



## 13<sup>th</sup> World Congress - People with Intellectual Disabilities: Citizens in the World

Submitted by:

Glynis Murphy, IASSID President

The 13<sup>th</sup> IASSID World Congress, held in Cape Town, South Africa, was a wonderful success and I would like to thank all presenters and delegates for their contribution. We had over 800 papers and posters, and nearly 900 delegates. They came from all over the world, including the following:

- 176 from Africa (including 137 from South Africa, 18 from Nigeria, and a few delegates from each of Cameroon, Congo, Ghana, Eritrea, Ethiopia, Kenya, Namibia, Rwanda, Tanzania, Zambia),
- 116 from the Asia Pacific region (including 58 from Australia, 16 from Japan, 15 from Singapore, 14 from New Zealand, 8 from Taiwan),
- 467 from Europe (including 158 from the UK, 141 from the Netherlands, 45 from Ireland, 25 from Norway, 18 from Finland),
- 109 from North and South America (including 71 from USA, 36 from Canada),
- 10 from the Middle East.

The conference started very well with plenary sessions from Diane Richler (from Inclusion International), Eric Emerson (from the UK) and Colleen Adnams (from Cape Town), all considering the topic of 'Intellectual Disability and Poverty'. These were followed by a welcoming reception with great food and an excellent African band, which got everyone dancing.

Setting up the conference had taken an enormous amount of work: I had over 4,000 emails about the conference, over 3,000 of these being about the abstracts themselves. My

two helpers, Nell Ellison (who you may have met at the conference) and Trish Barton had similar numbers of emails and I was deeply grateful for all their help. The Local Organising Committee (LOC) (John Cruickshank, Chris Molteno, Jennifer Cartwright, Jennifer Kromberg, Solly Mokgata, Vanessa de Santos) set up the very popular study tours and ran the desk selling t-shirts and bags (with the help of John's wife Jen Cruickshank). The bags, dolls and t-shirts, which were made by people with intellectual disabilities at Sunfield Fortuna and Cluny Farm, were extremely beautiful with a stunning logo designed by Louise Carmichael. The LOC also helped the indefatigable Conference Management Team (Deidre Raubenheimer, Jolandi Ackerman and others) in innumerable ways, making everything run smoothly and making possible all sorts of events such as those by United by Music.

Presenters at the conference included recipients of the IASSID 'Research in Africa' awards. These awards were not large but allowed research in intellectual disabilities to take place in various parts of Africa, which might not have been possible otherwise. We are grateful to the following presenters for telling us about their research, funded by these awards, and we hope to feature brief reports on the projects in a future newsletter:

- Amshuda Sayed, OT, University of Cape Town,
- Paul Ajuwon, Missouri State University and Nigeria,
- Evariste Karangwa, Kigali Institute of Education, Rwanda,

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Glynis Murphy

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Tony Holland: JIDR Editor

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Neil Ross: Web Editor

## Creating Possibilities for an Inclusive Society

*Submitted by:*

**Keith McVilly**

**Are you joining us at Singapore in June (Wednesday 24<sup>th</sup> to Saturday 27<sup>th</sup>)?** There have been over 250 abstracts submitted to peer review for the 2<sup>nd</sup> IASSID Asia Pacific Conference. In addition, a number of the IASSID Special Interest Research Groups and Affinity Groups will be hosting symposia and conducting meetings during the conference. These include: Quality of Life; Mental Health & Behaviour; Ageing; Health; Parenting; Down Syndrome; and Ethics.

The conference will be hosted in collaboration with the Australasian Association of Doctors in Developmental Disability Medicine, the International Society for Augmentative and Alternative Communication, and the Asia Pacific Down Syndrome Federation, among others. We also anticipate participation by Inclusion International and Disabled Peoples International. The conference is

chaired by Dr Keith McVilly of RMIT University, Australia and Professor Lisa Wang of the National Chung Cheng University, Taiwan. The Local Organising Committee is chaired by Dr. Balbir Singh of the Down Syndrome Association of Singapore and the Conference Secretary is Ms. Kristin Van Burm. The Scientific Programme Committee is chaired by Professor Libby Cohen and Dr. Kenneth Poon of Nanyang University at Singapore, who are assisted by a review panel of some 50 international experts.

The IASSID Academy will host workshops prior to and following the conference. Academy Chair, Professor Roy Brown, is finalising workshops, some of which will be conducted at Singapore and others in neighbouring countries.

The conference will host the "Asia

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## Citizens in the World

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- Chris Molteno, Groote Schuur Hospital, South Africa, and
- Patricia Struthers, University of Western Cape, South Africa.

We are very grateful to the Penrose Society, the Seattle club and all those Research Centres across the world who helped to fund these projects.

We are also grateful to Mencap and to the Lejeune Foundation for their very generous support for the printing of the Abstract and Programme books, the Mencap fellowships to attend the congress, and the printing of an accessible abstract book, kindly prepared for us by the Plain Facts Team at the Norah Fry Centre in the UK.

#### **Executive Team**

The new Executive Team (see insert), which will be taking IASSID work forward, together with the IASSID Council members, met in January, 2009. The minutes of the meeting are now up on the website [www.iassid.org](http://www.iassid.org), under Council Information.



The happy T-shirt, Key-ring & Bag sales team!

Eric Emerson, UK will be leading on WHO matters and he has already had a meeting with the WHO and agreed to four tasks for the next three years. He will be reporting on this to Council in Singapore.

I hope to see as many of you as possible in Singapore at the **IASSID 2<sup>nd</sup> Asia-Pacific conference** in June 09 – book your flights now!

# IASSID Academy on Education, Teaching and Research: Its Development and Practice

Submitted by:  
Roy I. Brown

The IASSID Academy was established by the IASSID Council at its 2006 meeting in the Netherlands.

The Academy's mission is to provide workshops and seminars in areas of pressing need, particularly in countries where there is a desire for knowledge. The Academy's seminars and workshops are developed around "cutting edge" research associated with our multi-disciplinary organization. Its aim is to communicate the research and applied expertise of IASSID members to those supporting and working in the field of intellectual disabilities. The Academy provides wrap-around workshops in conjunction with IASSID's international and regional conferences as well as stand-alone workshops.

The Academy's governance structure currently consists of senior IASSID members from several countries. Its activities result from proposals from members of IASSID and organizations in various countries. The Academy has already undertaken a week-long combination of seminars and workshops in Mexico which were pod cast across Mexico; a one-day workshop in Singapore; and four wrap-around workshops at the Cape Town Congress.

The Academy invites proposals and participation from members of IASSID through the SIRGs. In preparation for the 2nd Asia-Pacific Regional Congress in Singapore in June 2009, workshops on different aspects of intellectual disability are being organized. In

addition, the Academy is currently working with Malaysian and Canadian colleges in setting set up a series of 2-4 day workshops to be held in Malaysia. Additional workshops are being organized for India and Hong Kong.

In developing its program, the Academy Board has stressed the importance of high standards, the vetting of curriculum and materials and assessment and evaluation of the workshops and seminars. It has developed a package of materials for detailing curriculum. These documents are forwarded to the Academic Board for comment and approval. Our work is done in collaboration with local host agencies. The Academy authorizes two forms of certification: one of performance evaluation and the other of participation. Participant evaluations of the workshops and seminars have to date been very positive, with a high approval rating.

The Academy is archiving material of lectures and power points and Wiley-Blackwell has supported these activities with permissions to use journal materials.

The Academy's work is reported regularly to the IASSID Executive and to Council. Members of IASSID are invited to discuss their ideas and proposals for workshops with us. We strongly believe that the work of the Academy represents and reflects one major mission of the IASSID, which is the dissemination of its members' expertise throughout the world.



Roy Brown-Chair

## The Academy Board

Roy I. Brown, Canada  
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## Creating Possibilities for an Inclusive Society

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Pacific Research to Practice Round Table". This 3-day event will bring together researchers and practitioners from across the region and around the world to identify issues and plan projects that will be implemented in the region and then reported to the 3<sup>rd</sup> Asia Pacific Conference, already planned for Japan in 2013.

Registration details and conference programme are on the



IASSID website: [www.iassid.org](http://www.iassid.org).  
 Early Bird registration is available until 3<sup>rd</sup> April. Please send enquiries to: [iassid09@cma.sg](mailto:iassid09@cma.sg)

Submitted by:  
Tony Holland



"...a central role of both JIDR and IASSID - that of promoting knowledge and good practice in the field of intellectual disabilities, and of encouraging and reporting on research and its implications from very different perspectives across the world.

"...in this field of intellectual disabilities, we also have a responsibility to encourage research in areas where it is judged there is perhaps the need for more focussed work."

As Editor in Chief of the Journal of Intellectual Disability Research (JIDR) I have been keen to maintain and strengthen the links between the Journal and IASSID. This link was established some years ago when JIDR was under the editorship of Professor Bill Fraser and has been, and continues to be, to the mutual benefit of both parties. The publishers (Wiley-Blackwell), by making JIDR available at cost to individual IASSID members, ensure that the Journal can be received by IASSID members throughout the world. JIDR publishes the abstracts for the main international conferences and through its owners, the UK charity MENCAP, IASSID receives financial support for these conferences.

The link between JIDR and IASSID has been formalised through the Editor of JIDR now being an ex-officio member of IASSID Council and by the IASSID President, President-elect, and Treasurer all being members of the JIDR Editorial Advisory Board. This link between us facilitates a central role of both JIDR and IASSID - that of promoting knowledge and good practice in the field of intellectual disabilities, and of encouraging and reporting on research and its implications from very different perspectives across the world. JIDR achieves these aims in a number of ways:

#### More editions

We took the decision three years ago to expand the number of editions of JIDR each year from eight to 12. This was initially to deal with a backlog of accepted papers but was also undertaken to allow an expansion in special editions and to ensure room for annotations and other articles. This has been achieved.

#### Special editions

In addition to the regular editions we now publish two or three special Mental Health editions each year under the editorship of Professor Sally-Anne Cooper and a 'guest-edited' special edition each year.

Professor Chris Oliver has taken on responsibility for invited annotations and he also edits the annual edition that includes abstracts for the yearly meeting of the Society for the Study of Behavioural Phenotypes (SSBP). Professor Jan Blacher has also become an Associate Editor in order to facilitate our links with the USA and to ensure that we have her particular expertise.

#### New sections

Whilst the core responsibility of JIDR is to publish peer reviewed academic papers my own belief is that, in this field of intellectual disabilities, we also have a responsibility to encourage research in areas where it is judged there is perhaps the need for more focussed work. Several particular areas were brought to my attention by various people at the recent IASSID meeting in Cape Town. These included children with intellectual disabilities, the present state of community care and human rights. At present we have special editions planned on Resilience, Family quality of life and specific cognitive aspects of intellectual disability. JIDR also has a strong tradition of working closely with the Special Interest Research Groups (SIRG) of IASSID in the initiation and publication of special editions. As the new SIRG committees become established I hope that such joint editions will also continue and develop.

We are beginning to receive submissions for what we have termed a 'Hypothesis' section. The aim of this section is to encourage the submission of scholarly papers that challenge our thinking and perhaps allow some degree of informed and reasoned speculation.

I am very grateful for those of you who have submitted papers to JIDR and for the many of you who have been referees. Comments and suggestions as to how we might continue to improve JIDR would be more than welcome.

## News from the *Journal of Policy and Practice in Intellectual Disabilities*

**Stay E-Alert:** Did you know that you can receive an email table of contents delivered to your inbox every time an issue publishes online? To do this, simply [click here](#).

([http://www3.interscience.wiley.com/cgi-bin/anon/path\\_ok=%2Fcgi-bin%2Fsetalert%3FID%3D118492186%26alert%3Don%26CRETRY%3D1%26SRETRY%3D0](http://www3.interscience.wiley.com/cgi-bin/anon/path_ok=%2Fcgi-bin%2Fsetalert%3FID%3D118492186%26alert%3Don%26CRETRY%3D1%26SRETRY%3D0))

**Share the knowledge:** Ensure that your library is subscribing to the journal for 2009! Recommend it to your library using Wiley-Blackwell's [online form](#).

([http://www3.interscience.wiley.com/cgi-bin/mailform?item=118492186&skin=lib\\_](http://www3.interscience.wiley.com/cgi-bin/mailform?item=118492186&skin=lib_))

## 2012 World Congress in Halifax, Canada

Submitted by:  
Vianne Timmons

It's been only a few months since the 2008 Cape Town World Congress, and we're only a few months into 2009. As a result, it might seem like the June 2012 World Congress in Halifax is a long way off.

As President-Elect of IASSID and someone who is helping plan the 2012 World Congress, however, I can tell you that isn't the case! I've already got June 2012 marked on my calendar, and although I can't book my flight to Halifax quite yet, I'll be doing that as soon as the airline lets me!

I know you'll all want to do the same, because you won't want to miss



this World Congress! I grew up, went to university and worked in Atlantic Canada, so I'm really pleased that Halifax will be the second Canadian city ever to host the World Congress. The people are friendly, the weather will be spectacular, and there are so many attractions in and around this historic port city that it is the perfect place to hold the World Congress.

Museums, galleries, parks, historic sites, restaurants, pubs – Halifax has it all. There's no possible way I can do it justice in words, so you're going to have to see it yourself. A good start is the Halifax tourism website at <http://www.halifaxinfo.com/>, but don't stop there! Keep June of 2012 open on your calendar, and get ready to register for the World Congress and book your flight!

I'll be making a site visit to Halifax very soon, at which time the planning for the World Congress will begin in earnest. In the next few months, the committee members and I will provide you with more details such as exact dates, venue and registration information.

See you in Halifax!



Vianne  
Timmons

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

Submitted by:  
Keith McVilly

In an unprecedented accolade, both the 2008 *Journal of Intellectual & Developmental Disability (JIDD) Editor's Prize* and the 2008 *Australasian Research Prize* have been awarded to: Prof Alan Hudson, Dr Christine Cameron & Dr Jan Matthews for their paper titled "The wide-scale implementation of a support program for parents of children with an intellectual disability and difficult behaviour". This report is published in the *Journal of Intellectual & Developmental Disability*, Volume 33 (2).

ASSID has announced new editors for the *Journal of Intellectual & Developmental Disability*: Professor Susan Balandin of Molde University, Norway; and Associate Professor Ian Dempsey of the Newcastle University,

Australia. Much thanks and appreciation is extended to the outgoing Editor, Associate Professor Roger Stancliffe of the University of Sydney, who completed two 3-year terms as Editor-in-Chief. JIDD is available to IASSID Members at a discounted rate – refer to details on the IASSID site at: <http://www.iassid.org/iassid/content/view/46/62/>.

ASSID's quarterly magazine, *Intellectual Disability Australasia (IDA)*, also has a new Editor, Ms Susan Peden of the Disability Services Commission of Western Australia. Details are available at: <http://www.assid.org.au/Publications/Periodicals/tabid/68/Default.aspx>.

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## Report from Stevens-Shapiro Awardee— Ine Hostyn

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### **Ine Hostyn—Belgium**

Ine Hostyn is a PhD student at the Centre for Parenting, Child Welfare, and Disabilities at the K.U.Leuven in Belgium.



### **Kate McDonald—USA**

Katherine (Katie) McDonald is an Assistant Professor in the Department of Psychology at Portland State University in Portland, Oregon, USA.

My name is Ine Hostyn and I am working as a PhD student at the Centre for Parenting, Child Welfare and Disabilities at the Katholieke Universiteit Leuven in Belgium. Under the supervision of Prof. Dr. Bea Maes, in October 2006 I started a doctoral research project entitled 'evaluating and improving the quality of the interaction between persons with profound intellectual and multiple disabilities (PIMD) and direct support staff'. I developed a conceptual model based on a review of the literature and investigated the usefulness of existing caregiver-child coding instruments to bring the quality of the interaction with persons with PIMD into picture. Working on this for almost two years, the IASSID 13<sup>th</sup> World Congress took place at the ideal moment for me to share the obtained results and to gain new inspiration for the continuation of the project. Thanks to the IASSID Stevens-Shapiro Fellowship, I was able to join this conference which resulted in a very valuable experience.

The preparation of the conference was in itself an important part of the whole process. Writing an abstract, having a deadline, describing a problem statement for a part of my study, discussing results with colleague researchers, thinking about the main message of the study results, reflecting on limitations and necessary next steps, moulding all thoughts into a short but logical presentation ... are just a few examples of these congress preceding learning experiences.

Of course, the central focus and challenge of my congress participation was the presentation of my study for an audience of researchers and practitioners. The discussion afterwards was certainly interesting but, to my feeling, too short. I would have loved to discuss the study in more detail. Moreover, my presentation formed a real good basis to come into contact with fellow researchers and to exchange ideas with experienced persons.

I had the honour to be part of one of the three symposia about 'communication and interaction with persons with PIMD'. It was extremely interesting that this 'hot' topic was addressed from diverse points of view

and in different countries, which again proved to me the importance of quality interaction for persons with PIMD. In addition, the more philosophical reflections on these relationship processes were very appealing. Now I am even more convinced that gathering knowledge about persons with PIMD and their proxies is fascinating because they confront us with the most basic and fundamental processes of human interaction, communication, and quality of life.

These presentations about the target group were particularly inspiring for me and also form a motivation to work out the gained results and ideas in a written manuscript. But next to the in depth insights resulting from following symposia about the theme of PIMD, I also broadened my view at the IASSID World Congress. After only two years of working on my research project, I realised at the conference that I already became very selective in reading and even thinking. By being present at the plenary sessions but also by attending symposia of various themes, I obtained more general knowledge about persons with intellectual disabilities and their families, about education and setting up intervention for professionals, etc. Although not immediately useful or translatable for my project, I think it is valuable for a young researcher to know general trends in the field. Besides, and maybe most important for me as a doctoral student, I acquired more insight in doing good research.

In that respect, I learned something from every speaker: either with regard to the content or method, or with regard to the form of their presentation. By attending different presentations, I also concluded for myself that it is not the amount of information that counts but the clarity of a main point that is most important. A rush through a long presentation is not necessarily effective, but instead raising interest and awareness is the main goal of a presentation. After all, further information can always be read afterwards or exchanged in a person-to-person conversation. I will remember this for my own future presentations.

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I had the honour of presenting at the IASSID World Congress in Cape Town, thanks to the award of the Stevens-Shapiro memorial fellowship. The title of my presentation was "Sexual rights and intellectual disability in Ireland" and in it I discussed some of the findings of my PhD research – specifically, the findings of focus groups that I'd carried out with people with intellectual disabilities in a disability service in a small Irish town. During the focus groups, I'd spoken with men and women with intellectual disabilities about their experiences, attitudes and aspirations with regard to relationships and sexuality. I also spoke with family members, staff and management in the same service about their attitudes and experiences, but the primary focus of the research was on finding out what people with ID wanted, as nationally and internationally, there is very little research which has sought their views.

The research was unique because Ireland is at a stage where we are still slowly emerging from a climate of repressive, conservative attitudes towards sexuality and where people have traditionally had real difficulty talking about sexuality in an open manner. Add to this, attitudes towards people with ID, who throughout the world tend to be stereotyped as vulnerable, childlike and uninterested in sexuality, and you have an aspect of people with ID's lives that is full of challenges, neglect and a lack of appropriate service delivery. In Ireland, there is almost no published research on the topic of sexuality and ID so my research is helping shed light on an area where comparatively little is known and yet, which causes huge concerns for families and service providers.

The key findings which emerged from my focus groups with people with ID, and which I presented at the IASSID World Congress, is that men and women with ID are articulating a strong desire for romantic relationships, but are currently living within a climate of prohibition. Participants with ID spoke about getting into trouble for having boyfriend-girlfriend relationships and past experiences of having a relationship broken up. Service users believed that relationships were not allowed within their service. For

example, when asked, "What do you think staff think of you having a girlfriend?" Patrick responded: "They won't be happy either way! No, we are all friends or all roommates." Elizabeth explained how she had to end a relationship with a previous boyfriend and become "just friends" and Victoria explained how "when I was going out with this fella... One staff didn't like it. Didn't say why. Every time [my boyfriend] wanted to talk to me, [the staff member] used to pull him away". Participants also alluded to the fact that their relationships were being monitored. For example, Elizabeth said: "Me brother have to come out with me [on dates] because ... he has to watch us, just in case we might be up to something".

Participants with ID's responses to the climate of prohibition appeared to be threefold. Some appeared to have taken on board the prohibitions and spoke about relationships as something fearful or taboo. This was particularly the case for Sarah, who'd previously been in a relationship that had been broken up, and when I asked her about boyfriends responded with a lot of "No's" and "Keep away from them!"

The second response that a number of participants had adopted appeared to be one of secrecy. They were in relationships, but behind staff's backs. One woman, Elizabeth, whose previous boyfriend relationship had been broken up, now had a "special friend". When a staff member was present in our group she stated that she did not kiss or hold hands with this 'special friend', but when there was no staff member present, she admitted that she did kiss her boyfriend: "I watch and then, and then they won't be looking at me."

The third response to prohibition was the beginning of a questioning and challenging of restrictions. Victoria, for example, was aware that people were treating her differently because of her disability: "Because ... like we're in St Anne's, people think that we shouldn't have boyfriends, we shouldn't be doing this... it is hard, like ya know... Its discrimination." Responses like Victoria's could in the future pave the way for participants in these groups to become more aware of their rights and to begin to advocate on their own behalf. Indeed what I found was that

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### Grace Kelly—Ireland

Grace is a PhD student in the Dept of Applied Social Studies, University College Cork where she is currently undertaking research on "Sexual Rights and Intellectual Disability".



### Shaun Cleaver—Canada

Shaun is a physiotherapist whose main career interest is working with people with disabilities across cultures and in resource-poor environments.

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### 2008 Stevens-Shapiro Award Winners

Four promising young researchers were awarded Stevens-Shapiro Fellowships in 2008. They were from Belgium, USA, Canada and Ireland. Reports submitted by two of them are included in this issue.

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

*The Stevens-Shapiro fellowship is open to young researchers, under 30 years of age, who are actively involved in the field of intellectual disability.*

For more information about the Stevens-Shapiro Award, please visit the IASSID website:  
<http://www.iassid.org/iassid/content/view/82/81/>

as focus groups continued, more service users appeared to begin to question the fairness of restrictions that they'd previously taken for granted.

The conclusion which I drew from this stage of the analysis of my fieldwork is that the area of sexuality has not yet been seen as a positive aspect of life for many people with ID in my groups. The dominant response of parents and staff appears to have been of fear and a desire to protect, which as these focus group findings illustrate, can be experienced by people with ID as prohibition and restriction. Given the needs and desires that people with ID in my groups were strongly articulating and their rights in this area, as enshrined under EU and UN legislation, it is clear that the Irish focus must be readjusted from one of predominantly protection, to one of respect for people with ID's right to sexuality.

Reactions to my presentation at the IASSID World Congress on the whole appeared to be positive. Quite pleasingly it went down really well with people with ID, some of whom asked me afterwards if they could participate in a group talking about relationships. Other researchers also found something of interest in the presentation. Some contrasted the barriers highlighted by my research participants with findings of their own studies in other countries, which appeared to show a more positive approach to the sexuality of people with ID (e.g. Yacoub & Hall, presentation at IASSID 2008). Other researchers argued that they believed that the findings were not that unusual internationally, and that there are many people with ID who are forced to live secret sexual lives, and thus, unsafe ones (Johnson, based on the findings of the Living Safer Sexual Lives study, Johnson et al 2001).

I attended many fantastic presentations at the World Congress. Several of the presentations I attended were looking at the area of inclusive research, ethical issues around this and difficulties accessing people with ID to participate in research (e.g. McDonald; Cleaver). I was really interested in the inclusive research presentations as I would, in

future, like to find ways to co-present my PhD research findings with some of the people with ID who participated in the research and listening to these presentations (e.g. McGrath, Minogue & Hopkins) gave me useful ideas on how I might do this. Other presentations that I attended were of course in the area of relationships, sexuality and parenting by people with ID. I was delighted that there were so many presentations of this kind at the IASSID congress and that many of them had a strong advocacy and rights based focus. Gwynnyth Llewellyn spoke about people with ID as parents at a plenary on the Friday morning and was inspiring. People with ID as parents is an area of research which has been neglected so far in Ireland. Listening to Llewellyn, Tarleton, Sigurjonsdottir, Traustadottir and co. provided ideas for similar research and support initiatives which could be carried out here in Ireland.

I met fantastic people during the trip to Cape Town, bumped into others that I had not seen for a long time, and really had a wonderful trip. Some members of the group I travelled with (inclusive researchers from the National Institute of Intellectual Disability in Trinity College and the Brother's of Charity Ennis) became my good friends and we made sure that the trip was not all work by going on safari, shopping in the African women's market, eating dinner on a cruise on the waterfront, visiting Mama Africa's where the lively band, Abakhaya had everyone wanting to dance their way through dinner, and of course, we also did a spot of dancing and karaoke. It really was a fun, memorable time and I know I made friends and contacts that will last longer than the congress itself.

Since, I've come back to Ireland, I've been working on the analysis of my remaining PhD fieldwork and the write up of my remaining PhD chapters which I hope to complete over the next few months. Directly as a result of the congress, I've also however, been writing an article for submission to a forthcoming Irish edition of the BJLD, I'm putting together a programme for an Irish conference on sexuality and ID, I've visited the Brother's of Charity Ennis to assist their Inclusive Research Relationship group, I've been working

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Mencap Fellowships can be used to waive registration fees to attend the IASSID World Congress, cover travel and accommodation costs, and to assist with other costs associated with attendance at the Congress. The following people received Mencap Fellowships in 2008:

**Ereny Gobrial**, Egypt

**Evariste Karangwa**, Rwanda

*"Among the many benefits about the Congress is not only being able to meet and share ideas with a wide range of researchers from different schools of thoughts, but the fact that we had all congregated under the theme of Intellectual Disability, we were able to establish a focus on what we wanted to learn and share. I was personally impressed by the great work accomplished by many researchers, hailing from both the well resourced countries and deprived societies, for their work that actually complemented my own, relating poverty and intellectual disabilities."*

**Paul M. Ajuwon**, Nigeria

*"In my continued advocacy efforts, I plan to create a greater level of community awareness and legislative support so Nigeria and other African countries can begin to design and implement effective social and educational services that will enable their vulnerable and marginalized citizens to live within their communities and accorded full rights and dignity."*

**Professor Kelvin Mwaba, Ancent Muli Muvua, Nomonde Ngada and Elmari Janse van Vuuren**, South Africa

**Amshuda Sayed**, South Africa

*"The feeling of knowing that there are people from all parts of the globe interested in intellectual disability is overwhelming, but these kaleidoscopes of views make the research so rich and diverse. This larger than life feeling followed through to the Congress, which provided great networking opportunities during the tea and lunch breaks."*

**Marinda Roelofse and Amanda Roux**, South Africa

**Maletsatsi Annah Ttshabangu**, South Africa

**Karen Spencer and Craig Harte**, United Kingdom

*"We have many contacts in Europe and in English speaking countries. We were sorry not to have met any Africans that we might work with. However, having been to Cape Town we hope that it will be possible to make contact using the delegate list."*

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## Vianne-Timmons—Canada's Most Powerful Women: Top 100 Award

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IASSID President-Elect, Vianne Timmons, has been selected as a recipient of the 2008 Canada's Most Powerful Women: Top 100 Award. The Top 100 Award is an initiative of the Women's Executive Network (WXN) and is co-presented by the Richard Ivey School of Business and Scotiabank. The annual listing of the Top 100 most powerful women in Canada honours the accomplishments

of women in eight categories and all fields of endeavour. Winners are selected by an independent advisory board under the leadership of the WXN.

More information about WXN and the 2008 Canada's Most Powerful Women: Top 100 Award can be found at <http://www.wxnetwork.com/>

*"Mencap is the voice of learning disability. Everything we do is about valuing and supporting people with a learning disability, and their families and carers."*

*"We work with people with a learning disability to change laws and services, challenge prejudice and directly support thousands of people to live their lives as they choose."*

**For more information about MENCAP Fellowships, please visit the IASSID Website:**  
<http://www.iassid.org/iassid/content/view/82/81/>

## About the Newsletter

Past issues of the IASSID Newsletter are available online:

[http://seocura.org/IASSID/Updates\\_News.html](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: [oulette@queensu.ca](mailto:oulette@queensu.ca)

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## Stevens-Shapiro Award -Grace Kelly

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*(Continued from page 8)*

with a team of researchers on a joint Irish/UK research proposal which would look at the area of sexuality and ID in the two countries, plus I've also started working one day a week in NIID, Trinity on a "Life Story" project... So as well as having had the fantastic opportunity of sharing the results of my PhD research with an

international audience, a lot has already come out of my attendance of the IASSID World Congress –and long may it continue! So, I really want to thank the administrators of the Stevens-Shapiro Fellowship for the award –as a young academic, the IASSID conference has been a fantastic opportunity and a wonderful learning experience.

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## Stevens-Shapiro Award –Ine Hostyn

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*(Continued from page 6)*

Since the scope of this report is limited, I can not describe all my experiences. But: hearing the vision of policy workers, listening to persons and presentations that raised awareness of the situation and needs in Africa (which I consider very significant as a young person from a prosperous country), attending the meeting of the SIRG PIMD, visiting and living in Cape Town for a week (which was a pleasant side effect of the conference), were also worthwhile for me.

In conclusion, I can state that my experiences at the IASSID 13<sup>th</sup> World Congress in South Africa were valuable for me as a young person and researcher, and formed a confirmation of my current work and pursuits. However, this was/is closely aligned with the arising of doubt: How to take into account the work of international colleagues and integrate new insights in my research project?

How to set up a justified intervention and evaluate its effects thoroughly? And so on. This led to a kind of uncertainty at the moment of the conference, but as George Iles stated, 'doubt is the beginning, not the end of wisdom'. I am convinced that this (time for) doubt is a perfect occasion for me to become again aware of the presuppositions of my project and to think over again my research aims and methods.

I am grateful to have had the opportunity to attend the conference. The World Congress was an excellent chance to acquire motivation to go on, to extending my international network and to become more competent as a young researcher. For that, I would like to acknowledge all presenters and other persons who inspired me, and a special thank to IASSID for awarding me the Stevens-Shapiro Fellowship. I hope to share my further work with you in future manuscripts and I look forward to next conferences!

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

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*(Continued from page 5)*

Peer reviewed abstracts from the 43<sup>rd</sup> annual ASSID Conference (conducted with the theme "Principles, Policies & Practices: the search for evidence"), and abstracts from the 8<sup>th</sup> annual Disability Support Worker Conference (conducted with the theme "Working Well: on paper and in practice" are available on the ASSID website at: <http://www.assid.org.au/ConferencePapers/tabid/59/Default.aspx>.

Details of the 44<sup>th</sup> annual ASSID Conference, to be held at Hobart in Tasmania (4<sup>th</sup> to 6<sup>th</sup> November 2009) are available on the ASSID home

page: [www.assid.org.au](http://www.assid.org.au). The Conference Co-chairs are Ms Darryleen Wiggins and Mr Craig Jones. The theme of the 2009 conference will be "Power and Passion: progress through partnerships". Abstracts are now invited. Planning has also commenced for the 2010 conference, to be held at Brisbane, in Queensland.

The in-coming Executive of the ASSID Board for 2008/09 are: President, Dr Olive Webb (New Zealand); Vice President, Mr Richard O'Loughlin (South Australia); Secretary, Ms Darryleen Wiggins (Tasmania); Treasurer, Mr Craig Jones (Tasmania); and Registrar Ms Susan Peden (Western Australia).

**4<sup>TH</sup> ROUNDTABLE Meeting**  
**2<sup>ND</sup> YOUNG RESEARCHER COLLOQUIUM**  
**1<sup>ST</sup> Parents Organisation Meeting**

March, 2009

**SPECIAL INTEREST RESEARCH GROUP**  
**PERSONS WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES**  
**23. – 25. SEPTEMBER 2009**

**Cologne – Germany**

The University of Cologne will host the 4<sup>th</sup> International Roundtable of the IASSID-Special Research Group on Persons with Profound Intellectual and Multiple Disabilities. The aim is to bring researchers, young researchers, practitioners and parents to discuss actual themes about special behaviour problems, learning and education about persons with profound intellectual and multiple disabilities.

The 4<sup>th</sup> International Roundtable-Meeting will document the by now evolved cooperation and developments of the SIRG PIMD. Besides the exchange of research results of the selected themes on the 23<sup>d</sup> and 24<sup>th</sup> of September, Young Researchers will discuss theoretical and methodological research questions with experienced researchers within the framework of a colloquium on the 25<sup>th</sup> of September. Parents are professionals in the matters of their children with profound disabilities. The professionalism of the parents is essential for the research in the field of PIMD. Therefore parents are members of the SIRG PIMD. To get into intercommunication with the parents from different European countries, ambassadors of the parent-organisations PAMIS from Scotland and the "Stiftung Leben pur" from Germany will offer a discussion-group for parents on Friday, the 25<sup>th</sup> of September, as well.

**Venue**

23<sup>d</sup> – 24<sup>th</sup> September 2009

Maternushaus

Kardinal-Frings-Straße 1-3

50668 Cologne

Fon: (49) 221- 16 31- 0      Fax: (49) 221 – 1631 – 215

E-Mail: [info@maternushaus.de](mailto:info@maternushaus.de)      [www.maternushaus.de](http://www.maternushaus.de)

The board has selected three themes for this roundtable. For each theme there will be an introduction discussing the state of the art and/or actual research questions. After the introduction there will be plenty of time for discussion. For each theme one of the participants will be asked to make some concluding remarks.

<b>Wednesday, 23<sup>d</sup> September 2009</b>	<b>Thursday, 24<sup>th</sup> September 2009</b>	<b>Friday, 25<sup>th</sup> September 2009 Young Researcher Meeting</b>
<b>13h:</b> Registration	<b>8.30h:</b> Registration	<b>9.00 h:</b> Welcoming and introduction of each research project
<b>14h:</b> Welcome/Introduction	<b>9.00h: Theme 2</b> <i>Learning of and education for persons with profound intellectual and multiple disabilities</i>	<b>10.30 h:</b> 1 <sup>st</sup> presentation and discussion of research projects (in groups)
<b>14.30h: Theme 1</b> <i>Review of behavior problems and interventions for persons with profound intellectual and multiple disabilities</i>	<b>10.30h:</b> Break	<b>12.30 h:</b> Lunch
<b>16 h:</b> Break	<b>11 h:</b> Questions to speakers	<b>14.00 h:</b> 2 <sup>nd</sup> presentation and discussion of research projects (in groups)
<b>16.30h:</b> Questions to speakers	<b>12.30h:</b> Lunch	<b>15.30 – 15.45</b> Break
<b>17.30 h:</b> Poster Session and Market Place	<b>14 h:</b> PIMD SIRG Council—IASSID European Congress 2010	<b>15.45</b> Conclusion of each group, discussion and roundup
<b>18.30 h:</b> Dinner at Maternushaus—free to sample the wonderful pubs in Cologne	<b>14 h:</b> Poster Session and Market Place	<b>Friday, 25<sup>th</sup> September 2009 – Parents Organisation Meeting 9 – 12.30h</b>
	<b>16 h:</b> Discussion: UN-Convention-Human rights for Persons with PIMD	
	<b>18h:</b> "On the Top of the Cathedral" and Dinner at a typical restaurant of Cologne	

**IASSID MEETINGS in  
2009/2010**

**2009**

*2nd Asia Pacific Regional Congress  
"Creating Possibilities for an  
Inclusive Society"*

**Date:** June 24-27, 2009

**Location:** Singapore

**Special Interest Research  
Groups**

**Quality of Life**

June 2009

Singapore

**Health Issues**

September 8-10, 2009

Kingston, Canada

**Aging**

September 23-25, 2009

Edinburgh, Scotland

**Profound Multiple Disabilities**

September 23-25, 2009

Cologne, Germany

**2010**

*3rd Europe Regional Congress  
"Integrating biomedical and  
psycho-social-educational  
aspects"*

**Date:** October 20-22, 2010

**Location:** Rome, Italy

**Special Interest Research  
Groups**

**Comparative Policy and Practice**

October, 2010

Rome, Italy

Likely to focus on deinstitutionalization and the development of community-based services from an international perspective.

*Please note the dates and times of some  
meetings have not yet been set.  
Information on all meetings will be  
placed on the website as it becomes  
available.*

<http://seocura.org/IASSID/Meetings.html>



The International Association for the Scientific Study of Intellectual Disabilities (mental retardation and related developmental disabilities) is an international and interdisciplinary scientific non-governmental organization with official relations with the World Health Organization. It promotes worldwide research and exchange of information on intellectual disabilities. The association (originally named the International Association for the Scientific Study of Mental Deficiency) was founded in 1964 and has sponsored eleven World Congresses. IASSID is the first and only world-wide group dedicated to the scientific study of intellectual disability.

## IASSID Fellows

### 1996—Helsinki, Finland

R.J. Andrews Australia  
Masataka Arima Japan  
Adrian Ashman Australia  
Bente Beck Denmark  
M.J. Begab U.S.A.  
J.M. Berg Canada  
Alice Bernsen Denmark  
Hans K. Blomquist Sweden  
Nick Bouras United Kingdom  
Bernabe Cantlon Argentina  
Maria Cerna Rep. Of Czechoslovakia  
A.D.B. Clarke United Kingdom  
Renato Cocchi Italy  
Kenneth Day United Kingdom  
Coen de Jong The Netherlands  
Terrence R. Dolan U.S.A.  
Annalise Dupont Denmark  
William Fraser Wales  
Josef Jancar United Kingdom  
Matthew Janicki U.S.A.  
Stephen Kealy. Ireland  
Marty Krauss U.S.A.  
J.G.R. Kromberg South America  
Hiroshi Kurita Japan  
Sharon Ramey U.S.A.  
Martha Lieberhoff Argentina  
Paula Maatta Finland  
Ghislain Magerotte Belgium  
Leena Matikka Finland  
Hugo Moser U.S.A.  
Michael Mulcahy Ireland  
Gerhard Neuhauser Germany  
Trevor Parmenter Australia  
David Primrose United Kingdom  
Marcia Rioux Canada  
Neil Ross France  
G. Rossato Italy  
Sasumu Sato Japan  
Akihiko Takahashi Japan  
Yoshikazue Tomiyasu Japan

Gijs van Gemert The Netherlands  
Tien Miao Wang Taiwan  
Yv Wily New Zealand  
Jacek Zaremba Poland  
Edward Ziegler U.S.A.

### 2000—Seattle, Washington USA

Mark Bradshaw England  
Kurt Forrest Bennet U.S.A.  
Ivan Brown Canada  
Roy Brown Canada  
Helen Beange Australia  
Heleen Evenhuis The Netherlands  
David Felce England  
Bengt Hagstrom Sweden  
Helena Hiila Finland  
James Hogg Scotland  
Anthony Holland England  
John Jacobson U.S.A.  
Laurence Kebbon Sweden  
Henny Lanteman de Valk The Netherlands  
Travis Thompson U.S.A.  
Kuo-yu Wang Taiwan  
Philip W. Davidson U.S.A.  
Michael Guralnick U.S.A.  
Randi Haggerman U.S.A.  
Tamar Heller U.S.A.  
Matti Livanainen Finland  
David Mank U.S.A.  
Jan Francois Mattei France  
Peter Mitler England  
Thomas Mutters Germany  
Patricia Noonan Walsh Ireland  
Craig Ramey U.S.A.  
Louis Rowitz U.S.A.  
Robert Schalock U.S.A.  
Stephen Schroder U.S.A.  
Robert Stodden U.S.A.  
Ryo Takahashi Japan  
Lilian Thorpe Canada

### 2004—Montpellier, France

Giorgio Albertini Italy  
David Allen UK  
Charles Aussilloux France  
Steve Beyer UK  
Jan Blacher USA  
Tim Booth UK  
Janis Chadsey USA  
Arthur Dalton USA  
Eric Emerson UK  
Richard Hastings UK  
Chris Hatton UK  
Susan Hayes Australia  
Meindert Haveman Netherlands  
Mike Kerr UK  
Bill Lindsay UK  
Maria Malbran Argentina  
Roy McConkey UK  
Glynis Murphy UK  
Han Nakken Netherlands  
Vee Prasher UK  
Hans Reinders Netherlands  
Marsha Seltzer USA  
Wayne Silverman USA  
Harvey Switzky USA  
Ryo Takahashi Japan  
Stuart Todd UK  
Jan Tøssebro Norway  
Rannveig Trausadottir Iceland  
John Tsiouris USA  
Carla Vlaskamp Netherlands  
Warren Zigman USA

### 2008—Cape Town, South Africa

Roger Stancliffe Australia  
Robyn Anne Wallace Australia  
Chris Conliffe Northern Ireland