

**Minutes
September 17-18, 2004**

IASSID Executive Meeting

Location: Cardiff, Wales

Attendees: David Felce, Neil-John Ross, Matthew P. Janicki, Glynis Murphy, Stephen Kealy, Henny Van Schrojenstein, Patricia Noonan-Walsh, Vianne Timmons

Regrets: Tony Holland

Guest: Elaine Stott, Blackwell Publishing

1. Agenda Approval

The Agenda was approved as distributed

2. Publications

Elaine Stott from Blackwell Publishing distributed an update on subscriptions and the budget on the *Journal of Intellectual Disability Research* (JIDR) and *Journal of Policy and Practice in Intellectual Disabilities* (JPPID).

JIDR will be optional for members for approximately \$50.00. JPPID will be provided with the membership fee.

The Board reviewed the Draft Publication Policy for IASSID: Book suggestions will be sent to the Vice President Publications and he/she will seek reviews of the proposals and get back to the author within a couple of months. Recommendations and reviews will be sent to the Executive for final approval.

Books that IASSID supports should have international relevance and if there is more than one author, the collaborators should represent multiple countries. In general a minimum of 50% of the royalties and usually 100% should be directed to IASSID.

The Executive of IASSID will consider commissioning books either through proposals or the initiative of the Executive.

If the Vice President Publications has a vested interest in a publication, the Vice President Publications will excuse him/herself from the process for that publication. Glynis Murphy will step in for any conflict for Tony Holland 2004-2008. Glynis Murphy will oversee the review of the proposal for *The Cambridge Textbook of Intellectual Disability* submitted by Tony Holland.

Elaine Stott, Blackwell Publishing will provide a list of potential discounted publications to be put on the website. Blackwell Publishers may be approached to market the books in the journals. JIDR and JPPID leaflets could also advertise IASSID books. The books are advertised on the website and can be purchased through Amazon.

David Felce is developing an e-mail list for 2004 World Congress IASSID presenters and maybe the books can be advertised through the listserv.

3. **Review of the 12th World Congress**

David Felce distributed and spoke to the report on the 12th World Congress, Montpellier. There was significant discussion and the following are some of the points highlighted for 2008 conference.

- Maintain the themes as they worked well
- Possibly reduce the number of plenaries
- Include theme on policy and practice
- May want to have someone look at charter flights from a couple of US sites
- May ask Blackwell to push back the deadline for the journal so that there is have a requirement for people to register at a certain date or the abstract is removed from the program. A presentation submission fee could be considered. This is to deal with the no-shows.
- People with obscure e-mail addresses were difficult to find in the data base. May need to address this through using an access data base.
- The registration fee should not need to increase in 2008. May want to have a early registration fee. If there is a two tier fee for developing country participants it would have to be by country. The World Bank organization has a list of countries that may be considered developing.
- For the final call for papers for 2008, a simpler mail out should be considered.
- The Executive would need to ensure the Capetown organizers have the capacity to respond to e-mail inquiries. For every e-mail enquiry there should be a response.
- Glynis will need support for the administrative details for Congress 2008.
- There will need to be a program developed for people with intellectual disabilities.

Finances: Neil distributed the budget for Seattle IASSID Congress 2000, and a summary of the IASSID Congress 2004. The 12th World Congress did generate a surplus. David's estimates for the Congress were quite close to actual budget. Neil provided explanation for the budget sheets distributed. 350 000 Euros (approximate amount) will be

transferred to the IASSID International account.

For financing Capetown 2008, the accounting procedures, registrations, etc will need to be discussed with the South African organizing committee.

4. **Website**

The Villepinte Association in France has been doing the website support. When Neil needs help it costs 400 Euros per day. Neil spends time with the designer so that he can learn the skills. Neil is requesting a budget for 10 000 Euros per year, for two years, to manage the website. He is committed to also look for sponsorship of the website. Matt will transfer 10 000 Euros to IASSID Europe for the website support.

David Felce has asked that executive members look at the website and e-mail recommended changes to David.

Matt is interested in ensuring the website is developed to accept the membership fees for this year. Matt will send Neil an updated list of members. The website can manage individual e-mails **name@iassid.com**.

Matt spoke about the password access for the electronic journal. Most people are not aware that there is access to the journals electronically. Neil sent out to every individual a user name and password. Matt can send out a massive e-mail to members letting them know that their passwords can be used for chat groups and journals. It will also be included in the newsletter.

There needs to be contact information for IASSID on the website. This address should be on the website. The President, Treasurer and Secretary's contact information should be on the website. This could be done as a **contact us** link. The World Congress 2008 also needs to be on the website.

The Executive wants to thank Neil for all the work he has undertaken with the website and the savings realized by IASSID through his commitment.

5. **Finance/Treasurer**

Matt suggests that we have a workplan for the year and a budget can flow from there. There are annual expenses such as Executive and Council meetings. There are also costs for support for administration costs.

David is proposing a financial plan to deal with the demands of administration support. David and Matt will develop the plan for the Executive.

Matt provided an update on the membership:

The membership fees include journal subscription and costs such as credit card costs. 793 paid and gratis members as of Sept. 2004. 49 paid as of 2005. 537 JIDR and 625

JIPPID. 15 are paid subscriptions. There are 51 Research Centres (up from previous years). There are approximately 33 Association members.

Matt is requesting approximately \$10 000 to cover the costs of the administration for the Treasurer's Office. The heavy work load for the Treasurer's Office begins approximately October 15th. The Executive approves \$5000 until December 31st to cover the administrative costs for the Treasurer's Office. IASSID also pays \$4000 costs to the editor of JPPID to manage JPPID administrative costs.

Finance Committee membership was reviewed. Matt recommended *Joel Levy, Fabrizio Fea, Richard Hastings* and *Lisa Wang* as members of the Finance committee. The Committee will meet once a year and participate in e-mail or teleconferencing as needed. The secretary will write the members and notify them they have been appointed to the Committee and provide a listing of their roles and responsibilities.

The President needs access to a bank account to cover costs that goes through the President's Office. David will work with Neil for access to the account in France so that he can deal with Euro costs. \$5000 was given to Neil to cover President's costs. This needs to be transferred to David and an accounting provided to Matt for the \$5000. that was given to Neil.

In the next Council meeting a resolution will be made to have IASSID Europe as European expression of IASSID International. Stephen Kealy and Neil-John Ross will work the details to present this resolution to the Council.

Investment Strategy: Some money may be placed in short term time deposits to generate a better interest rate. Any investment needs to be cautious and low or no risk. The Finance Committee will look at this issue. Once the budget for the year is developed the amount of money for investments can be determined.

6. **Membership/Secretary**

The secretary will liaise closely with the membership committee chair to ensure that all facets of membership communications are run smoothly. The president appointed the secretary as a member of the membership committee in addition to the following members recommended for the Membership Committee: Matt Janicki (Chair), Helene Ouellete-Kuntz, Ulla Jacobson, Keith McVilly, and Phil Davidson and Jan Blacher. Henny van Schroyenstein, will be assigned to the Committee as an Executive liaison. Giorgio Albertini will be asked to serve as a support to the Committee as a representative representing Research Centres The expectations of the Committee will be a face to face meeting in conjunction with Council meetings and other meetings as needed (ie: teleconferencing).

Benefits of Membership: This needs to be explicit and further development of membership should be developed. Communication is presently the main benefit. This

needs to be explored by the Membership Committee. The Research Centres could also look at this issue through a working group led by Giorgio Albertini.

Support for the Secretary will be \$3000. Canadian as an honorarium for the Administrative Assistant. There will also be costs for fax, phone, mail outs etc. Invoice will be sent to Matt for reimbursement of office costs.

Letterhead: David distributed an example of letterhead with the names of Council Members along the side. The Secretary will have a designer look at the letterhead and fix it up. The Japanese and German wording needs to be reviewed. The address and website will be added. We need it A 4 format and North American format. Envelops will also be printed.

Meeting Schedule: Taipei June 12th-15th 2006. The Council meeting will be the 11th of June and the Executive Committee and other IASSID committee meetings on the 10th of June. The Executive may need to look at supporting Committee members accommodations for one night. The Secretary will need to organize the hotel bookings and verify Council member attendees. A letter should be sent to Council. Council members will be responsible for their own travel and accommodations.

The IASSID-Europe Maastricht Conference is August 2nd-August 5th, 2006. The Committee and Executive meetings will be July 31st and the Council meeting August 1st.

In March, a meeting of the Executive Council will be held on March 18th and 19th, 2005 in Dublin. The place will be confirmed by Patricia Noonan-Walsh. The meetings will start at noon on Friday and conclude on Saturday night.

In November/December 2005 there will need to be an Executive Committee Council meeting. This will need to be confirmed in June. Giorgio Albertini may be asked to host the meeting.

In 2007 the Council meeting may be held in Eastern Europe.

Helene Ouellette-Kuntx, Richard Hastings, Miguel Verdugo and Maria Malbran represent individual members and will receive US \$500. as a stipend for attending Council meetings. Executive officers will be reimbursed for travel expenses..

Stepen Kealy will develop a document that summarizes the practice of supporting travel and provide it to the Executive.

SIRG's will be notified that they are required to support a member to attend the Council.

7. **13th World Congress August 25th-30th, 2008/President Elect**

Glynis Murphy proposes the funding of some projects with South Africa which could be

highlighted at the Congress 2008. There is a concern that the conference reflect research, examples and interests of developing countries.

Matt Janicki suggested a link with WHO's agenda for South Africa.

IASSID could provide a small amount of research money for universities in South Africa to apply for support for projects that could be highlighted at IASSID. Other monies could be tapped to support the research. David Felce suggested setting up a two year research fellowship. Tosinvest may be able to provide some funding that IASSID could match for a research fellow at WHO. Some one on the Program Committee could be responsible for this initiative. This could also be highlighted in the newsletter. There could be a call for donations on the website and in the newsletter to support these initiatives. A goal should be set as a fund raising target. Glynis Murphy and Patricia Noonan will co-ordinate this effort.

Program Committee: An administrative Program Committee needs to be established. Glynis Murphy (Chair), David Felce, Matt Janicki, Vianne Timmons, Richard Hastings, Patricia Noonan-Walsh, and Carla Vlaskamp will be asked to be on the Committee. A sub-committee needs to be established to deal with strategic involvement of South African researchers. Membership will include Glynis Murphy, Shelia Hollins. Patricia Noonan, Frank Sturtz, Roy McConkey, Geert Van Hove, Carla Vlaskamp, and Phil Davidson. A member of the South African organizing committee will be asked to join the sub-committee. The sub-committee will be expanded with South African members. Patricia Noonan-Walsh will also serve as the liaison on both committees.

Update: Glynis Murphy distributed and discussed the Capetown Preparation Schedule. Social program and study tours may be assumed by the local organizing committee. Minor modifications were suggested. Members could be asked if they have any contacts from Africa for advertising contact. Glynis Murphy is encouraged to delegate numerous responsibilities so her main responsibility will be to promote IASSID at the Congress.

Office Support: Glynis Murphy will need some support for 2007-2008. Glynis Murphy does not have dedicated secretarial time and will need this support.

8. **Conferences**

Asia/Pacific 2005: Matt Janicki is the liaison for the Asia Pacific conference. Lisa Wang is requesting some financial support (\$5000 US) for scholarships for participants from the Asia Pacific area. The Executive approved this request.

Europe 2006: The conference is on schedule. A program committee has been appointed. Poster sessions will be considered for this conference. There is a 500 cap on enrollment. A logo was designed and the Executive agreed to pay 100 Euros to the designer. Henny van Schroyenstein will invoice David. Felce. The Maastricht abstracts will be published in *Journal of Applied Research in Intellectual Disabilities* (JARID).

North America 2006: There needs to be a way to connect with AAMR and find out about this connection. Matt Janicki and Vianne Timmons will follow up and find out the status of this conference and the relationship of the partnership. Yves La Chapelle is the contact in Canada.

South America 2007: This will need to be discussed next year.

South Africa World Congress 2008: See above discussion

IASSID Pacific 2009: Singapore was interested in hosting this conference in 2009 and the Executive will support this. In the thank you letter as a contender they could be encouraged to pursue it David Felce and Vianne Timmons will send a joint letter to them..

IASSID Europe 2010: Giorgio Albertini will be asked to organize it in Rome.

9. **NGO/WHO/EU Collaborations**

In the past IASSID had a relationship with WHO leading up to the Seattle Congress. This was a very positive relationship and needs to be repeated. Patricia Noonan-Walsh is encouraged by IASSID to pursue this renewed relationship. Trevor Parameter wrote WHO and suggested regular meetings between WHO and IASSID (with Patricia Noonan-Walsh as the liaison). Patricia Noonan-Walsh is developing a brief with a plan for IASSID to follow in approaching WHO to develop a productive working relationship. Patricia Noonan is already on a EU/WHO working group and will be able to gather information.

10. **SIRG, Affinity Groups and Research Centre Co-ordination**

Henny Van Schrojenstein will be presenting a plan for this co-ordination. At the Assembly meeting in June 2004, a recommendation was endorsed that a SIRG coordination Committee be set up with Henny Van Schrojenstein (Chair), Matt Janicki, Vianne Timmons and an appointed member from each SIRG. This Committee may meet in Dublin in March 2005.

Present SIRGs and Contacts

- Quality of Life: Robert Schalock/Ivan Brown
- Family: Jan Blacher
- Aging: Philip Davidson/Christine Bigby
- Heath: Mike Kerr
- Mental Health: Tony Holland and Anna Cooper
- Profound and Multiple Disabilities Loretta Lambe
- Ethics: Hans Reinders
- Parenting: Gwynnyth Llewellyn

Present Affinity Groups

- Early Childhood/Child Development
- Employment
- Empowerment and Citizenship
- Forensics
- Nursing (led by Kathy Service)
- Policy
- Spirituality
- Social Integration (not active)
- Women's Issues (not active)
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Stuart Todd's proposal for a new Affinity group on Death and Dying was approved.

There needs to be a system to keep track of the status of Affinity Groups as some are no longer active.

Eastern Europe: A plan may need to be designed to develop and delivery curriculum on a social model of disability to eastern Europe. A network of IASSID members who have worked in eastern Europe will be established. Matt and David will use some of Tosinvest monies for journal subscriptions for eastern Europe universities.

12. **Constitutional Affairs**

One Committee with joint membership will fulfill the responsibilities of the following two committees

Awards Committee: Six members plus Secretary and Vice President. Bob Davis, Miguel Verdugo, Bob Schalock, Monica Bjorkman, Illiana Duvdevany, Shigeru Suemitsu.

Nominations: Chair plus four members. Four of the above committee members will serve on the Nominating Committee.

Stephen Kealy will let the Secretary know the roles and responsibilities for the letters of appointment.

The Awards need to be rethought. The committee needs to work on this area.

14. **Collaborations**

The collaborations are not clearly laid out. Collaborations could serve as resources for conferences (ie: Organize a symposium). There needs to be agreements which lay out the cooperative relationship. David Felce will confer with Neil Ross and follow up by writing the organizations and follow up on the collaboration.

The European Association of Service Providers for People with Disabilities (EASPD) has sent David Felce a collaborative agreement for Executive consideration. Any collaborations need to be consistent with the objectives of IASSID as in the Section 2. Means of By-Laws of IASSID.

This will be further discussed at the March 2005 meeting.

15. Electronic Council Meeting (January, 2005)

Vianne Timmons will follow up with Helene Ouellette-Kuntz who agreed to initiate this meeting.

The Council would have to approve the June Council Meeting Minutes before they can be distributed.

16. Ad hoc Committees (eg. Ethics)

Art Dalton and Keith McVilly will be contacted to see if the Ad Hoc Committee on Ethics has completed its work. If needed the Committee is reinstated by the executive.

17. Tosinvest-IASSID Oversight Committee

Matt Janicke and David Felce had a conference call with Giorgio Albertini which formally established an agreement of Tosinvest and IASSID. Possible areas of further collaboration was discussed.

18. Roles and Responsibilities

This will need to be visited in March 2005 with the entire Executive. The main role of Executive members is communication however there is discretion of the Executive members to fulfill their role.

19. Other Business

- Newsletter: This has been done twice a year and circulated to all members. It was also sent to anyone who had enquires and put on the website. We will be looking at an electronic copy. The Secretary will look the development of a newsletter before the March meeting and the executive will review it.
- Coen DeJoug has retired from the Council and David Felce will send him a letter acknowledging his contributions. Stephen Kealy will send

- The Secretary will check with the Council members on how they would like their names represented on official letterhead. The Council members will also be asked for a short bio and digital picture for the website.
- The Secretary will maintain a file of appropriated images related to IASSID. David Felce will forward images he has.
- Jim Mansell is interested in setting up a SIRG on Policy. Vianne Timmons will follow up with him and connect him to Henny van Schrojenstein. If he is ready to recommend the SIRG it could be taken to the January electronic Council meeting.
- Matt Janicki proposed that the IASSID endorse the effort of the aging sirg to produce a report on needed research in the area of aging and id. Discussion on the proposal was deferred to the march executive meeting.

What criteria and whose approval is needed for projects to have IASSID endorsement? This should be discussed at the March meeting as it is similar to the discussion on collaborations.