



Международное, Зо.

NEWSLETTER

International Association for the Scientific Study of Intellectual Disabilities

MESSAGE FROM THE PRESIDENT

It hardly seems like nearly a year since the Montpellier Congress, so vivid are the memories in my mind. Much has been done in that time by the wider IASSID network. I will raise five points of interest concerning developments and ongoing work of IASSID.

First we are sustaining a dynamic and impressive series of **Scientific Meetings**. In the next 15 months we can look forward to the:\

- ▶ 14th International Roundtable on Ageing and Intellectual Disabilities in Dortmund, Germany 17-20 May, 2005 (see <http://www.iassid.org/> for details)
- ▶ 1st Asia-Pacific Regional Congress in Taipei, Taiwan 12-15 June, 2005 (see <http://www.iassid.org/> and <http://www.asiapacificiassid.org/> for details)
- ▶ 2nd Joint Roundtable of the Health and Mental Health Special Interest Research Groups in Melbourne, Australia 28-30 September, 2005 (see <http://www.iassid.org/> for details)
- ▶ 2nd Roundtable of the Quality of Life Special Interest Research Group in Vancouver, Canada 26-28 April, 2006 (see <http://www.iassid.org/> for details)
- ▶ 2nd Conference of IASSID-Europe in Maastricht, The Netherlands 2-5 August, 2006 (see <http://www.iassid.org/> and

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<http://www.unimaas.nl/congresbureau/e-iassid2006> for details)

I know how much work organizing such events entails and I would like to thank all those involved in putting on such a stimulating programme.



INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF INTELLECTUAL DISABILITIES
 Association Internationale pour l'Étude Scientifique de la Déficience Intellectuelle
 Internationale Vereinigung zum wissenschaftlichen Studium von Intelligenzstörungen
 Asociación Internacional para el Estudio Científico del Deficiencia Intellectual
 Associação Internacional para o Estudo Científico da Deficiência Intellectual

See Internet at <http://www.iassid.org>

The **Executive** has met twice since June last year. We took the decision at the last General Assembly to expand the number of Vice Presidents to give a broader base to the Executive. In addition, to myself (President), Neil Ross (Past President), Glyn Murphy (President-elect), Vianne Timmons (Secretary) and Matt Janicki (Treasurer),

- ▶ Henny van Schroyen Lantman - de Valk has taken on a brief to develop liaison with and between Special Interest Research Groups, Affinity Groups and Research Centre members, as well as look at the possibilities for strengthening involvement from Eastern European countries

- ▶ Tony Holland has responsibility for publications - two additional books have recently been approved by a peer-review process to carry the IASSID impress

- ▶ Patricia Walsh has undertaken to provide a focus for our relationship with international agencies such as the WHO and EU - we will be developing the workplan associated with our NGO status with the WHO in the coming months and this will need to be carefully determined so that what we propose can be delivered

- ▶ Stephen Kealy has responsibility for our constitutional affairs - he will chair the Awards and Nominations Committees which have an important role in putting forward potential awardees and office holders.

I hope that strengthening the Executive will give the Association capacity to sustain and expand its recent growth in activity. I also hope that it will promote greater interplay between our many membership and topic-related networks and generate a feeling of interconnectedness and involvement in our affairs. Earlier this year, Vianne circulated all Council members with a short statement describing developments and raising issues for their consideration in an attempt to keep individuals better involved in between formal meetings. We hope to sustain and develop this kind of initiative.

I am happy to report that the Association is in a better **Financial Position** now than at any time in its past. The Montpellier Congress was financially successful not least because of the level of sponsorship attracted, largely through the efforts of Neil Ross and Charles Aussilloux. We now have the opportunity to invest some of the assets we hold to provide an income. We are looking initially to use this to develop administrative and organizational capability, but it also gives us some freedom to fund worthwhile causes, such as scholarships to the Asia-Pacific Regional Congress later this year. As you know, the Association depends on people volunteering their time and

efforts. This, of course, will remain largely unchanged but we are now in a position to support the administrative workload of the Secretary and Treasurer, which have increased with expanded membership, and to meet the financial implications of maintaining and updating the website. That the Executive could be expanded and be able to meet a number of times in between Council meetings is also related to our improved finances. In addition, we are also now examining our ability to support the travel and accommodation costs of members attending Council Meetings.

Our new journal, the **Journal of Policy and Practice in Intellectual Disabilities**, was successfully launched last year. We took the decision at the Executive Meeting in September, 2004 to make the journal available to all full members as a member benefit. This has given the journal a very strong initial subscriber base from which to expand. We are still able to offer the *Journal of Intellectual Disability Research* to members at a heavily discounted rate. So far, renewal of subscriptions has been on a par with previous years.

And one last thing ... we are looking at the possibility of changing the **Logo**.

And another ... I find it terribly reassuring to be surrounded by such a strong and competent Executive, an exciting and diverse Council and a set of well mobilized Special Interest Research Groups, Affinity Groups and burgeoning Regional networks. Working for IASSID always results in people creating pressures for themselves in their day jobs, donating their evenings and weekends and being out-of-pocket. I'd like to take this opportunity to thank everyone for their commitment.

David Felce
President

IASSID MEMBERSHIP

IASSID has several categories of membership, one for individuals and two for organizations. IASSID has always been a membership organization, originally formed in the 1960s by a number of national membership-based scientific associations with interests in intellectual disabilities. In the 1990s, the Association broadened its membership base to include individuals, and in the past



few years has opened up its membership to research centers, foundations, and related staff-based organizations. In addition to groups, IASSID welcomes membership from persons involved in the study of intellectual disabilities, workers serving persons with intellectual disabilities or their families, and administrators, educators, advocates, and others interested in research concerned with intellectual disabilities.

The IASSID is an affiliated organization to the World Health Organization and has inter-organization affiliative agreements with a number of other international membership-based organizations.

Full membership in IASSID permits total involvement in the affairs of the Association. Reduced fee memberships are also available for students and colleagues who are pensioners and special accommodations are available for colleagues living in countries with limited or developing market economies.

Full Members receive a subscription to the Journal of Policy & Practice in Intellectual Disabilities (JPPID) – the official IASSID international journal – and are entitled to a substantial discount to IASSID-sponsored conferences, meetings, and workshops. Full, student and pensioner members are also eligible for reduced-rate subscriptions to the Journal of Intellectual Disability Research (JIDR) and the Journal of Intellectual and Developmental Disabilities (JIDD). Subscribers to the IASSID-Blackwell journals receive both print versions and have on-line access to the journals at Blackwell Publishing's Synergy Internet site. Membership benefits also include discounts for IASSID books.

Currently, IASSID has 25 national associations maintaining affiliative status with IASSID, representing 19 nations. In addition, some 45 groups maintain research center membership (29 are in Europe, 5 in Asia-Pacific, and 12 are in North America). As IASSID is a multi disciplinary organization, its individual members reflect a diversity of disciplines: 31% are psychologists, 12% are psychiatrists, 11% are physicians, 11% are pedagogues or educators, 7% are social workers, 6% are nurses, and the balance represent a range of other interests or professions. Members also come from all over the world; current members represent about 40 countries. IASSID represents an excellent vehicle for networking and connecting with colleagues with similar interests all over the world.

Joining IASSID and maintaining membership has been

made easy via the use of IASSID's Internet site – www.iassid.org. Potential or active members can organize their membership via credit card payment on the site as well as updating their member information. IASSID maintains a member directory which is posted on the members' only pages of the IASSID website.

SECRETARY'S REPORT

Well, this has been a year of learning for me as the new secretary for IASSID. I have to acknowledge the amazing support of my executive assistant Edith Cardy who has taken on a lot of the communication with the members.

We are looking at revamping the IASSID logo and have selected three for your consideration (see page 8). Please e-mail vtimmons@upei.ca with your preferred choice and we will be deciding on the new logo in Taipei at the Council meeting..

We will be sending the newsletter out through electronic means in the future. This is to save costs and increase distribution. Please forward this newsletter to any of your colleagues you think may be interested.

The Council members are:

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



We will be having a Council meeting in Taipei at the Asia regional IASSID conference June . Please communicate any concerns or issues to any of the Council members so they can bring them forward at the June meeting. Have a great summer.

*Vianne Timmons,
Secretary*

CAPE TOWN VISIT

In early December 2004, David Felce (President of IASSID), Glynis Murphy (President-Elect) and Matt Janicki (Treasurer) flew to Cape Town for four days. The aim of the visit was to meet with the Local Organising Committee (LOC) and the conference managing centre representatives, and to inspect the conference site for the IASSID 2008 World Congress. Interestingly we discovered that Cape Town is becoming an extremely popular conference site. There was a big conference for the visually impaired while we were there and there are major conferences planned for the next few years (in medicine, disability and other topics). We were not planning too far ahead!

LOC

At present, the LOC consists of Dr Jennifer Cartwright, John Cruikshank and Prof Chris Moltano. Jennifer and John are based in Johannesburg; Chris is based in Cape Town. All three have lengthy experience working in intellectual disabilities in South Africa. The LOC is an informal group who will liaise with the professional community in South Africa and the government there (they will not have financial responsibilities for the conference). The LOC are very committed to making the World Congress a success and they gave us a great deal of their time over the four days. They attended all the site visits with us. They also helped us to see as much of Cape Town and the surrounding area as we could manage in our time there.

They will be expanding their LOC group over the next few months and working to attract participants from South Africa and further afield to the conference, both as speakers and as delegates.

Conference Management Centre

The CTICC (see below) is the venue for the conference but

like many such venues, the building is what you get and just about everything else (registration, hotel booking, powerpoint, poster displays, coffee/tea, lunches, catering for the reception, flowers for the stage, banners, etc) is extra and done by a separate organisation. The Cape Town University Conference Management Centre is going to be the organisation providing all this for us. They will run registration and hotel arrangements for us, plus organising the other items. During our visit a number of CMC staff attended our meetings with CTICC (our main contacts were Alana James and Debra). The CMC also arranged visits to a variety of hotels for us and arranged a trip to Table Mountain and the surrounding areas for our last day. They seem to us to be well-organised and helpful.

Cape Town International Conference Centre (CTICC)

The conference centre is where the conference will be based. It is centrally located in Cape Town, near some good hotels and not far from the waterfront, a vibrant restaurant and tourist area. The building is very large and beautiful, with pale wooden floors and plenty of light (the architect was Swedish). The main auditorium is excellent for our purposes and the ballrooms just nearby will be well-suited to us for the welcome reception, for poster displays and tea/coffees/lunches during the conference. The venue has a number of very large rooms and we will also be using some rooms in the hotel adjacent to the CTICC so as to have 16 parallel sessions, throughout the conference.

The dates of the conference will be: 25th – 30th August 2008. These dates are now booked with CTICC. We felt this was as late in the year as we could manage (given school start dates especially in USA) and we understand that this is the beginning of spring in South Africa. The weather will not be very hot and can sometimes be showery.

Cape Town

The CTICC is well placed for the city centre, close to the up-market hotels and is near the waterfront (15 minutes walk), where there are plenty more hotels, restaurants and tourist shops.

Outside the city there are an enormous number of possible activities, including climbing Table Mountain (cable car available), visiting numerous beaches, wine growing areas and so on. We plan to make these kinds of leisure tours separately bookable. Study tours are still to be decided.



SIRG COORDINATION COMMITTEE

This new committee will have its first meeting just before the next Council meeting in Taipei, on June 10, 2005. As the Chair of this Committee I am happy to announce you its existence and the plans. The Committee may well need your input to make it work.

The aim of the SIRG Coordination Committee is underlining the benefits of SIRG membership, such as create opportunities for networking with colleagues from all over the world, sharing information with them and getting involved in policy related to your expertise. As you may know, SIRG members are eligible for Council representation.

The first meeting will be dedicated to making a workplan for the next couple of years. Issues will include a process of standardization of SIRG organisation, creating a system for updating information on the IASSID website, and producing annual overviews of meeting data and locations. If you have any additional suggestions, please let me know by email.

*Henny MJ van Schroyensteyn Lantman- de Valk
MD, PhD,
Department of General Practice
Maastricht University
Email: henny.lantman@hag.unimaas.nl*

POLISH GROUP OF IASSID

Polish Group of IASSID, Academy of Special Education and Polish Association for Persons with Mental Handicap will organize in November 2005 the international symposium, "Included in Society" to celebrate the 30th Anniversary of activity of Polish Group of IASSID."

*Prof. Anna Firkowska-Mankiewicz
The Maria Grzegorzewska Academy of Special Education,
Warsaw*

AIM

Aim, is presently building a mission to host the many oldfolks after the 14 years of civil war in Liberia. We are also appealing to organizations with IASSID to help support our project in the areas of watsan (wells and sanitation). this is to save the lives of these many children and oldfolks we are catering to.

*Pastor Bobby B. Moore
General Overseer*

FIRST ASIAN-PACIFIC IASSID REGIONAL CONGRESS TAIPEI, TAIWAN 12-15 JUNE 2005

The First Asian-Pacific Regional Congress of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) will held from June 12th to 15th, 2005, in Taipei.

This is the first IASSID conference to be held in Asia and will address research on a number of lifespan issues. Submissions of papers and posters are welcome and should be sent via the Congress website <http://www.asiapacificiassid.org/main.html>. This address can also be accessed for information and for registrations.

IASSID Member Affairs Office

14TH INTERNATIONAL ROUNDTABLE ON AGING AND INTELLECTUAL DISABILITIES

The 14th International Roundtable on Aging and Intellectual Disabilities in Dortmund, Germany was held May 17-19. A special regional conference on Disability and Aging will be held on the 20th at the University of Dortmund.

IASSID Member Affairs Office



AUSTRALASIAN SOCIETY FOR THE STUDY OF INTELLECTUAL DISABILITY (ASSID)

The Australasian Society for the Study of Intellectual Disability (ASSID) includes members in each of the states and territories of Australia, in New Zealand and a number of other countries in the Asia-Pacific region. Our quarterly peer-reviewed journal, the *Journal of Intellectual & Developmental Disability* (Edited by Associate Professor Roger Stancliffe of the University of Sydney's Centre for Developmental Disability Studies, and published by Taylor & Francis) has an international readership, and has recently been accepted for indexing in *Med-line*. Our 'newsletter' has now evolved into a quarterly, practitioner-focused magazine, *Intellectual Disability Australasia*. Under the editorship of Dr Deborah Keen of the University of Queensland, the magazine is progressively including more articles with a 'best-practice' focus.

Each of the seven Regional Associations which comprise ASSID are currently planning regional conferences for 2005 / 06, as well as specialist conferences for direct support staff in Victoria and Queensland. Our Australasian Board is finalizing arrangements for holding our first Australasian Conference in New Zealand: 9-14 October 2005 at Waipuna Lodge, Mt Wellington (30 minutes drive from Auckland). The conference theme is "*Out of the ordinary: creativity, co-operation, collaboration*". The Convenor is Fran Hartnett (Tel: [64] + (0)9 + 3787046; E-mail: samsfh@actrix.co.nz). Abstracts are due by 15th July 2005. For further details see - www.assid.org.au or www.assid-conf05.org.nz.

ASSID has recently recognized the contribution of Dr Helen Beange AM to both ASSID and the wider community by awarding her the inaugural *Fellowship of ASSID*. Also, Ms Sheridan Forster has recently been awarded the *ASSID Research Grant* for 2004 / 05, for a project entitled "*Communicative Interactions between Adults with Profound Intellectual Disability and Support Workers*". This project is being conducted as part of Ms Forster's Master of Biomedical Science at the Centre for Developmental Disability Health Victoria, in the Faculty of Medicine, Nursing and Health Sciences, Monash University. The project is being supervised by Dr Teresa Iacono.

Last year, ASSID members were involved in the IASSID Quality of Life SIRG Round Table at Sydney. This year,

ASSID members will be involved in the combined IASSID Physical Health SIRG / Mental Health SIRG Round Table to be held at Melbourne, from September 28th to 30th. Also, ASSID's research community is expected to be well represented at the inaugural IASSID Asia-Pacific Regional Congress, in Taiwan, 12 to 15 June 2005.

Keith R. McVilly PhD
ASSID Secretary &
ASSID Representative to IASSID
kmcvilly@med.usyd.edu.au

ASIAN-PACIFIC REGIONAL ORGANIZATION OF IASSID: WHY IT IS IMPORTANT TO BRING ASIAN-PACIFIC INTO THE STUDY OF INTELLECTUAL DISABILITIES.

As deadline for the first Asian-Pacific Regional Congress of IASSID is approaching, which will be held in June 2005, and with the pressure of making all the arrangements. I wonder sometimes what this conference will bring to IASSID. One thing that I think is important is that it will show the cultural diversity of Asia and what this region of the world has to offer. For me, as a social policy major, to see the unique nature of the Asian-Pacific region is just like seeing the structural side of research in intellectual disabilities. Every couple months, JIDR, JPPID, AJMR or MR journal arrives at my mail box and provides me opportunity to read and to learn about the state of art research in intellectual disabilities. Many scientists publish their findings, telling us what behavior problems that people with ID have, and how to apply new methods to help them, or what kind of types of health problems that people with ID have and what nature or courses of these disease might be. If we examine all these findings carefully, we find that the data are collected in regions or states in America, or in cities or countries of Europe and not in Asia. When I read all these exciting findings and projects, I learn a lot from colleagues who I know or I don't know. Meanwhile, I also asked myself if the same project or data collection procedures were duplicated in Asian countries, would the results be the same or different. Deep down, a serious question is, if researchers in poor countries cannot afford to engage in such long term and timing demanding research or afford the expensive equipment to collect data,



then what are the implications for existing research findings?

The point is that IASSID needs much broader view about life of people with intellectual disabilities who live in different parts of the world. Most importantly, IASSID also needs to move beyond individual, micro level analysis of issues relate to people with intellectual disabilities and take into account the social factor on quality of life for people with intellectual disabilities. For example, what are the effects of social structure and which apply? We must take into account poverty as relevant fact for life of adults with intellectual disabilities, we also must take into account a gender perspective to the study of issues related to adults with intellectual disabilities. But, as we rarely published papers on surveys of income status of people with intellectual disabilities who live in different parts of the world, we rarely have a substantial sense of the living support for people with intellectual disabilities. If people with intellectual disabilities are poor, alone, and lack from sufficient support from society or from family, then, how could they possibly survive? The question for me is what policy can do to change all this in a structural way.

A few years ago, I had the opportunity to participate in WHO project on aging issues related to people with intellectual disabilities. It was an excellent experience for me, and I learned a lot from my colleagues during the preparation process for the reports. What I came away with from that experience is a vexing policy question. Should elderly people with intellectual disabilities share the same long term care system as the general aging population or they should be a separate system? Without many group homes being established as Western countries' model, then what is the best way of accommodating the needs of housing for poor elderly persons with intellectual disabilities? To say something such as establishing trust funds or making living well which, for me, is too far from reality. To set aside a trust fund, could only be possible for those with families who have substantial income, but in reality, most families who have member with an intellectual disability live with minimal income or without the means for saving money to do so. To me, a related policy question is, how to establish an income security system for elderly people in general; and for elderly people with intellectual disabilities in particular? This may be the most important challenge all countries face over the next couple decades. Thus, my point about the important role of Asian-Pacific region is that many countries here do not have good social security system, and also lack of good service system for population with intellectual disabilities. Therefore, we could

use Asian-Pacific countries to collect baseline data to see how such model could apply to regions with less development than Asian, and it also apply them to advanced regions to make comparison.

Clearly, I have two thoughts in my mind. First of all, I think the future research direction needs to pay attention to social factor rather than clinical dimension so that it will allow us to gain global view of lives of people with intellectual Second we should pay attention to the development of service and policy in less advanced regions of the world under which to extend the bases for comparison. Finally, I think that to bring diversify to IASSID would help to strength the organization's leading role of promoting quality of life for people with intellectual disability around the world.

This past year or so, preparation for this upcoming conference has allowed me to have an excellent opportunity to communicate with scholars, researchers, policy makers within and outside the Asian-Pacific region. To organize such a conference has been difficulty for me, but when I see the interest that people have shown in participating in this conference, it has kept me going. I don't know how many people will come or actually attend, but no matter what turns out to be, this process for me will be a life long memory. I wish to see all of you this June in Taipei, and please joint us in a lively debate and discussion about various issues relate to population with intellectual disabilities.

By Wang Kuo-Yu, Ph.D.

ISSUE OF JIDR DEVOTED TO QOL AND FQOL COMING OUT LATER THIS YEAR

Bob Schalock has taken the heroic task of editing the special issue. Bob says that Part I will include three invited papers on the conceptualization, measurement, and application of the quality of life concept. Those articles are currently being completed by Bob Cummins, Miguel Verdugo, and Ivan Brown and Roy Browns. Part II will consist of the 17 submitted and accepted articles reflecting current research in the area of quality of life. Of these 17, 11 will be full reports (1500-3000 words representing major studies, and interpretive reviews) and 6 will be brief reports (500-1500 words representing replication studies,



methodological research, or technical contributions). Ten of the articles focus on the individual, 4 on the family, and 3 on the organization/system. It is a nice balance and probably reflects the historical emphasis on the individual and the emerging emphasis on the family and the extension of the concept to the organization/ system.

We are gathering again at the end of April in Vancouver Canada - Roy Brown is hosting and organizing this roundtable.

Rosemary F. Dybwad International Fellowship Trust

The Rosemary F. Dybwad International Fellowship Trust, Inc., which provides fellowships for international travel and study projects in the field of intellectual and developmental disabilities, has announced its 2005 Call for Applications.

Interested persons are invited to apply for one of the Trust's fellowship awards. Awards are given out when linked to a travel-oriented project designed to advance knowledge and understanding between and among the nations of the world. In the past, project grants have ranged from comparative studies, research, experiential learning, and program analysis.

Individuals submitting project applications should:

- a) have a demonstrated track record and interest in the field
- b) be able to leverage additional resources in support of their work
- c) have clearly identified avenues and strategies for dissemination of the Fellowship funded results
- d) produce high quality written reports of their experiences and study
- e) demonstrate to the Trustees a plan for achieving a broad impact from the Fellowship

Applications are due **August 1, 2005**. For more information, the detailed protocol for application and copies of the application forms are available on the IASSID website at www.iassid.org.

Help Choose Our New Logo

We have narrowed new logo choices down to the following three. Your input is important. Tell us which one you like.

Logo # 1



Logo # 2



Logo # 3



Please e-mail your preference to IASSID Secretary, Vianne Timmons, vtimmons@upei.ca

A decision will be made at the June Council meeting in Taipei.

