remain the only journal to devote space specifically to this aspect of intellectual disabilities. These editions will continue and develop under the editorship of Professor Sally-Ann Cooper. We will also continue the yearly special themed editions and in 2007 this will be on Down's syndrome and edited by Professor Jake Burack. In 2006 for the first time we published abstracts for the Society for the Study of Behavioural Phenotypes (SSBP) international meeting in Dublin. We hope that this will be a regular yearly feature and expanded to include original papers and

reviews. Through the efforts of Professor Shoumi Deb and Dr Kathy Lowe the number of our book reviews has increased and they are now a regular feature of the Journal.

To undertake these various tasks we are continuing to develop the Editorial Advisory Board and we are looking for ways to expand the editorial team internationally. We would be pleased to receive suggestions from you as to how JIDR can both better serve those who are doing the research, as well as ensure that research is disseminated effectively. In 2006, of the major journals in intellectual disabilities, we had the most citations and during that year JIDR articles were downloaded over 144,000 times – a growth of 27% from the previous year. To the end of September 2006 we had had a total of over 126,000 papers downloaded. In 2006 we published 157 papers and will continue this level for 2007. We would like your continued support by submitting high quality papers and reading the Journal. We also encourage you to sign up to receive the automatic contents page of JIDR by going to this link:

<http://www.blackwell-synergy.com/action/doUpdateAlertSettings?journalCode=JIR&action=addJournal>



### Journal of Policy and Practice in Intellectual Disabilities

Editor-in-Chief *Matthew P. Janicki, Ph.D.* University of Illinois at Chicago

#### Call for Papers

Members are invited to submit papers and brief reports for consideration of publication in JPPID. Papers should concern research on practice, reviews, or analyses of practice or policies related to intellectual disabilities. Brief reports provide information about particular outcomes of work or policy implementations. Papers and brief reports must be submitted in APA format and are submitted to peer review.

### IASSID Europe Congress, Maastricht by H. Lantman de Valk van Schroden

From 2-5 August 2006, the second IASSID Europe congress took place in Maastricht. The theme for this Congress was: Bridging Research, Policy and Practice.

The congress was attended by 600 participants, 50 of whom were people with intellectual disability.

In total, 415 abstracts were submitted, resulting in 321 presentations within 10 parallel sessions on Thursday, Friday and Saturday morning. There were 85 posters accepted for 3 half-day sessions.

The abstract book was the summer edition of JARID. Separately, there was a programme book and a user-friendly abstract book with 80 abstracts in plain language, both in English and in Dutch.

#### Contents

Symposium themes were: Policy and Organisation; Program Evaluation and Quality of Services; Challenging Behaviour and Mental Health; Education; Families; Parents with ID; Assessment, Public Health and Health Inequalities; Epidemiology & Lifespan; Ethics, Genetics, Legal Offenders & rights; Biological Aspects and Pharmacology, and Empowerment and De-institutionalisation.

Invited symposium planning and abstract selection based on the criterion of scientific quality led to a good level of presentations.

Plenary presentations consisted of scientific presentations and more political ones,

both at the opening and closing ceremony. There were no plenary sessions on Thursday and Friday so as to be able to host more parallel sessions. The establishment of a poster award stimulated submission of posters; the award included free entrance for the Cape Town conference.

### Organisation

The organising Committee (Wil Buntinx, Marian Maaskant and Henny Lantman) was assisted by a Program Committee (Bea Maes, Eric Emerson, Luigi Croce, Kristiina Patja and Leopold Curfs). Prof. Hans Reinders coordinated the participation of people with intellectual disabilities. A user-friendly abstract book was developed. Congress participants were invited to support people with ID in sessions – by explaining scientific language and by assisting their participation in the discussion. People with ID also assisted in handling congress rucksacks at the registration and in catering: there was a training group which was about to start a job in a new café. Such assistance in catering had a sort of spin-off for University of Maastricht staff doing their normal work in that week and using the ordinary catering facilities in the same building.

### Parallel meetings

Several Special Interest Research Groups (SIRG) had their AGM or other meetings during or before the congress. The SIRG on Profound and Multiple Disability had a young researchers meeting. Three ID journals held editorial meetings. The 2006 IASSID Council Meeting took place immediately before the congress.

### Finances

The higher than expected number of participants resulted in a positive balance, which was entirely transferred to IASSID. Sponsorship was obtained from local and national service providers (Koraalgroep, Stichting Pepijn en Paulus, RADAR, Dichterbij, Stichting Philadelphia Zorg), and from Vodafone. Blackwell and Wisepress paid for book and journal exhibitions. The art workshop from RADAR, a local service provider, had an art exhibition and sale in the poster room. The opening reception was hosted and sponsored by the Provincial Government.

### In Summary

A highly successful congress both in exchange of expertise and inclusive participation.

***For those planning ahead for a trip 'down under', the 2007 Australasian conference is to be held at Fremantle, in Western Australia; 5<sup>th</sup> to 8<sup>th</sup> November. The conference theme is "Active Citizenship and Community Engagement".***

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### Australasian Society for the Study of Intellectual Disability (ASSID)

Dr K. McVilly - ASSID Representative to IASSID [keith.mcvilly@rmit.edu.au](mailto:keith.mcvilly@rmit.edu.au)

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ASSID held its 41<sup>st</sup> annual conference at Canberra, Australia's national capital, in September 2006. The theme chosen for the conference was "*Risk and Resilience: hope for the future*", and was convened by Linda Goddard of Charles Sturt University. Key Note Speakers included Mr Robert Martin, a self-advocate from New Zealand, Professor Levan Lim from Singapore, Professor Gwynnyth Llewlyn from Sydney, Professor Tony Shaddock from Canberra, Professor Jeff Sigafos from Hobart, and Assoc. Professor Roger Stancliffe from Sydney. Many of the papers from the conference are available on the ASSID website: [www.assid.org.au](http://www.assid.org.au) (go to the dedicated "Conference Papers" page).

For those planning ahead for a trip 'down under', the 2007 Australasian conference is to be held at Fremantle, in Western Australia; 5<sup>th</sup> to 8<sup>th</sup> November. The

## UPCOMING EVENTS

Please check the website for more details - [www.iassid.org](http://www.iassid.org)

The International Association for the Scientific Study of Intellectual Disability Special Interest Research Group

### Conference on Physical Health "Chronic Disease Management in People with Intellectual Disability"

May 21st to 23d, 2007  
Prato, Italy

### The 16th Annual Roundtable International Association for the Scientific Study of Intellectual Disability

#### Special Interest Research Group on Aging and Intellectual Disability

May 31st-June 1st, 2007  
Oslo, Norway

The Roundtable will be preceded by a Nordic Conference on Aging and Disability on May 29-30, 2007

### Comparative Policy and Practice Special Interest Research Group First Roundtable

16th and 17th November 2007  
Moevenpick Hotel, Prague,  
Czech Republic

### IASSID Sudamerica Conference to be held September 4-6, 2007

The IASSID-Sudamerica planning group has been busy organizing the upcoming second IASSID Sudamerica Conference in Santiago, Chile. The dates and venue are September 4-6, 2007 and the locations is the Law School for the Diego Portales University. Local group chairperson Prof. Soledad Cisternas has organized a comprehensive program within the theme of human rights. IASSID-Sudamerica is collaborating with the Pan American Health Organization (PAHO), and a number of South American universities and organizations to make this a successful event. A number of IASSID members will be key speakers as well be local persons working in the area of intellectual disabilities. Information about attending the conference and submitting a poster abstract can be found on the IASSID website.

conference theme is "Active Citizenship and Community Engagement". The call for papers is now open, and there is an option to submit full papers for peer review purposes. For further details, contact the Convener, Dr Angus Buchanan; [angusb@dsc.wa.gov.au](mailto:angusb@dsc.wa.gov.au). Planning for the 2008 Australasian conference has also commenced. The conference will be conducted at the University of Melbourne, the week of the 24<sup>th</sup> to 28<sup>th</sup> November and will be held in conjunction with the 8<sup>th</sup> Annual Disability Support Worker Conference. There is to be a focus on 'evidence-based practice', and an option for peer reviewed papers will also be available. For more details contact Assoc. Professor Karen Nankervis of RMIT University; [karen.nankervis@rmit.edu.au](mailto:karen.nankervis@rmit.edu.au). The 2009 Australasian Conference will be at Hobart, Tasmania. Further details will be available on the ASSID website: [www.assid.org.au](http://www.assid.org.au)

IASSID Special Interest Research Groups (SIRGs) are most welcome to conduct their meetings and host special interest streams during ASSID conferences. In the past, these have proven a great success for all involved; providing an organised venue for the SIRG meeting and enriching the conference with scholarly papers from around the world. SIRGs are encouraged to contact the conference conveners with proposals for such meetings and special interest streams.

During the recent Australasian conference at Canberra the ASSID Board for 2006/07 was elected: President – Dr Olive Webb (New Zealand); Vice President – Mr Richard O'Loughlin (South Australia); Treasurer – Mr Glen Jose (Victoria); Registrar – Ms Sue Peden (Western Australia); and Secretary Ms Linda Goddard (New South Wales). Dr Keith McVilly (Victoria) continues as the ASSID representative to IASSID.

Associate Professor Roger Stancliffe (e-mail: [rogerst@med.usyd.edu.au](mailto:rogerst@med.usyd.edu.au)) of the University of Sydney continues as Editor 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 Dr Tim Griffin of the University of Western Sydney (e-mail: [T.Griffin@uws.edu.au](mailto:T.Griffin@uws.edu.au)). Dr Griffin would welcome submission of recent academic and practitioner-focused publications for consideration for review. JIDD is now available to IASSID members at a discounted subscription rate. You can subscribe via the publisher, Taylor & Francis, by using the link on the IASSID website (on the 'Books / Journals' page).

Dr Debora Keen (e-mail: [deb.keen@uq.edu.au](mailto:deb.keen@uq.edu.au)) of the University of Queensland continues as Editor of the ASSID quarterly magazine, *Intellectual Disability Australasia* (IDA). Dr Keen would welcome contributions from service providers overseas, particularly detailing service achievements and examples of good practice.

The annual ASSID Journal Editor's Prize for 2006 has been awarded to Lesley Steptoe, William (Bill) Lindsay, Diane Forrest and Mick Power (all from Scotland) for their paper on *Quality Of Life And Relationships In Sex Offenders With Intellectual Disability*, published in JIDD Vol 31, Issue 1 (March 2006), pages 13 - 19.

The annual JIDD Australasian Research Prize has been awarded to Margaret Kyrkou, Michael Harbord, Nicole Kyrkou, Debra Kay and Kingsley Coulthard (all from South Australia) for their paper on *Community Use Of Intranasal Midazolam For Managing Prolonged Seizures*, published in JIDD Vol 31, Issue 3 (September 2006), pages 131-138.

The annual ASSID Research Grant for 2006 has been awarded to Dr Jennifer Stephenson (Macquarie University) and Dr Katrina McFerran (University of

Melbourne) for their project examining the impact of music therapy interventions in special education.

The ASSID Media Award, for outstanding contributions to enhancing the image of people with a disability and raising community awareness and understanding, has been awarded to Ms Margaret Wenham, an investigative Journalist with the The Courier-Mail Newspaper, Brisbane, Queensland. Ms Wenham's body of work over a number of years has brought public attention and political pressure to bear on a range of issues, resulting in positive changes for people with disability.

Two further members of ASSID have been inducted as *Fellow of ASSID*, to recognise their 'exceptional and significant contribution to the field of intellectual disability, with broad impact, sustained over many years'. *Angus Capie* (New Zealand) has held significant positions of leadership as Director of Services for IHC, a national parent-governed service provider and Chief Executive Officer for the Standards and Monitoring Services in New Zealand. Angus Capie has been a champion of legislative reform, service development, including consumer-lead service evaluation, and research into quality of life for people moving from institutional to community living. *Richard Bruggemann* (South Australia) was Chief Executive Officer of the Intellectual Disability Services Council from 1984 to 2006. He developed a co-ordinated state-wide infrastructure to provide services in the community for people with disability. Richard Bruggemann was a strong advocate for deinstitutionalisation of services, including the establishment of community-based services for people formally accommodated in 'secure facilities'.

Website: [www.assid.org.au](http://www.assid.org.au)

Address: PO Box 84 ROSANNA, Victoria, Australia, 3084.

**The IASSID 13th World  
Congress  
will be held on  
25th - 30th August 2008**

**at the  
International Conference  
Centre  
in Cape Town, South  
Africa**



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### **Update from the Secretary**

*by V. Timmons*

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As Secretary of IASSID we are always looking for articles for our newsletters as we feel it is an important that our members are kept well informed on all activities taking place within our organization.

This year we have included the minutes of the last Council meeting as well as reports provided by the SIRG Committees. Due to circumstances beyond my control I was not able to attend the 2006 Council meeting, and Stephen Kealy very graciously filled the role of Acting Secretary. I want to publicly thank him for serving in this capacity.

Feel free to pass along any news items or events that you would like to have published in our next newsletter - we are targeting to publish another in the Fall 2007. I can be reached by email [vtimmons@upei.ca](mailto:vtimmons@upei.ca)

Looking forward to seeing everyone at the May 2007 Council meeting in Paris.

# Minutes - Full Council Meeting in June 2006

**Date and Venue: August 1 and 2, 2006, Maastricht, The Netherlands (August 1: Crowne Plaza Hotel Maastricht; August 2: RADAR)**

Attendance: Giorgio Albertini, Monica Bjorkman, Jan Blacher, Robert Davis, Philip Davidson, Ilana Duvdevany, Fabrizio Fea, David Felce (Chair), Richard Hastings, Tamar Heller, Anthony Holland, Ulla Jacobson, Matthew Janicki, Stephen Kealy, Mike Kerr, Henny van Schroyenstein Lantman-de Valk, Keith McVilly, Glynis Murphy, Helene Ouellette-Kuntz, Hans Reinders, Neil Ross, Shigeru Suemitsu, Carla Vlaskamp, Miguel Verdugo, Patricia Noonan Walsh, Kuo-yu Wang.

Apologies: George Jesien, Joel Levy, Maria Malbran, Frank Sturtz, Vianne Timmons.

David Felce called the meeting to order at 13:10 on August 1, and welcomed all to the meeting in Maastricht. He made a proposal to have Tamar Heller of the USA (nominated by the AAMR [American Association on Mental Retardation, now the American Association on Intellectual and Developmental Disabilities]) to replace Robert Schalock, who resigned from Council. Robert Schalock was thanked for his contributions to Council. Proposed by Stephen Kealy, seconded by Neil Ross. Passed.

#### Minutes:

With respect to the corrections to Minutes, Philip Davidson asked that the spelling of his first name be corrected from Phillip to Philip. Acceptance proposed by Neil Ross and seconded by Keith McVilly. Passed.

#### Matters arising:

#### Sponsorship

General discussion took place on sponsorship with respect to the upcoming Cape Town Congress. The importance of coordinating actions in respect of securing sponsorship was stressed by those who contributed to the discussion. Glynis Murphy thanked people for their input to date and agreed to set up a subcommittee to the program committee, comprising Monica Bjorkman, Sheila Hollins, Neil Ross, Mike Kerr, and herself.

Although their financial support is welcome, it was agreed to avoid any sole financial dependence on a pharmaceutical company. Such support would be acceptable as long as it did not compromise the independent integrity of the scientific program. Glynis Murphy noted that IASSID had a number of tools available for seeking sponsorship, including a sample letter (available on the IASSID website), information on IASSID, and information on Cape Town. A document setting out sponsorship options prepared for the last World Congress was also available.

Frequently asked questions area on the IASSID Web site

Glyn Murphy reported that this continues to be a work in progress, and will liaise with members of Council in formulating responses to frequently asked questions.

Website updates will occur as needed. Council was asked to contact Neil Ross regarding suggestions.

Research plans and goal to develop a Special Research Interest Group on Sport Research

General discussion took place with respect to the comments made by Trevor Parmenter and Joss Mulder at the Taipei Council meeting in 2005. The issue stems from the continued bias of Para-Olympics Organization in preventing people with intellectual disabilities from participating in the competitions. At the time, it was proposed that the Association stimulate the organization of a Special Research Interest Group (SIRG) on Sport-Related Research. Keith McVilly raised this issue again and explained the nuances that are involved. No resolution was reached on this issue.

#### President's Report

David Felce identified a series of specific achievements over the past years, including the holding of successful regional meetings, having a functioning publication policy in place, establishing collaborations with other associations, the archiving of abstracts of congresses and regional meetings in journals, and a refocused collaboration with World Health Organization (WHO). With regard to the success of the Asia-Pacific IASSID Conference, David Felce thanked Kuo-yu Wang for her excellent organization of the first regional Asia-Pacific congress in Taipei.

David Felce also thanked Henny Lantman de Valk for the work she and her colleagues had done in making the second European Regional Congress in Maastricht a reality. Hans Reinders was also thanked for his efforts to help make the conference accessible to people with intellectual disabilities. In responding, Hans Reinders commended the support being provided by volunteers acting as "buddies" to people with intellectual disabilities.

David Felce identified the importance of SIRGs in the development of conference programs. The continuing development of the SIRG structure also had implications for increased representation on the governance structures of IASSID, as does increased individual membership. The need to strengthen the relationship with and between SIRGs, individual members, organizational members, and research center members was identified as a primary objective between now and the next World Congress.

Other activities included the Association's relationship with WHO. Patricia Walsh gave a synopsis of the current situation (detailed later in the minutes).

David Felce also noted that the AAMR Social Inclusion Conference was held in Montreal in May 2006, and IASSID supported by way of organizing a series of research-oriented sessions and provided a grant of US\$3,000 for its North American operations. He also outlined some possible changes in the structure of IASSID, and indicated he would be bringing an outline of a proposal to the next Executive meeting. The acceptance of the President's report was proposed by Sheila Hollins and seconded by Helene Ouellette-Kuntz. Passed.

#### Treasurer's Report

Matthew Janicki went through a detailed report of the Association's financial standing and invited questions in respect of its content.

Philip Davidson raised the question of what happens in relation to royalties. Matthew Janicki noted the Association currently receives royalties for its publications with Blackwell Publishing. He also noted that members are asked to assign royalties to IASSID when submitting a project to the Association for publication under its logo. Neil Ross queried outstanding organizational member fees. Matthew Janicki noted that collecting these fees can present a particular challenge, as this involves a significant amount of work. He forwards the invoicing information to Vianne Timmons, who then invoices the organization in question. It was also noted that the fee structure for organizations has changed, so no organization pays more than US\$350, and some in developing countries pay only a token amount.

Matthew Janicki reported that the Association's accounts have been audited, and that a not-for-profit association report has been filed with the United States Internal Revenue Service for 2005. The reports are due May 15 of each year. The adoption of the Treasurer's report was proposed by Fabrizio Fea and seconded by Carla Vlaskamp. Passed.

David Felce thanked Matthew Janicki for his work and, in doing so, acknowledged how his work has contributed to the strengthening of the financial position of the IASSID.

#### Membership

Matthew Janicki, as the Chair of the Membership committee, presented a breakdown of the Association's individual, research center, and organizational members. A proposal was made to appoint a liaison person to link with organizational and research center members. David Felce indicated he would follow up and designate one of the officers to do this. A discussion took place on SIRGs

charging a membership fee. Not all SIRGs currently seek fees from their members. There are difficulties in tracking members and obtaining funds to support SIRG activities. It was proposed by the SIRG representatives at Council that IASSID collect a general fee that would be distributed to the SIRGs each year. After much discussion, it was agreed the individual IASSID membership fees be raised by US\$20, so that the \$100 membership be changed to \$120, and the \$150 membership be changed to \$170. How the funds will be distributed was not resolved, and David Felce indicated that the Executive would decide on a mechanism at its December 2006 meeting. Motion was made by Patricia Walsh and seconded by Steven Kealy. Passed.

A general discussion on SIRGs ensued that covered a number of topics, including membership benefits, how to broaden member participation, the evolution of new affinity groups not currently covered by existing SIRGs (e.g., neuro-psychiatry, special education), the issue of retention of members, welcoming new members, student memberships, putting in place a virtual members joining pack, language as a barrier to membership, the question of whether discounted journal subscriptions are a strong enough incentive to maintain membership, and how to promote discounted subscriptions to other journals. All the foregoing to be brought into a strategic discussion document to be drafted by David Felce. The document will be sent to SIRG leaders for consultation, and will also take account of the discussions which Henny Lantman de Valk has had with SIRGs in her role as Executive member responsible for SIRG coordination.

#### Secretary's Report

David Felce thanked Vianne Timmons and Edith Cardy at the University of Prince Edward Island (Canada) for their work on behalf of IASSID, particularly in the preparation of documentation and organization for Council and Executive meetings. The use of the Web site for making documents available to Council was particularly commended.

#### World Health Organization Relations

Patricia Walsh outlined progress on work to date, detailing a formal letter from the WHO re the working relationship. She described the contact made with the Pan American Health Organization (PAHO; covering Canada, the United States, Central America, and South America) by Matthew Janicki and herself in relation to the regional meeting in Santiago, Chile, in September 2007. PAHO has a strong human rights orientation, which will be embedded in the regional congress. PAHO has recommended a contact person in Chile, Dr. Maria Soledad Cisternas, who met the executive in Montréal during the AAMR Social Inclusion Conference in May. Patricia Walsh and Matthew Janicki noted that they are building a network of support and collaborators for the regional conference. This will also involve contacts with health ministry officials from the region's countries. Cognizance should be taken of the cultural backdrop of the host country. PAHO agreed to look at institutional support in the United States. Maria Malbran, from Argentina, was also enlisted to aid with the planning effort.

In terms of external support, Giorgio Albertini volunteered to explore financial support from Tosinvest Sanità. Neil Ross also noted that the IASSID website now contains a significant number of pages in Spanish, which should help with making inroads with colleagues in South America.

It was also noted that IASSID now has a working affiliative agreement with Down Syndrome International (DSI), and that there was the potential of enlisting DSI's involvement in the Santiago effort. Matthew Janicki, who will be attending the DSI Board meeting in Vancouver in August, was asked to raise this issue with the DSI leadership. With regard to external support, Tamar Heller volunteered to explore institutional support in the United States.

David Felce asked whether there were any other new organizations with which IASSID should form a working relationship. Giorgio Albertini suggested the International Child Neurology Association (ICNA), and said he would follow up with his contacts at ICNA about this.

#### SIRG Section Report

Henny Lantman de Valk presented her report of the SIRG leadership group, noting that many of the larger SIRGs were progressing actively to hold roundtables and circulate information. Jan Blacher queried whether some SIRGs could be taking on a life of their own. Henny Lantman de Valk explained that the SIRGs were evolving, and that they were taking a more important role within the Association's activities. She cited as an example their involvement in organizing symposia and training courses in association with the IASSID Congress and regional conferences. Henny Lantman de Valk outlined steps undertaken in respect of SIRG coordination. The question of secretarial support for SIRG coordination was identified.

There was a discussion on the contribution which SIRGs can make to IASSID, particularly in the context of contribution to journals, papers, workshops, individual SIRG meetings, and the involvement of a greater number of the membership in SIRGs, producing policy statements, and making available professional expertise. A follow-up discussion took place on the importance of having a very strong working relationship between the Council and SIRGs. David Felce asked Henny Lantman de Valk to liaise with Matthew Janicki in respect of reimbursement of financial support to SIRGs. David Felce again restated the need to look at a root-and-branch review of IASSID, particularly how membership is linked to the aims and objectives of the association and involved in its governance. He noted how the regional conferences and world congresses provide an opportunity for SIRGs to be involved in the development of program themes. The importance of identifying gaps which need to be filled by SIRGs was highlighted. There was a suggestion that the Association could have up to 15 SIRGs.

Henny Lantman de Valk noted that the SIRGs are obliged to keep a financial record and provide a financial accounting of the expenditure of their funds to the Treasurer annually. In addition, the importance of involving

students and affinity groups in conferences and congresses was identified, as was the difference in focus between a world congress, a regional conference and SIRG meetings.

A new SIRG on comparative policy and practice was proposed by Henny Lantman de Valk and seconded by Glynis Murphy. The proposal was agreed by Council, and the new SIRG was welcomed to the Association.

#### IASSID International Course

Matthew Janicki presented the report of the ad hoc working group on the IASSID Academy, and explained what was meant by the group's recommendations. The working group recommended that IASSID establish an Academy on training on a provisional basis, to determine its viability and role within IASSID, identify a faculty governing board, and vet courses that could be offered under the aegis of IASSID. The proposal led to extensive discussion, which was eventually postponed at the close of business of the first day and resumed on the second day. In the resumed discussion, a proposal was put forth by David Felce for a 6-month trial period, with funding of up to US\$6,000. The proposal was to ask Professor Roy Brown of the University of Victoria (Canada) to be Chair of an initial development/steering group of his own choosing and to produce a report in six months' time to cover:

1. Proposed names of an initial Academy, with brief CVs itemizing training and other relevant experience, for the Council to consider. (It would be important to know that the proposed people had agreed to serve.)
2. More specific proposals for the initial focus of the Academy, with goals and deadlines in the next few years. (Two particular areas where development might be focused were suggested: (1) on training relevant to Africa, which might be delivered in conjunction with the 2008 World Congress in Cape Town, and (2) on a proposal to build training capacity in one or more countries where evidence-based training was considered to be relatively underdeveloped.)

The proposal was presented by David Felce and seconded by Patricia Walsh. Passed.

#### Conferences

Asia-Pacific Meeting—The next Asia-Pacific IASSID meeting will be held in Singapore 2009. A working group, led by Keith McVilly, was charged to oversee conference organization, and to take account of the experience of the Taipei meeting in 2005. Kuo-yu Wang's feedback on the first Asia-Pacific Conference highlighted the amount of support, financial, and other, received which contributed to increased participation and overall success of the conference. The involvement of local health officials on the organizing committee was seen as an important strategy decision. It was recommended that Shigeru Suemitsu join the committee.

European Meeting, Maastricht—Henny Lantman de Valk gave a brief report on the 2nd IASSID-Europe Conference. She noted that there were at least 550

registrants and 50 service users in attendance. The Council thanked Henny Lantman de Valk and colleagues for their work on behalf of IASSID. David Felce acknowledged that he will write a note of thanks to Henny Lantman de Valk and her colleagues, Marian Maaskant, and Wil Buntinx. Council agreed that the 3rd IASSID-Europe Conference will be held in 2010 in Rome, Italy. Giorgio Albertini confirmed the interest in Rome to host the Conference.

South Africa—Glynis Murphy circulated a card providing preliminary information on the upcoming 2008 Congress. She also noted that advertising has commenced in the IASSID-related journals. Matthew Janicki indicated that the Congress notice will appear on the back cover of the next issue of JPPID, and agreed to follow up with Blackwell and further publicity. Jan Blacher volunteered to follow up with the Exceptional Parent and other publications.

With respect to Congress preliminaries, David Felce and Glynis Murphy were to visit Cape Town at the end of August to look at the venue, and meet with the local organizing committee and the commercial conference organizer. They were timing their visit so as to experience Cape Town during the same dates as the Congress was to be held.

Glynis Murphy announced that she is looking for suggestions for plenary session speakers—specifically a speaker with knowledge of Africa and, in particular, the local challenges to be addressed (poverty, child development, Aids, etc.). Glynis Murphy also spoke about the allocation by IASSID of US\$30,000 to fund research projects within Africa, and that she welcomed support from other national/international agencies or organizations. Council members with links to funding organizations who could support the fund were asked to contact her. An application form to make a request for research support can be accessed from the IASSID website. The deadline for applications is the middle of September, with regional limits to Africa and African region (e.g., Madagascar). She noted that the Preliminary Call for Papers will be issued in March 2007, with a second Call issued in June 2007.

David Felce noted that his committee was at work with examining potential sites for the World congress in 2012. A number of possible cities have been identified, and the committee will be making contact with local conference offices over the next year. Possibilities include: Warsaw (Poland), Budapest (Hungary), Prague (Czech Republic), Vienna (Austria), Lisbon (Portugal), a Canadian city, and Edinburgh (Scotland).

#### Journal

Matthew Janicki provided the editor's report and noted that JPPID was now in its third volume. In his detailed report, he said that Blackwell Publishing was very pleased with the progress of the journal and its subscriptions, as well as the high quality of the manuscripts. In 2007, Blackwell will be submitting the journal to abstracting services, such as Medline and others. He highlighted the advantages of using the Manuscript Central system, which was put into

effect by Blackwell Publishing to aid with manuscript submission and tracking. He noted that Blackwell has had some turnover of editorial staff, but overall the journal had a positive relationship with Blackwell, and was experiencing a high standard of journal submissions and was receiving a substantial supply of manuscripts. Council commended Matthew Janicki's work in bringing the journal to its present stage of development. The Council also acknowledged the generous support of the Tosinvest Sanità Organization for its continued financial support of the journal.

#### Web site

Neil Ross gave an extended report on the website covering its visual presentation, and raised some questions about how it could be revamped as, and when, needed. Glynis Murphy volunteered to seek some information on "re-skinning." The issue was raised about "gate-keeping" of the information posted on the IASSID website. It was agreed that there was a need to have one person to act as gatekeeper. The notion that the website should be accessible was raised, and Tamar Heller agreed to provide information on accessibility developed at her center. With respect to the maintenance of the website, Neil Ross noted the costs associated with its maintenance, and proposed that Council needs to think in terms of IASSID's business plan over an 8-year period. He noted that equivalent website costs can range from €10,000 to €15,000 Euros. He also noted that, with the growing number of SIRGs, the updating of SIRG information is becoming more time consuming, partly owing to the lack of guidelines on what materials can be posted and how to submit materials for posting. Henny Lantman de Valk noted that SIRGs need to identify a named person to liaise with the webmaster. It was proposed that Council empower Neil Ross to formulate a proposal on the website with rules for engagement, including updating, and revamping, with particular reference to accessibility. Proposed by David Felce and seconded by Matthew Janicki. Passed.

#### Publications Committee

Tony Holland reported that books approved by IASSID must first receive a "Nihil Obstat" from the Publishing Committee. However, members of Council expressed a view that IASSID is not a publishing house. Importantly, it was incumbent on authors to gain a publisher for their proposed publication. There should be no expectation that IASSID would do this.

Keith McVilly identified the potential of the website for dissemination, and suggested alternatives for presenting scientific information under the aegis of IASSID, such as pod-casting via website and using CDs. The meeting did not have sufficient time to explore the potential of these dissemination avenues. David Felce asked Henny Lantman de Valk to liaise with Tony Holland on SIRG representation on Publications Committee. Matthew Janicki enquired as to whether Council wanted to encourage members to assign royalties to IASSID from publications. Discussion ensued and there was an acknowledgment of authors who have done this (such as Dr. Vee Prasher). David Felce asked the

Committee to look at publication options other than JPPID and JIDR for articles from IASSID-related conferences.

Tony Holland identified the need to avoid an appearance of competition between journals and to make sure that there was coordination to achieve maximum spread and a fair process.

#### Next Council Meeting

Council agreed to meet again in May 2007 in Paris. It was felt that waiting to September and holding the meeting in Santiago would be too late in the year for Council to meet and would also be costly for member travel. The Executive was asked to seek out venue arrangements, confirm the date, and then notify Council. Consideration should be given to a date in between the Health SIRG Roundtable to be held in Prato, Italy, in late May and the Aging SIRG Roundtable to be held in Oslo, Norway, in early June.

#### A.O.B

#### IASSID Concern over the Policies of Para Olympics

Keith McVilly updated Council on the issue related to the Para Olympics and their prohibition of persons with intellectual disabilities participating. He lauded the work of Dr. Jennifer MacTavish of the University of Manitoba in attempting to resolve this issue. It was agreed that David Felce would write to the chair of Para Olympics Association (Keith McVilly and Trevor Parmenter would supply background matter) to ask for a meeting to secure a resolution of the impasse.

#### Japanese Association

Shigeru Suemitsu gave an outline of the Japanese Association for the Study of Developmental Disabilities, and volunteered to identify a number of people who could link with the IASSID Executive and SIRG leaders with a view to increasing cooperation with IASSID and individual membership. Shigeru Suemitsu noted that at least 30 people in Japan had indicated an interest in going to the Cape Town meeting. He indicated the need for himself and the IASSID Secretary to stay in contact.

#### Adjournment

The 3rd Meeting of the 2004–2008 Council was adjourned at 12:45 on August 2. In closing the meeting, David Felce thanked everybody for their contributions, attendance, and willingness to support the IASSID work agenda. Respectfully submitted  
Vianne Timmons, Secretary  
Stephen Kealy, Past-Secretary

## SIRG REPORTS SUBMITTED TO COUNCIL 2006

### Report of the Special Interest Research Group on Aging and Intellectual Disability (SIRGAID) - June 2006

#### Past Activities

The Special Interest Research Group on Aging and Intellectual Disability held its 14<sup>th</sup> Roundtable and Annual Meeting in Dortmund, Germany on May 17 through 19, 2005. It was organized by Dr. Meindert Haveman. Approximately 34 SIRGAID members attended the meetings. The themes included Health Outcomes, Death and Dying, and Social Aspects of Aging with ID. A parallel conference was held on the 20<sup>th</sup> of May attended by over 75 local providers and University faculty. Four members of the SIRGAID gave presentations.

The SIRGAID 15<sup>th</sup> Roundtable was held in Toronto, Canada on April 26 -29, 2006. The University of Rochester, located in nearby upstate New York hosted the meetings. The meetings were held jointly with the SIRG on Quality of Life. The University of Toronto and the Ontario Federation for Cerebral Palsy were co-hosts. There were three thematic foci: Health and aging, Service Policy, and Low Incidence Conditions. 52 people attended the meetings. The SIRGAID designated Oslo Norway as its venue for the 16<sup>th</sup> Roundtable, to be held May 20-22, 2007. It will be sponsored by the Development Program on Ageing in People with Intellectual Disabilities (JAU) at The Norwegian Centre for Dementia Research.

The current officers continued in leadership, including Philip Davidson and Christine Bigby as co-Chairs, Dawna Torres Mughal as Treasurer, Heather Wilkinson as Secretary, and Matthew P. Janicki as Past Chair. Dr. Davidson also continued to serve as the SIRGAID Council Representative.

#### Membership

Dr. Dawna Mughal, our Treasurer reports that we currently have 36 IASSID members who have paid their \$20 SIRG dues for 2006.

#### Budget

At its Business Meeting at Toronto, Dr. Mughal reported cash on hand of \$ 5,101.37 anticipated additional revenues of \$800.00, anticipated expenses of \$2,200.00, and an anticipated end-of-year balance of \$3,701.37. The budget was

approved, although discussion recommended caution in adopting a spending plan that overestimated dues revenues. There was strong sentiment to limit travel expenses of Officers attending IASSID sponsored events without substantial sharing of costs with IASSID.

*Submitted – PW Davidson, Co-Chair/Aging SIRG*

*15 June 2006*

### Report of Health SIRG IASSID Council Meeting

August 1 and 2, 2006

#### Summary of Past Year Activities

The SIRG held a major conference on Health Issues hosted and funded by The Centre for Disability Health Victoria and held in Melbourne Australia. This was a great success and consolidated the position of the SIRG as a leading player in disability Health. The SIRG published a Key report into the disparity in health experienced by people with an intellectual disability:

Scheepers M, Kerr M, O'Hara D, Bainbridge D, Cooper S-A, Davis R, Fujiura G, Heller T, Holland A, Krahn G, Lennox N, Meaney J & Wehmeyer M (2005) Reducing health disparity in people with an intellectual disability: A report from Health Issues Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *J of Policy & Practice in Intellectual Disabilities*, 2(3/4), 249-55.

The SIRG continues to produce regular newsletters and have teleconferences of the board

#### Plans for Upcoming Year

The SIRG will hold a joint roundtable on medical student education with MAMH at the Maastricht meeting

The SIRG will hold a business meeting in Maastricht SIRG members are developing Guidelines for the management of epilepsy and other guidelines have been mooted

Initial plans are in place for a SIRG conference to be held at Monash University premises in Tuscany in 2007 on the theme of standards and guidelines for Intellectual disability health

*Prepared by Professor Mike Kerr 20<sup>th</sup> June 2006*

### Report on the Mental Health Special Interest Research Group IASSID Council Meeting Maastricht, August 1<sup>st</sup> and 2<sup>nd</sup> 2006

The MH-SIRG was a co-sponsor with the Health SIRG of a conference held in Melbourne, Australia in September 2005 organised by Professor Bob Davies. The conference was well attended with days allocated to the themes of mental and physical health.

Members of the MH-SIRG attended a meeting of the World Psychiatric Association (WPA) at the invitation of Professor Luis Salvador to establish a formal link between the recently formed section of the WPA on intellectual disabilities and the MH-SIRG, and co-hosted meetings on ID and mental health.

At the AGM of the MH-SIRG held at the Melbourne meeting Tom Cheetham (Canada) was formally appointed as the new treasurer. Anna Cooper and Tony Holland agreed to continue as co-chairs. At the AGM plans were considered for the future work of the MH-SIRG. It was noted that for many countries there was a lack of expertise available to assess and treated psychiatric disorders as they affect people with intellectual disability. It was proposed that the MH-SIRG should organise a workshop to consider the training in ID of psychiatrists and psychologists in particular. It was agreed that this would be scheduled for 2007. Venue to be determined. It was noted that the position paper prepared by the MH-SIRG was on the IASSID web-site. There was some discussion about whether further position papers would be helpful. It was noted that there were special editions of JIDR that focus on this issue.

The next meeting of the MH-SIRG would be held as part of IASSID Europe in August 2006 in Maastricht.

*Tony Holland  
June 2006*

## Report of SIRG Parents and Parenting with Intellectual Disabilities

### Summary of Past Year Activities

The Parents and Parenting with Intellectual Disabilities SIRG held their third meeting at the first Asia Pacific IASSID Conference in May, 2005 in Taipei.

Although the Parenting SIRG did not formally mount a Parenting stream at this conference there were several presentations primarily from Australia on parenting for people with intellectual disabilities. These presentations attracted good audiences and a great deal of interest from attendees.

The Parenting SIRG held an informal meeting with attendees including Professor Hans Reinders to discuss, in particular, the symposia for the IASSID Europe conference in Maastricht in 2006. The meeting agreed to approach the Chairs of the E-IASSID conference with a proposal to have parenting as a keynote topic. The meeting also agreed to actively pursue several symposia building on the topics agreed at Montpelier.

The Executive Committee of the Parents and Parenting with Intellectual Disabilities SIRG is as follows:

Chair: Professor Gwynnyth Llewellyn, Australia  
Deputy Chair: Dr David McConnell, Australia  
Secretary/ Treasurer: Professor Peter Vietze, USA  
Executive members:  
Dr Sue McGaw United Kingdom  
Dr Marie Gustavsson Holstrom, Sweden  
Dr Jytte Faureholm, Denmark  
Professor Rannveig Traustadottir, Iceland  
Professor George Singer, USA

The Parenting listserv has again been of benefit to members. Up to date information is regularly shared by this list serv about events in member countries. For example, the development and implementation of the Australian National Strategy for Parents with Learning Difficulties; the release of the UK Report, *Finding the Right Support?* prepared by our colleagues at the Norah Fry Research Centre, University of Bristol.

### Plans for Upcoming Year

1. To ensure good representation at E-IASSID at Maastricht in August, 2006.
2. To explore opportunities for cross country collaboration and particularly in areas identified as critical concerns and noted above in summary of past year activities.
3. To attract additional members to the SIRG and to promote our activities by way of the Parenting Listserv and the SIRG's website attached to the IASSID website.
4. To ensure ongoing and timely reporting of member's activities worldwide and in particular to announce new publications, research and development activities and policy issues or development and public media attention to parents and parenting with intellectual disabilities.
5. To identify appropriate ways to effectively utilize additional SIRG membership fees including for example student sponsorship for presentations at IASSID conferences.

### Issues or Acting Items

To further streamline pathway between IASSID Council and the SIRG to ensure timely relay of IASSID members indicating their interest in the Parents and Parenting SIRG to the Secretary/ Treasurer to ensure that interested parties have full access to SIRG activities.

### Discussion Points for Council

1. The SIRG requests an update on the progress of new and streamlined pathways of communication from the IASSID Executive to the SIRG's as discussed by the incoming President in Montpelier. The SIRG continues to experience difficulty in getting timely information about the membership base and subscriptions due to the SIRG.
2. The SIRG is keen to be informed about the Council's strategy, timeline and process in publishing books on the area of interests of the SIRGS. It would be helpful for example if there was an identified plan and timeline so that SIRG members could mobilize their efforts to work towards an outstanding international publication in a timely and orderly way.

3. The SIRG is also keen to be informed about the strategy in place to secure special editions of the *Journal of Policy and Practice in Intellectual Disabilities*. It may be helpful for example to have a schedule of special editions with SIRG's signing up well ahead of time to coordinate a special edition in their area of expertise and interest.

## Report on the SIRG Profound Intellectual and Multiple Disabilities (PMD) 2005-2006

### Terminology

Although in the 12<sup>th</sup> World Congress of 2004 there was an impressive number of presentations on planning, executing, and organizing education, health care, and support for individuals with 'PMD', it was not absolutely clear, if the speakers were talking about the same 'group' of persons. As a number of different terms were used to describe the target group, it may very well be that different (sub)groups were being referred to. This brings us to the urgency for an international agreement on a general accepted classification, which will facilitate communication and prevent misunderstanding. As the term Profound Intellectual and Multiple Disabilities is the term most widely used and accepted, we decided to favor this term over the term Profound Multiple Disabilities.

### Round Table

A Round Table invitational conference was held in Brugge, Belgium, in October 13-15<sup>th</sup>. Two broad topics were chosen as key topics for the conference:  
(1) quality of service provision and support in community services and families, with special attention to staff attitudes, skills, working methods and training  
(2) procedures and evaluation of educational and developmental programs and activities and of (pseudo)treatment programs and methods

As part of the Invitational conference, which was attended by members from the UK, Scotland, Sweden, Ireland,

Japan, Germany, Belgium and the Netherlands, the contribution of our SIRG to the 2nd European IASSID-conference at Maastricht (the Netherlands) was discussed. As the program committee had already decided that there will be 4 symposia under the theme 'PMD', topics and our contribution was discussed. Convenors were designated for each symposium. In each symposium there will be 4 presentations.

#### Newsletter

In the beginning of 2006, our sixth Newsletter was sent to all our members. The newsletter also included the request to fill in a so-called 'membership card'. The members were also brought up to date on the development of a website.

#### Web-site / E-mail

The SIRG information can be found on the web-site of the IASSID under [IASSIDoffice@aol.com](mailto:IASSIDoffice@aol.com), SIRG, Profound Multiple Disabilities. The information on this web-site has recently been revised.

Next to the information on the IASSID website, another website is up and running, on <http://www.sirgpmdb.be>. On this website, our 'mission statement' can be found. An important part of this website is the 'membership card'. With these cards, vital information on members is gathered and can be used to facilitate contact between members. In the sections 'announcements' and 'reports', information on e.g. recent research projects is stated. This website needs further development but will hopefully grow to an interactive site that can run next to the regular IASSID website.

#### International Masters

Members from the Netherlands, Belgium, Germany and Scotland have started an initiative on the development of an International Masters. After initial contact by e-mail, a meeting was organized in Cologne, Germany, in March 2006. It was decided upon that we would start with the development of preliminary modules. The group will meet again in August 2006.

#### Colloquium for young researchers

At the round table conference, a suggestion came forward to organize a colloquium for young researchers. This idea has been worked out steadily but surely by Colin Griffiths in close cooperation with some board members. Arrangements have now been made, and the colloquium will be held in August 1 - 2<sup>nd</sup> at Maastricht.

#### Financial Statement

The report on the financial statement was completed by Bea Maes. This report is attached.

*Carla Vlaskamp, chair.*

*Bea Maes, secretary and treasurer.*

### **REPORT OF SIRG ON FAMILIES**

#### Summary of Past Year Activities

The Families Research group of IASSID remains active and involved with IASSID. Highlights of activities of the last year or so include:

(1) Two meetings of the Families Research group, at the Gatlinburg Conference 2005 and 2006. Members in attendance represented most regions of the U.S.; there was representation from Wales and the U.K. as well.

The goal of the 2005 meeting was to discuss the number of symposia to submit to the Maastricht meeting, since we had been told that presentations would be limited. We considered invited symposia, as well as a more general call for papers. At the 2006 meeting, we discussed the upcoming Special Issue of JIDR (see below), and confirmed plans for Maastricht. Laraine Masters Glidden provided a report of the first Asia Pacific IASSID Conference.

(2) In response to the overwhelming interest in families research, among IASSID members and the field of ID at large, the JIDR Editors (Tony Holland, Editor; Jan Blacher & Chris Oliver, Associate Editors) and Editorial Board

approved a second Special Issue on the topic. As in the first issue, the call for papers for the current one (co-edited by Richard Hastings, Ann Turnbull, & Bruce Tonge) has resulted in a large number of submissions – too many for one issue. Accepted papers that do not make it into the Special Issue will appear in regular issues of JIDR.

(3) Membership of the Families SIRG continues to be strong, and we have maintained a mailing list of 110.

#### Plans for the Upcoming Year

Families SIRG plans include:

- a) maintenance of an active membership with ongoing and active email communication
- b) continue to solicit papers on families for JIDR and other journals associated with IASSID
- c) a feature on families research highlights from Maastricht in Jan Blacher's "Research Reflections" column for *Exceptional Parent* magazine
- d) plans to attract even more cross-cultural research on families, and more cross-country collaboration
- e) plans to assure families research representation and highlights at the IASSID meeting in Cape Town

#### Issues or Action Items for Council

The Families SIRG would be delighted with more communication and involvement with the Executive body of IASSID. Conversely, the Families SIRG would like to better inform the IASSID Council and Executive of the SIRG's active research agenda. While the Families SIRG has prominence in the JIDR arena, it might be well to include Special Issues on Families in JARID and/or JPPID.

*This summary of Families SIRG activities is respectfully submitted by Jan Blacher, C-Chair, Families SIRG.*