

IASSID Executive Meeting

Minutes

**Friday, March 18, 2005 and Saturday, March 19, 2005
University of Maastricht**

Attendees: David Felce, Neil-John Ross, Matthew Janicki, Glynis Murphy,
Henny Van Schroyenstein Lantman de Valk, Patricia Noonan-Walsh,
Vianne Timmons

Regrets: Stephen Kealy, Tony Holland

Guests: Wil Buntinx & Marian Maaskant : Organization Committee for the
Maastricht 2006 EASSID Conference

Giorgio Albertini: Tosinvest

**Executive Committee information was updated. It will be typed and sent to
Executive by E. Cardy.**

1. Approval of Minutes: Review of Action Log

Minutes Approved for September 17-18, 2004

SIGS: Contacts

Early Childhood/Child Development: Society for Early Intervention:

Michael Guralnick-possible contact

Employment: Michael Kamp

Empowerment and Citizenship: Jan Siska

Forensics: Bill Lindsay

Nursing: Kathy Service

Policy: Jim Mansell

Spirituality: Bill Gaventa

Death and Dying: Stuart Todd

Social Integration: Not Active

Women's Issues: Not Active

Action Log Issues Resolved and Outstanding, Some Items will be
discussed at this Meeting:

Place List of Discounted Publications on Website: Blackwell Press
Contact: Jennifer Payne and Elaine Stott: **D. Felce will follow up**

Financing Capetown: \$5000 forwarded to Organizing Committee from M. Janicki

Details of World Congress on Website: **G. Murphy waiting for photos and will forward to N. Ross for website**

Send Neil updated membership list for website: **M. Janicki will send N. Ross information in June 2005**

Send out group reminder for password for electronic journal: M. Janicki and N. Ross work on this.

Access to Bank Account for D. Felce: **To be done**

Thank you to Singapore & Hong Kong: **Will be done V. Timmons.** M. Janicki will send V. Timmons contact info.

D. Felce sent Coen DeJoung thank you letter.

1. Finance

i) Final Accounting from Montpellier:

Still, waiting, for a \$5000. payment - N. Ross working on this. N. Ross will send attendance list of the conference to G. Murphy and H. Van Schrojenstein P. Noonan will send Dublin list to H. Van Schrojenstein, if possible.

N. Ross distributed a document on the financial statements for IASSID Europe.

M. Janicki gave an update on IASSID finances.

M. Janicki will add a note on the conference registrations that conference e-mail addresses will be shared with conference organizers.

ii) 2004-2008 Budget for Administrative Costs

D. Felce gave an update on administrative costs for 2000-2004.

There was a discussion around investment potentials. D. Felce projects that there will be approximately \$30,000 annually for operation of the Association

Administration Costs for 2004-2008: D. Felce feels that we will have \$30 000 for Administrative Support

Treasurer: 10 k per year
Website: 10 k per year

Secretary 3 k per year

There will need to be some funds for G. Murphy for Administration Support for the conference 2008.

iii) JPPID as part of membership fee:

M. Janicki provided an update:

JIDR Subscriptions	\$295 (513 in 2004, 350 in 2003)
JPPID Subscriptions	\$445 (763 in 2004, 487 in 2003)

There was concern raised about JIDR becoming an add-on subscription in lieu of the membership subscription, which JPPID has become. This was raised by MENCAP because of the fear of a loss of JPPID subscriptions. **D. Felce and T. Holland will speak to D. Condgon at MENCAP about allaying their concerns and ask for a commitment for an annual amount for scholarships for Congress.**

iv) IASSID Europe Status:

N. Ross indicated the Executive of IASSID Europe is the same as the one for IASSID International. IASSID Europe refers to two different entities. One is the Charitable organization IASSID Europe overseen by members Executive of IASSID (D. Felce: Pres., N. Ross: VP, M. Janicki: Treasurer, V. Timmons: Secretary). The second IASSID refers to the European conference organizers, ie: Dublin, Maastricht. In the document it states that IASSID Europe (the charitable organization) will work as a regional group of IASSID. **This will be taken up by Council at its meeting in Taiwan.**

v) Investment plan:

There needs to be a long range plan. Income is generated through memberships, royalties and conferences. Where do we want to be in 2008? Do we want an office and staff person?

There are a number of options for funds:

- Funding Research
- Supporting the Administration of the Association
- Funding someone in WHO
- Supporting poorer nations in participating in IASSID

D. Felce asked that a development plan be proposed and asked P. Noonan and N. Ross to do this. There may need to be a meeting or tele-conference. They were asked to submit a one-page proposal to the IASSID Executive.

Do we need to have an investor oversee the investments of IASSID? **N. Ross will ask a Hong Kong investor to provide feedback on whether it is economical to hire an investor. D. Felce will send M. Janicki an article on British investments.**

2. Secretary Matters

- i) Council records, communication with Council members, etc..

A listserv will be developed for future communication. E. Cardy will continue to work on Web CT and attempt to have it by Taiwan. If there are replies from last communication send to Council E. Cardy will forward to Executive. It may be easier to just summarize any responses. V. Timmons and E. Cardy will look into this. If there is difficulty getting information from Council members Executive members will call them individually.

- ii) Letterhead and other practical matters

The logo needs the IASSID and the box. There is a figure in the middle not a dot but is supposed to be a person.

Logo: Strengths- Familiarity,
Weaknesses- The meaning seems to be lost

V. Timmons will have Graphics look at options with the iassid letters in lower case. G. Murphy gave an overview done by her son. She will copy the overview and forward it to the Executive.

Letterhead will be redesigned without the listing all the Council members' names there.

There are two articles on the history of IASSID: one by Alan Clarke in JRDR (1992 Blackwell Publishers) and Trevor Paramenter's (2004) in JIPPID.

V. Timmons will send them to Council members before the June meeting. V. Timmons will call S. Kealy (+353 872 517 054 cell phone) and ask for any records he may have and will look at potential of digitalizing them.

- iii) Policy on support for travel

IASSID policy is that the Executive Committee members have all of their authorized travel expenses reimbursed. S. Kealy has a list of Council members who represent individual members. Four members have a US \$500 stipend for Council meetings (in September 17-18, 2005 minutes). **M. Janicki will let these Councilors know that they are eligible up to US \$500 for the Taiwan meeting. The 2008 Program Committee**

gets all reasonable travel expenses reimbursed for Council meetings. M. Janicki will develop a travel reimbursement policy. The Executive will determine which Council members are eligible for travel support, and what should be the policy for past presidents (ie: waived registration for conferences), vice presidents and other officers who served more than one term. Executive will get reimbursed for the travel to Council meeting (Taiwan) and conference (hotel and food) expenses, L. Wang has waived registration for all Executive members. **M. Janicki needs to be contacted if Executive Council members needs travel prepaid.** It was agreed that Council members will be reimbursed for 3 nights at the Taiwan meeting at the Howard International Hotel.

- iv) Benefits of membership: Promotional Material

Work in ongoing. As a service provider

- v) Newsletter

Only e-mail copy. Deadline for submission April 1st. Tosinvest will be asked to submit something. It will be copyedited. It will be sent out by mid April.

3. 2008 Congress

- i) Feedback from Cape Town visit

D. Felce, G. Murphy and M. Janicki went to Cape Town. They met with the local organizing committee. An update was written in the letter to Council members. The conference site was visited, the Cape Town International Convention Centre. The Centre is a lovely site but there are not enough meeting rooms for 20 parallel sessions. There are rooms in the Sheraton Hotel which is linked to the Convention Centre. The decision was to run with 16 parallel sessions and more posters and alter the last day so that there is just a plenary. G. Murphy distributed a draft programme with options and reviewed the document with the Executive.

- ii) Preliminary Budget

G. Murphy distributed and reviewed the draft budget for the venue. There is an attempt not to raise the registration fee and an attempt to provide a reduced fee for African participants.

- iii) Timetable and Progress

G. Murphy distributed a draft timetable. The timetable is on track. There needs to be a MOU with the local organizing group. **G. Murphy will draft the MOU.**

There was a discussion about whether there should be a mailout or advertise just electronically. An electronic version may take up too much space for many servers.

Maybe there could be a last call that is a mailout and also do it electronically. The decision will need to be made for the budget calculations. There will be a need for some mailout costs. There will need to be advertising at Maastricht.

iv) Research fund for Africa

G. Murphy developed a sheet to send to sponsors to support IASSID in Africa for research funds. There will need to be an application form for people to fill out. There will need to be a connection to a University or Research Centre. If a package can be developed we can mailout the package to the membership where we ask for volunteers to work on fundraising for this project. If there is sufficient interest we will go ahead with the project, if there is no interest we will have to reconsider this.

There will need to be fundraising to support this project. The membership will need to be asked for assistance in raising funds. Members will be asked to approach two organizations for fundraising. It was agreed that IASSID would commit \$30 000. (US) to this project. There will be a commitment to have an amount allotted from the registration fee of IASSID 2008 conference to repay this amount (perhaps by having a paper submission fee).

The grants will need to be awarded in a timely fashion so that the research could be undertaken in time for the conference. Projects have to be led by an African researcher. The package for sponsors will be developed by a working group initiated by G. Murphy which is scheduled to meet just before Taiwan. It may be helpful to link the call for proposal to an overarching theme of something such as maternal and child health.

4. Conferences

i) Taiwan: The Executive voted to authorize the transfer of US \$5000 to L. Wang for scholarships. Over 100 submissions for presentations have been received and L. Wang is expecting 400 registrations. **E. Cardy to send an update (check with Matt on wording) letting Council members know that their accommodations are covered and they need to confirm the date.**

Anyone interested in moderating please let Lisa know.

ii) Maastricht Conference IASSID Europe: Aug. 2-5 2006. H. Van Schroyen distributed a one page update.

Wil Buntix & Marian Maaskant (Organization Committee for the Maastricht 2006 IASSID Conference) attended as guests. Website is up and running. It can be accessed from the mail IASSID site. There is a program committee (5 members). One member from Poland resigned that will need to be replaced. Will Buntix gave an update on the conference program planning.

M. Janicki will put an ad on the last page of JPPID for the conference. D. Felce will get a list of presenters from Montpellier and P. Noonan will look into the possibility of sending the list from Dublin. Abstracts will be published JARID.

Sponsorships are going well. The aim is 450 participants. Discussion was held about additional potential sponsors.

There will be a Council meeting scheduled at the conference. It will be on Tues. August 1st, 2005. There will need to be a meeting room and accommodations arranged.

Could there be a Charter service set up for flights? If there is a member interested in organizing Charters the organizing committee would be interested in supporting it as long as it was independently operated. Is there the possibility of having a dedicated airline that will provide special rates?

ii) South America 2007. We need to nurture interest. P. Noonan will liaison with Miguel Verdugo around potential interest in a conference in Chile, possibly in September/October 2007. We may wish to have a Council meeting along with the conference.

iii) Other dates

2009 potential Singapore

2010 potential Rome

5. Publications

T. Holland sent a brief e-mail report which indicated that there are a number of books agreed on:

- Health Problems of Growing Older. Editors: Wallace and Dalton.
- The Cambridge Textbook of Intellectual Disabilities: Editors: Holland, Clare, Gunn, Goswani, & Raymond
- Mental Health and ID by P. Sturmey.

Royalties in the past have come 100% to IASSID. IASSID has allotted some money to the editors or authors for expenses. T. Holland as the VP can develop a policy on royalties for the Executive. **D. Felce will speak with T. Holland.**

Blackwell: M. Janicki has had a discussion with Blackwell. Blackwell is recommending that we need 50 additional subscriptions per year to keep costs down. M. Janicki recommends that this year is a baseline that we will ramp up. M. Janicki has the agreement in writing which is revised annually.

6. SIRG, Affinity Groups & Research Centre Co-ordination/Eastern Europe

H. Van Schrojenstein is planning a SIRG meeting in Taiwan. Affinity groups will be invited to attend. **H. Van Schrojenstein will send N. Ross an update for the website and a template to standardize the information from SIRGs.**

You need to be a member of IASSID to serve as an officer of SIRG. You can be a member of IASSID to be a member of SIRG. You need 10 members to set up a SIRG. An Affinity Group is more informal. There are no benefits until your bylaws are developed and you have enough interest to move towards a SIRG.

H. Van Schrojenstein will develop a definition of SIRG and Affinity Groups for the website. The main benefits are networking, representation on Council, etc. **H. Van Schrojenstein will on developing information on benefits.**

M. Janicki will work with the treasurer (not all SIRGs have treasurers) of the SIRG to identify who has paid or indicated an interest in SIRGs. He does not track the membership for each SIRG. **H. Van Schrojenstein will collect information on the officers of each SIRG. She will also encourage the SIRG to have a representative at Council meetings H. Van Schrojenstein will also need a list of SIRG meetings and a workplan for the upcoming years. H. Van Schrojenstein will forward the list of SIRG meetings to N. Ross to put on the website. Regional conferences are convenient for SIRG meetings.**

There are 54 Research Centres members of IASSID. **H. Van Schrojenstein will update them on IASSID information and updates. H. Van Schrojenstein will gather profiles for the Research Centres and their interest in networking. In Maastricht there may be an opportunity to bring representatives from the Research Centres for a networking meeting. They may be interested in participating in the South Africa Research fund. H. Van Schrojenstein will coordinate with G. Murphy on distributing this information.**

One of the benefits of being a service provider member of IASSID is the access to research information. There has been an interest in systematic reviews over the last few years. Is there a way under an IASSID banner that Research Centres can apply for research funds to engage in systematic reviews? IASSID would agree to publish these reviews. This has the potential to appeal to the membership; it will be discussed further at the next Executive meeting. **D. Felce will write a half page to initiate discussion.**

H. Van Schrojenstein is continuing to network with Eastern Europe on behalf of IASSID. She has been invited to serve on an editorial board for a journal that is starting up in Poland. Blackwell is interested in giving free journals JIDR to Eastern Europe. **H. Van Schrojenstein will check with T. Holland on the numbers he will provide.**

7. WHO/EU Liaison

P. Noonan reviewed the history of the relationship with WHO. P. Noonan has been actively approaching WHO for a meeting. There has been no response. There is a large project (15 countries) looking at health and disability led by WHO. None of the partners have expertise in intellectual disabilities. P. Noonan will monitor this.

The Executive of WHO will be discussing the relationship with IASSID in January 2006. P. Noonan proposes sending a formal letter to WHO indicating that we are interested in maintaining our relationship with WHO and offering to meet with them. The letter will ask for a contact person for IASSID as a liaison. The topic of the Capetown conference could be on the agenda with WHO.

There is a project that IASSID discussed (Atlas project) with WHO. WHO is interested in this project with a focus on the developing world. WHO may have approached a Quebec researcher and P. Noonan will follow up on this. Y. Lachappalle is with an research centre connected with IASSID and P. Noonan may suggest that the data collection for the Atlas project could be coordinated through the research centres that are members of IASSID. This may be a topic for the Taipei meeting.

WHO is interested in an IASSID workplan. D. Felce is concerned that we agree to work we do not have the capacity to fulfill.

8. Constitutional Affairs

S. Kealy will bring information on this to Taiwan. A specific issue is the mandate of the Awards and Nomination Committee. It will be distributed to Executive before Taiwan.

9. Tosinvest

Guest: G. Albertini. On the 2nd of February G. Albertini's organization was designated as a research institute.

- Tosinvest Agreement: Under the terms of the Agreement there is a requirement to do an annual review. D. Felce will forward a short report after this Executive meeting. M. Janicki will need a copy of the new logo that has been developed. G. Albertini indicated that they are pleased with the agreement. **D. Felce will write to G. Angelucci indicating satisfaction with the agreement. D. Felce will send a letter requesting the payment of 25 000 EUROS for JPPID to Astrid vanRijn, copied to G. Albertini for JDDIP. G. Albertini will send a summary of the development to a research centre to V. Timmons for the newsletter and to M. Janicki for JPPID.**
- International Course on Intellectual Disability

G. Albertini is interested in working with a few researchers from IASSID to develop the curriculum for an international course in intellectual disabilities (over 2-5 day courses, attached to the conferences and sites such as Rome). Language of instruction will need to be English. There may need to be translation services if the costs can be covered.

Potential Topics for courses with a multi-disciplinary approach:

Integration between medicine and other professions
Evaluation in a lifespan perspective
Education
Communication and speech therapy
Psycho-therapy
Pharmacological approaches
Mental and physical health
Employment

There will need to be a working group to undertake a workplan and business plan. The SIRGs can be asked to suggest someone who will agree to volunteer time to participate on a working group. **H. Van Schrojenstein will poll the SIRGs for interest. M. Haveman will be asked to participate in the working group. M. Janicki agreed to participate as part of the working group.** The goal would be to offer the course in 2007 in Rome. The IASSID Executive supports this initiative.

P. Noonan brought up some issues around the development of European courses and the issues that need to be addressed. P. Noonan has agreed to meet with G. Albertini the next time she is in Rome. D. Felce brought up the potential of a web based course.

- IASSID Europe 2006

The abstract book will be a special issue of the JARID. There will also be a need for a program book. G. Albertini was asked if Tosinvest would be interested in supporting theses and scholarships for participants from Eastern Europe.

- Capetown 2008

G. Murphy discussed the research fund for African researchers. She asked if Tosinvest was interested in supporting the research fund. G. Albertini will explore this with Tosinvest. G. Murphy will forward sponsorship information.

- IASSID Europe 2010 is tentatively planned for Rome.
- Executive meeting will be held in the fall, on (tentatively) Nov 4th, 2005 in Rome. G. Albertini will arrange a meeting room. It would be advantageous to invite Tosinvest to the Executive meeting and explore further collaborations.

10. Website

N. Ross distributed a summary of the website usage. \$10 000 has been allotted to support the website. **N. Ross will attempt to get a sponsor for the website.** Overall the hits on the website are increasing. The site has been translated into Spanish (not all the pages are in Spanish) and it will be also translated in French. The workload is not overwhelming but if the forums were active there would be a lot of work for the moderator.

The website may need to be revamped in the near future. N. Ross will have information on costs of website re-design for Taiwan.

11. Formal Collaborative Relationships- ISAAC, AESPD

International Society for Alternative and Augmentative Communication (ISAAC): We have a collaborative agreement with ISAAC. This agreement is up for review. Phillippe Lonke was the contact for ISAAC. **D. Felce will renew the agreement until December 31, 2009. When the agreement is renewed it will be advertised in the Newsletter.** ISAAC has sessions planned in Taiwan.

Down's Syndrome International (DSI). N. Ross wrote to S. Buckley in 2003 about the possibility of developing an agreement. R. Brown, on behalf of DSI, approached D. Felce about partnership opportunities. **An Agreement may be presented to the Council in Taiwan similar to the one developed with ISAAC. N. Ross will link DSI on our website.**

D. Felce will approach Alzheimer's Disease International about an agreement.

Executive discussed the proposal for a draft agreement between the European Association for Service Providers for People with Disabilities (EASPD) and IASSID. S. Kealy was approached by two members from the EASPD Board and D. Felce was also approached by Luk Zelderloo to pursue this collaboration. Decision was that EASPD can be an organizational member of IASSID. There was a discussion about whether there was a match between the organizations in mandate or geography. The Executive does not recommend agreements with regional bodies. D. Felce will approach EASPD and offer support for research and scientific advice and networking. We would also agree to partner on potential research bids.

There is a long standing, albeit dormant, relationship with Inclusion International which could be fostered.

12. Planning for next Council Meeting

Secretary's Role:

Develop the agenda with relevant reports in a draft working group with discussion, background information and action items. There could be a template for Reports.

The agenda needs to be developed and circulated in early May and reports collected by early June and circulated approximately 10 days ahead of the Council meeting.

We will need reports from SIRGs, Officers, Conference reports. Need to title attachments to Council members. Lisa Wang will be invited to present on the conference at the Council meeting.

13. Other Items:

- **Ponoma 2: Health Indicators for People with Disabilities (3 year project) Project**

This is a three year project and involves a number of IASSID members. **P. Noonan will send a brief report to JPPID and the newsletter.**

- **Site Selection**

D. Felce reviewed the history of the site selection. A process should be developed where potential locations for Congress could be developed. The Past President, the Treasurer and the current President could lead the site selection process. The above team could go and investigate the sites and develop a recommendation for the Council. N. Ross reviewed the process he followed when selecting Montpellier (information distributed) and ideas he has for future site selection. **N. Ross and D. Felce will write up a process for consideration at Council.**

- **ASSID**

D. Felce attended the ASSID conference in Australia and met with ASSID about the relationship with IASSID. D. Felce will explore ways to enhance the connection.

- North America AAMR meeting in Montreal 2006 (self determination and inclusion). They would like IASSID to organize a symposium. M. Janicki will approach AAMR about the symposium.
- D. Mank has resigned as a Council member and will need to be replaced. He represented AUCD. They are a supporter of IASSID. **G. Jesien will be asked for another representative by D. Felce.**

Meeting adjourned at 3:35 pm. March 19th, 2005. The Executive thanked H. Van Schrojenstein for hosting the meeting.