

**Minutes - IASSID 2004-2008 Council Meeting No. 3  
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, Phil Davidson, Ilana Duvdevany, Fabrizio Fea, David Felce (Chair), Richard Hastings, Tamar Heller, Anthony Holland, Ulla Jacobson, Matthew Janicki, Stephen Kealy, Mike Kerr, Henny van Schroyen Stein 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 1st and welcomed all to the meeting in Maastricht. He made a proposal to have Tamar Heller of the USA (nominated by the AAMR) to replace Robert Schalock, who resigned from Council. 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 co-ordinating 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 sub-committee to the programme 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 programme. 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 website:**

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.

Web site updates will occur as needed, Council was asked to contact Neil Ross regarding suggestions.

### **Research plans and goal to develop a SIRG 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 Paralympics 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 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 WHO. With regard to the success of the Asia-Pacific IASSID Conference, David Felce thanked Kuo-yu Wang for her excellent organisation 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 disability.

David Felce identified the importance of SIRGs in the development of conference programmes. 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, organisational members, and research centre members was identified as a primary objective between now and the next World Congress.

Other activities included the Association's relationship with World Health Organization. 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 organisational 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 organisation in question. It was also noted that the fee structure for organisations has changed, so no organisation 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<sup>th</sup> 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 centre, and organisational members. A proposal was made to appoint a liaison person to link with organisational and research centre members. David Felce indicated he would follow-up and designate one of the officers to do this. A discussion took place on SIRG's 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 a mechanism at its December 2006 meeting. Motion 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 co-ordination.

### **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 organisation for Council and Executive meetings. The use of the website for making documents available 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 PAHO (Pan American Health Organization - covering Canada, United States, Central 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 to be taken of the cultural backdrop of the host country. PAHO agreed to look at institutional support in the United States.

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 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 if there were any other new organisations with which IASSID should form a working relationship. Giorgio Albertini suggested the International Child Neurology Association 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. Hanny Lantman de Valk outlined steps undertaken in respect of SIRG co-ordination. The question of secretarial support for SIRG co-ordination 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 programme 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 six month trial period with funding of up to US\$6,000. The proposal was to ask Prof. 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 itemising 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 were suggested where development might be focused: (a) on training relevant to Africa, which might be delivered in conjunction with the 2008 World Congress in Cape Town, and (b) 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 organising 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 2<sup>nd</sup> 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, meet with the local organising committee, and the commercial conference organiser. 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 organisations. Council members with links to funding organisations 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 web site. 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 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 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.

### **Website:**

Neil Ross gave an extended report on the website covering its visual presentation and raised some questions about how it could be re-vamped 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 there was a need to have one person to act as gate keeper. 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 due 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 web master. 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.

### **Publishing 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 acknowledgement of authors who have done this (such as Dr. Vee Prasher). David Felce asked the Committee to look at publication options other than JPPID, JIDR for articles from IASSID-related conferences. Tony

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

**Next council meeting:**

Council agreed to meet again in June 2007, possibly in Paris or another European venue. 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 the 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 MacIntosh 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 on 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 co-operation 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 3<sup>rd</sup> Meeting of the 2004-2008 Council was adjourned at 12:45 on August 2nd. 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