



International Association
for the Scientific Study
of Intellectual Disabilities

Council Meeting

May 27th-28th, 2007

Hotel Novotel Paris Vaugirard
257-263 Rue de Vaugirard
75015 Paris

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**ATTENDANCE - August Council Meeting
As of May 15, 2007**

NAME	OFFICE	MEETING CONFIRMED
Felce, David	President	Yes
Murphy, Glynis	President-Elect	Yes
Janicki, Matthew	Treasurer	Yes
Timmons, Vianne	Secretary	Yes
Ross, Neil	Past-President	Yes
Holland, Anthony	Vice-President	Yes
Kealy, Stephen	Vice-President	Yes
Noonan Walsh, Patricia	Vice-President	Yes
Lantman, Henny	Vice-President	Yes
Albertini, Giorgio	Council	
Bjorkman, Monica	Council	Yes
Blacher, Jan	Council	Yes
Davidson, Philip	Council	Yes
Davis, Robert	Council	Yes
Duvdevany, Ilana	Council	Yes
Fea, Fabrizio	Council	Yes
Hastings, Richard	Council	Regrets
Heller, Tamar	Council	Yes
Hollins, Sheila	Council	Yes
Jacobson, Ulla	Council	
Jessien, George	Council	Regrets
Kerr, Mike	Council	Yes
Levy, Joel	Council	Yes
Malbran, Maria	Council	
McVilly, Keith R.	Council	Regrets
Ouellette-Kuntz, Helene	Council	Yes
Reinders, Hans	Council	
Strutz, Frank	Council	
Suemitsu, Shigeru	Council	Regrets
Verdugo, Miguel	Council	Yes
Vlaskamp, Carla	Council	Regrets
Wang, Lisa	Council	Regrets

AGENDA
IASSID COUNCIL MEETING
May 28th, 2007 – 10:00 a.m. – 4:00 p.m.
Hotel Novotel Paris Vaugirard

1. Commencement and Roll Call
2. Previous Minutes and Matters Arising
3. President's Report
4. Treasurer's Report
 - a) Finance Committee Report
 - b) Membership Committee Report
 - c) Financial Arrangements with Blackwell/Tosinvest
 - d) Travel Reimbursement Policy
5. Secretary's Report
6. SIRG Co-ordination (H Lantman) & SIRG & Affinity Group Reports & Financial Statements
7. Conference Reports and Updates
 - a) 2007 Sud America (P Walsh/M Janicki)
 - b) 2008 Congress & African Working Group (G Murphy)
 - c) 2009 Asia-Pacific
 - d) 2010 Europe (G Albertini)
8. JPPID Editor's report
9. Website Report
10. Publications Committee
11. Paper on IASSID Development (D Felce)
12. Constitutional issues (S Kealy)
 - a) Awards
 - b) General Assembly
13. Policy of Para Olympics
14. The Academy
15. Other Business

**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 Schrojenstein 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 15th 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 2nd 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 be 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 3rd 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



International Association for the Scientific Study of Intellectual Disabilities

President's Report to Council 2007

May, Paris

Highlights since the last meeting include:

1. Continued SIRG activity, with the Council meeting sandwiched between the Health meeting in Prato and the SIRGAID meeting in Oslo. The PMD and parenting SIRGs held successful meetings in the course of the Maastricht European meeting and the Comparative Policy and Practice SIRG is up and running with a planned meeting in Prague in November.
2. Henny Lantman, Marian Maaskant and Wil Buntinx hosted the excellent Second IASSID-Europe Conference, which helped to swell IASSID's coffers by €65,000.
3. Patricia Walsh and Matt Janicki have worked very effectively with colleagues in Chile, Argentina, Spain, Brazil and PAHO to stage and develop the programme for the 2nd South American IASSID Conference to be held in Santiago in Chile. Thanks go specially to them and to Maria Malbran and Miguel Verdugo. They will report in greater detail later in this meeting.
4. Keith McVilly, Trevor Parmenter, Lisa Wang and Matt Janicki continue to oversee arrangements in Singapore for the Second Conference of IASSID-Asia Pacific. There is a good local organising group and programme committee established. Again my thanks go to them for taking on this responsibility. They will report in greater detail later in this meeting.
5. Glynis Murphy and the Cape Town programme committee have also been making progress. The structure of the congress is now clear, plenary speakers are being invited and the final call is being prepared. We now have a Congress logo. Arrangements for the abstracts to be printed in JIDR are set. Glynis will report in greater detail later in this meeting.
6. The Africa Research Initiative has some good projects to fund. As you will recall, IASSID allocated \$30,000 to pump-prime the fund. The projects we wanted to fund would have cost more than this, so the Executive took the decision to guarantee the funding while asking organisations and research centres to offer support (in the region of \$500). An appeal letter is producing great results. Again, Glynis will be able to report on what is being funded in more detail.

7. The finances of the Association are still in a good state.
8. Plans are in hand to revamp the website.
9. IASSID has agreed to be a sponsor of the 2nd International Conference on Intellectual Disabilities/Mental Retardation in Bangkok in November.

My sincere thanks go to everyone who has contributed to IASSID's activities in 2006/7.

David Felce
President



International Association for the Scientific Study of Intellectual Disabilities

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Treasurer's Report

1. Statement of Finances

- a. 2006 Income and Expense Statement (Attachment 1)
- b. Statement of Reserves (Attachment 2)
- c. Obligated Funds (SIRGs and JPPID) for 2007

2. Internal Control

Internal control report involves a review of the financial operations of the Association and an audit of the revenue and expenses. Finance Committee members conducted this on May 27, 2007.

3. Arrangements with Blackwell Publishing

- a. Summary of agreement on JIDR
Per member cost is \$52 remains the same for 2008
- b. Summary of agreement on JPPID
Per member cost is \$52, will increase to \$54 in 2008
- c. Status of royalties from IASSID book series
Royalties received – nil

4. Commentary

- a. Status of new SIRG Funds Distribution Process
- e. Comparable Financials 2001-2007 and Recommendations



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2006 Income and Expense Statement

Budget Period - 1 January 2006 to 31 December 2006

A. Income

Membership Dues	\$ 66,381.23
Interest Income	\$ 21,581.78
JPPID-Blackwell	\$ 6,000.00
Tosinvest Support Funds	\$ 30,792.00
SIRG Roundtable Registrations	\$ 5223.45
Refunds	\$ 999.28

Income - 2006

\$ 130,978.26

B. Expenses

Blackwell Publishing (JPPID Subscriptions)	-\$ 24,402.00
Blackwell Publishing (JIDR Subscriptions)	-\$ 16,692.00
Credit Card Fees - VISA/MC/AMEX	-\$ 2,479.43
Executive Expenses	-\$ 56,767.86
General Administrative Expenses	-\$ 5,713.88
IASSID Council Expenses	-\$ 2,837.20
JPPID	-\$ 5,147.04
Member Expenses	-\$ 456.64
SIRG Transfers	-\$ 7,421.45

Expenses - 2006

\$ 121,917.50

Balance

\$ 9,070.76



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Statement of Reserves

May 15, 2007

Funds held at the Bank of America (Washington, DC USA)

Funds carried in Savings Account	\$ 35,821.96
Funds carried in Checking Account	\$ <u>22,391.15</u>
 Liquid Funds - USA	 \$ <u>58,213.11</u>
 Fixed Term CD #0394	 \$ 107,281.47
Fixed Term CD #0404	\$ 107,281.47
Fixed Term CD #7975	\$ 108,537.52
Fixed Term CD #0417	\$ 107,274.22
Fixed Term CD #9911	\$ <u>108,641.34</u>
 Total US dollar funds	 \$ <u>539,016.02</u>

Funds held at Banque Populaire (Paris, France)

Account #1 (time)	€ 25,000.00
Account #2 (demand)	€ <u>25,659.71</u>
 Total Euro funds	 € <u>50,659.71</u>
 (equivalent US\$ funds = \$68,382.73)	
 Total IASSID funds	 \$ <u>665,611.86</u>



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2006-07 Obligated Funds

Budget Period - 1 January 2006 to 15 May 2007

SIRG Funds

Legacy SIRG assessments collected and held

	2003	2004/5	2006	Total
Aging	0	0	60	\$ 60.00
Families	0	685	60	\$ 1,145.00
Mental Health	1420	1550	540	\$ 3,510.00
Quality of Life	480	560	500	\$ 1,540.00
Parenting	160	280	220	\$ 660.00

Legacy funds held for SIRGs from 2003-2006 \$ 6,915.00

Legacy funds held for Affinity Groups

	2003	2004/5	2006	Total
Prof/Multiple Dis	330	160	200	\$ 690.00 [@]
Nursing	120	60	0	\$ 180.00
Ethics	100	60	20	\$ 200.00
Employment	20	0	0	\$ 20.00
Social Integration	60	0	0	\$ 60.00
Women's Issues	20	0	0	\$ 20.00
Forensics	120	0	0	\$ 120.00

Legacy funds held for AGs from 2003-2006 \$ 1,290.00

Total funds held for SIRGs & AGs \$ 8,205.00

[@] (Check 11096 issued 10/25/06 for \$690 - not cashed)

SIRG funds available for disbursement for 2007 (see attached table)

\$6,140.00

Other Funds

Funds held for JPPID

Funds reserved for 2007	\$ 4,000.00
Funds collected from Blackwell	\$ 6,000.00
Total	<u>\$ 10,000.00</u>



International Association for the Scientific Study of Intellectual Disabilities

Treasurer
PO Box 870
Rockport, ME 04856-0870
Tel: 1 207 236-2715 • Fax: 1 207 236-8070 • E/M: iassidoffice@aol.com

Internal Control Audit

Date Performed: May 27, 2007

IASSID Council Members - Members of the Finance Committee

We, the undersigned ad-hoc members of the IASSID Finance Committee, do attest that we conducted an internal control review of the finances and bookkeeping for the Treasurer's Office of the IASSID on the above date, in keeping with the policy and procedures of the IASSID and its insurers.

Recommendations	Comments and
1. _____	
2. _____	
3. _____	
4. _____	

2007 (May) Distribution of SIRG funds collected from IASSID membership fees.

SIRG	Aging	Comparative Policies & Practices	Families	Health Issues	Mental Health	Parenting	Quality of Life	Profound and Multiple Disability
$\Sigma = 451$	77	39	48	65	85	19	68	50
% of Σ	17.1%	8.6%	10.6%	14.4%	18.8%	4.2%	15.1%	11.1%
1 st distribution	\$383.75	\$383.75	\$383.75	\$383.75	\$383.75	\$383.75	\$383.75	\$383.75
2 nd distribution	\$525.35	\$264.40	\$325.80	\$442.46	\$577.54	\$129.32	\$463.95	\$341.15
Allocation	\$909.10	\$648.15	\$709.55	\$826.21	\$961.29	\$513.07	\$847.70	\$724.90

Note: 307 members paid \$20 each toward the SIRG fund; totaling \$6140. 50% of the funds was distributed equally and 50% was distributed proportionally by % of members. SIRGs N=8. 1st instance distribution is \$3070 - divided by 8 = \$ 383.75 each. Balance of \$3070 divided proportionately.

April 23, 2007

IASSID Comparable Financials - 2001-2007

	2001	2002	2003	2004	2005	2006	2007
Income	\$41,076 ¹	\$106,146 ^{1,2}	\$41,477	\$88,748	\$112,127	\$130,978	-
Expenses	\$42,002 ¹	\$45,813 ¹	\$57,165	\$73,182	\$106,444	\$121,917	-
Reserve³	\$137,236	\$170,985	⁵	\$244,048	\$588,218 ⁴	\$ 662,221	\$665,611

¹ Approximate figures as approximate midyear-to-midyear was used for Council reports

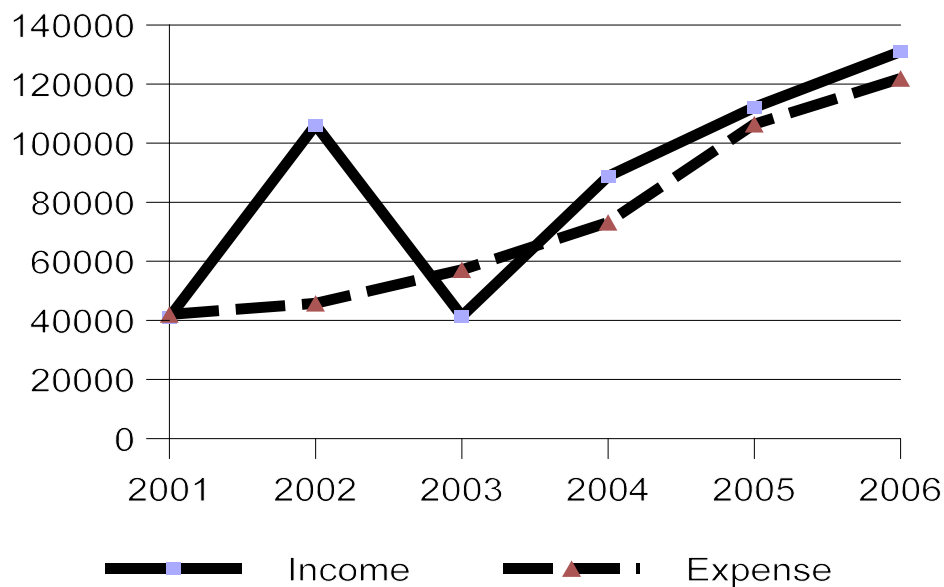
² Includes funds from Dublin IASSID-Europe Conference

³ Funds held by IASSID at time of annual Council meeting

⁴ US Dollar and Euro conversions (Euro estimated at par with US Dollar)

⁵ Unavailable

Income-Expense 2001-07



Commentary

The state of IASSID finances are relatively healthy, but more needs to be done to ensure a stable income stream. Things to consider:

A. Royalties:

1. Royalties from Blackwell have diminished and are no longer a reliable source of income. No new products are in the pipeline at this time.
2. Royalties from Radcliffe, while modest, will most likely diminish next year. No new products are in the pipeline at this time.
3. No new revenue is expected from our agreement with MENCAP regarding JIDR, but MENCAP has agreed to contribute funds for special causes associated with the quadrennial Congress.
4. JPPID is currently in its fourth year and not yet generating any revenue for the Association. Most subscriptions are from the Association at this time. Expectations are the as JPPID becomes mainstream and institutional subscriptions pick up, some revenue will be forthcoming - but this may not be for another three to four years. With the Tosinvest Sanità grant, JPPID is currently cost-neutral for the Association.

B. Toinvest Sanità:

The Toinvest Sanità grants will end in 2008. They have provided a considerable cushion against financial difficulties for the Association. [This was five-year grant program, renewable annually, designed to provide support for JPPID and related activities.

C. Memberships:

Membership fees for Full Memberships (\$120 and \$170) have been sufficient to cover the fixed costs associated with journal invoicing by Blackwell, when the JPPID was subsidized, but may be insufficient to cover costs of Association business in the long run. Some 12% of each \$170 and 17% of each \$120 membership is devoted to the SIRG disbursements, as well as 62%, and 43%, respectively, cover the cost of JIDR/JPPID and JPPID of each membership fee. Thus, 60% of each \$120 and 74% of each \$170 membership fee are spoken for. This means that \$60 of each \$120 membership and \$45 of each \$170 membership can be used for paying expenses and invested toward reserves.

Given that we may have 420 members in 2007, we can expect to have \$5,820 to cover expenses from the \$120 memberships, and \$14,535 from the \$170 memberships (after SIRG and Blackwell costs are paid),

respectively, to cover expenses – or \$20,355 in total from individual memberships. In addition, if we have some 75 research centers renew, that will provide \$5475 additional revenue (assuming \$73 each left after covering JPPID costs). With Associations, if we generate another \$5,200. **All told, membership revenue can provide approximately \$31,000 in 2007 to cover expenses** (beyond SIRG disbursements and Blackwell obligations)

D. Conferences

To date, the IASSID-Europe Conference has been very successful in generating revenue for IASSID. In 2002, some \$30,000 was received after expenses, and in 2006, some \$60,000 was received after expenses. We could expect similar returns in 2010 as the venue will be Rome, an attractive venue for conference attendance. The 2005 Asia-Pacific IASSID Conference was essentially cost neutral for us, with no new revenue generated. Expectations are that the 2009 Asia Pacific IASSID Conference (to be held in Singapore) will generate modest revenue for the Association - the exact amount it is too early to estimate. The 2007 Sudamerica IASSID Conference (in Santiago) will probably end in a modest deficit.

The 2004 Montpellier World Congress was exceptionally profitable for the Association, generating some \$300,000 in revenue. What the 2008 Capetown Congress will bring is difficult to assess. This site is more costly in terms of travel and the registration fee may have to be kept artificially high due to contractual obligations engendered with the Conference Center. If the Congress is cost-neutral or makes a small profit then that will aid the bottom line, but if it runs a deficit that will be a hardship on the Association.

The new Academy is only beginning its work with some workshop planned for several locations in the world, mostly in low economic regions -- which may not bode well for generating income, but at least may cover costs. Once more fully established it is possible (and expected) that the Academy will be a profit center that will contribute modestly to the annual revenue of the Association.

RECOMMENDATIONS:

1. Begin in earnest a program of solicitation of texts that can be brokered for publication with revenues ensuing to IASSID. It is recommended that at minimum some 3-4 works be in the pipeline each year. This should generate from \$4,000 to \$7,500 in royalties annually.
2. Ensure that the Asia-Pacific IASSID Conferences have a built-in revenue

generator with a goal of providing IASSID with from \$10,000 to \$20,000 in revenue.

3. Organize a rotating series of conferences on the year following and preceding the quadrennial Congress to generate revenue. Areas for consideration should include North America on the years when the AAIDD Conference is not held, and the Middle-East, Carribean Region, and the Indian subcontinent when conditions are auspicious.
4. Actively solicit additional membership from staff-based organization at universities and related facilities to build up the Research Center membership and create a more active benefits program for Research Center members.
5. Enhance the activities of the Academy so it can offer more fee-based courses and workshop throughout the world, with the goal of generating at minimum \$15,000 in revenue annually.
6. Expand IASSID's involvement in international affairs in order to generate grants and development funds for special projects and activities that will off-set administrative costs and provide a revenue stream.
7. Site the 2012 World Congress in a city that will attract the most delegates and maximize revenue by securing favorable contractual conditions with conference venue vendors.



International Association for the Scientific Study of Intellectual Disabilities

Treasurer
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Rockport, ME 04856-0870 USA
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Report on Membership - 2007

1. Individual Memberships

As of the end of May 2007, there are **385** paid or otherwise recognized active individual members in good standing with IASSID, a decrease of 79 members from 2006. In 2006 we had 464 members, in 2005 we had 517 members, and in 2004 we had 763 members. In 2003, we had 487 members (an increase of 64% over the number in 2002). In 2002 we had 370 members

In 2007 we instituted a new membership fee schedule, with JPPID only memberships costing US\$120 and JIDR and JPPID memberships costing US\$170. US\$20 of each membership is dedicated to a SIRG fee fund. Pensioner and Student memberships remained at US\$30 each.

The statistics for individual members are shown below.

Applications for membership can be made via the internet at www.iassid.org, by completion of the Individual Membership Form, or by submission of the required membership application information via an email or letter. Payment is automatic and can be made via our website using a credit card or through a check sent to the Treasurer.

2001-2007 Member Stats

In 2001 we had 356 members	
In 2002 we had 370 members	(14 additional members)
In 2003 we had 487 members	(117 additional members)
In 2004 we had 763 members	(276 additional members)
In 2005 we had 517 members	(246 loss of members)
In 2006 we had 464 members	(53 loss of members)
In 2007 we have 385 members	(79 loss of members)

2003-2007 Member Category Stats^{1,2}

2003	FU - 383	AS - 34	SJ - 17	AM - 9
2004	FU - 481	AS ³ - 26	SJ - 25	AM - 13
2005	FU1 - 154	AS ³ - 3	SJ - 9	AM - 10
	FU2 - 275			
2006	FU1 - 95	SJ - 3	AM - 11	PO - 5
	FU2 - 285			
2007	FU1 - 75	ST/SJ - 17	AM - 4	RC - 39
	FU2 - 243	Other - 7		

¹ FU1 = Full member with JPPID, FU2 = Full member with JPPID and JIDR, ST = Student/no journal, SJ = Student with journal, AM = Association Designated Member, PJ = Pensioner with journal, PN = Pensioner - no journal, RC = Research Center Designated member, PO = Past Officer, FU = Full with journal, AS = Associate.

² Other categories include non-paying members, such as past officers and courtesy memberships

³ Effective April 1, 2004, we dropped the AS (Associate) category of membership

⁴ Effective January 1, 2005 we dropped the FN category of membership

Countries of Members

Europe	47.7%	(GB: 16.5%; NL: 6.6%; IRL: 7.5%)
North America	32.1%	(CND: 7.0%; USA: 24.8%)
Oceania	14.7%	(AUS: 13.2%; NZ: 1.5%)
Asia	3.7%	(JAP: 2.0%)
Middle East	1.8%	(IL: 1.5%)
Africa	<1%	
South America	<1%	

Payment Type

	Credit card	Check	Cash	EFT
2007	318 - 87.0%	44 - 12.0%	0	4 - 1.0%
2006	390 - 88.0%	49 - 11.1%	1 - <1%	3 - <1%
2005	438 - 88.7%	50 - 10.1%	0	6 - 1.2%
2004	658 - 93.2%	45 - 6.4%	0	3 - 0.4%
2003	389 - 84.7%	69 - 14.8%	1 - <1%	1 - <1%
2002	248 - 67.9%	116 - 31.7%	1 - <1%	0

EFT = Electronic Funds Transfer

Timing of Membership Payments for 2004 - 2007

	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
2007	5.0%	18.8%	46.3%	25.9%	10.6%	1.6%	10.9%	2.5%	.01%
2006	11.5%	13.4%	24.7%	20.1%	14.9%	7.2%	4.8%	2.2%	1.2%
2005	0.04%	17.2%	28.8%	19.2%	14.4%	8.5%	7.4%	2.0%	2.0%
2004	14.1%	10.3%	7.9%	6.5%	9.6%	26.0%	11.5%	2.8%	4.3%

☞ The above information shows that most payments are made in the last part of the year following the issuance of general email notices to members to pay their following year dues. Compared to 2004 - the Congress year - we saw less activity in payments in the early part of 2005 - most of the activity was the latter part of 2004. In 2005, we made a concerted effort to get renewals notices out early and this led to an increase in renewals in September. In 2006-07, we endeavored to stimulate membership payments early in the last quarter of 2006 and this resulted in a bump-up in November and December. In January we sent out a mailing to all members who had not renewed resulting a slight bump in March 2007.

Blackwell requires us to submit to them the list of subscribers for the following year no later than 15 January. Payments received in mid- to late January and thereafter cause a problem with the journal send-outs as these are then fed piecemeal to Blackwell and increase our workload. We begin sending out electronic reminder notices to pay dues in September and continue sending them to those members who have not renewed (only a small number of non-renewing members reply that they will not be renewing). We only send paper notices to those members without email or whose email addresses have proved faulty.

Payment Forward

8 are paid to end of 2008

1 is paid to end of 2009

JIDR Subscribers

287 had paid for the JIDR for 2002

350 had paid for the JIDR for 2003

516 had paid for the JIDR for 2004

319 had paid for the JIDR for 2005

306 had paid for the JIDR for 2006

246 have paid for the JIDR for 2007

JPPID Subscribers

478 had JPPID included in their membership fee for 2005

443 had JPPID included in their membership fee for 2006

361 have JPPID included in their membership fee for 2007

616 were given gratis subscriptions for 2004⁶

7 had paid for JPPID for 2004

2. Association Memberships

Currently, we have **5** national associations as paid-up members and **30** which have not paid for 2007. In 2006, we we had **17** national associations as paid-up members and **16** which had not paid for 2006. In 2005 we had **20** national associations with paid-up status, and **14** national associations which had not paid their assessment. In 2004, we had **25** national associations maintain affiliative status with IASSID, representing 19 nations (with three associations' dues payments pending - representing 2 additional nations). In 2003, we had **21** national associations maintain affiliative status with IASSID, representing 15 nations.

Payment of association membership dues payment are down, with 30 organizations' dues in arrears. The list of current, paid associations can be found on the IASSID website and on Appendix A.

Applications for association membership are submitted to the IASSID Secretary and approved once payment is arranged and processed. At this time payment is arranged via the Treasurer.

3. Research Center Memberships

In 2007, we have **44** paid-up Research Centers, and **35** which have not renewed. In 2006, we had **49** paid-up Research Centers, and **12** which had not renewed. In 2005 we had **36** paid-up Research Centers and **20** which did not renew. In 2005, of paid-up Centers, 19 were in Europe,

12 in North America, and 5 in Asia/Pacific. In 2004, we had **45** (29 were in Europe, 5 in Asia-Pacific, and 12 are in North America). In 2003, we had **32** institutes, university departments, foundations, and other staff-based organizations classified as IASSID research center members.

The list of current, paid Research Centers can be found on the IASSID website and on Appendix B. A list of Research Centers taken from our website is shown in Appendix C.

Applications for research center memberships are submitted to the IASSID Treasurer and approved once payment is arranged and processed. At this time payment is arranged via the Treasurer.

Submitted 14 May 2007
M.P. Janicki
Membership Committee Chair



Appendix A

Paid-up Affiliative National Organizations of IASSID

A.P.A.E.
Deutsche Interdisziplinäre Gesellschaft zur Förderung der Forschung für Menschen mit geistiger Behinderung e.V.
MAMH - Medical Aspects of Mental Handicap
Polish Association for Persons with Mental Handicap
South African Association for the Scientific Study of Mental Handicap

Appendix B

Paid-up Staff-Based Research Centers and Organizations

Academic Department of Psychiatry of Disability
Aging & Health Centre for Research, Education & Service Development for Aging People w/ID
Akademia Pedagogiki Specjalnej im. Marii Grzegorzewskiej
Beach Center on Disability
Centre for Developmental Disability Health Victoria
Centre for Developmental Disabilities Studies
Centre Medical Jerome LeJeune
Centre for Research on Families and Relationships
Centre for Disability Studies
Department of Social Welfare
Department of Experimental Psychology
Department of Psychology
Department of Psychiatry and Mental Health
Department of Disability & Human Development
Division of Disability Studies
Down Syndrome Research Foundation
Fundacion ITINERIS
Governor Kremers Centrum
Institute for Health Research

Instituto APAE
 John Langdon Down Foundation
 Lebenshilfe Visakhapatnam
 National Institute of Child Health and Human Development
 Neurodevelopmental Psychiatry Services
 Nippon Care-Fit Service Association
 Open Doors for Special Learners
 Physiotherapy Department
 Praxis Care Group
 Research Department COPE Foundation
 San Raffaele Pisana Clinic
 School of Health and Rehabilitation Sciences
 School of Medicine, Health Policy & Practice
 Scottish Consortium for Learning Disability
 Services de Réadaptation L'Intégrale
 Special Education Department
 Specialist Physician Training in Intellectual Disabilities
 Strong Center on Developmental Disabilities
 Tizard Centre
 UH-Manoa Center on Disability Studies
 Unit for Development in Intellectual Disabilities
 Vuxenhabiliteringen
 Waisman Center
 Welsh Centre for Learning Disabilities
 Young Adult Institute, Inc.

Appendix C

Staff-Based Research Centers and Organizations (From Website)

[AFRICA](#)

[EUROPE](#)

[NORTH AMERICA](#)

[SOUTH AMERICA](#)

[ASIA-PACIFIC](#)

[MIDDLE-EAST](#)

AFRICA

RC-070

Department of Psychiatry and Mental Health
 Western Cape Forum for Intellectual Disability
 University of Cape Town
 Groote Schuur Hospital
 Observatory, 7925 Western Cape Province
 South Africa
 Contact: Dr. Christopher D. Molteno (molteno@curie.uct.ac.za)

RC-072

School of Health and Rehabilitation Sciences
 Division of Occupational Therapy
 University of Cape Town
 F45 Old Main Building
 Groote Schuur Hospital
 Observatory, 7925, Western Cape Province
 South Africa
 Contact: Ms. Amshuda Sayed(amshuda.sayed@uct.ac.za)

RC-073
 Physiotherapy Department
 University of the Western Cape
 Private Bag X17
 Bellville, 7535, Western Cape Province
 South Africa
 Contact: Dr. Patricia Stuthers (pstruthers@uwc.ac.za)

RC-074
 Open Doors for Special Learners
 P.O. Box 6417
 Jos, Nigeria
 Contact: Prof. Joanne Umolu (joanneumolu@yahoo.com)
www.opendoorsnigeria.org

EUROPE

RC-001
 Department of Psychiatry
 Developmental Psychiatry Section
 University of Cambridge
 Douglas House
 18b Trumpington Road
 Cambridge, England CB2 2AH
 Contact: Dr. A.J. Holland (ajh1008@hermes.cam.ac.uk)

RC-005
 Developmental Disabilities Research & Education Group
 University of Plymouth
 c/o LDS Westbourne Unit
 Scott Hospital
 Beacon Park Road
 Plymouth Devon England PL2 2PQ
 Contact: Dr. Judith McBrien (judith.mcbrien@pcs-tr.swest.nhs.uk)
 Web site: www.sword.nhs.uk/ddreg
 Research interests: Down's syndrome and dementia; ASD; epilepsy; forensics

RC-007
 Down Syndrome Educational Trust
 The Sarah Duffen Centre
 Belmont Street
 Southsea, England PO5 1NA
 Contact: Prof. Sue Buckley (sue.buckley@downsnet.org)
www.downsed.org

RC-009
 Welsh Centre for Learning Disabilities
 Centre for Health Sciences Research
 Cardiff University
 2nd Floor, Neuadd Meirionydd
 Heath Park
 Cardiff, Wales CF14 4YS
 Contact: Dr. David Felce (felce@cardiff.ac.uk)
http://www.cardiff.ac.uk/medicine/psychological_medicine/research/welsh_centre_learning_disabilities/index.htm
 Research/focal topics: post-institutionalization research, quality of life, health disparities, epilepsy, transition to adulthood and employment, death and dying, language development in autism

RC-010

Centre for Disability Studies
National University of Ireland Dublin
Room D004B, JHN Building
Belfield Dublin Ireland 4
Contact: Prof. Patricia Noonan Walsh (patricia.walsh@ucd.ie)
<http://www.ucd.ie/uip/directory/csdd.html>

RC-011
Institute on Community Integration
Faculty of Psychology
University of Salamanca
Avda. De la Merced, 109-131
Salamanca SPAIN 37005
Contact: Dr. Miguel Angel Verdugo Alonso (inico@usal.es)
www.usal.es/inico/inico/html
Research/focal topics: quality of life, supported employment, self determination, aging, school inclusion

RC-014
Governor Kremers Centrum
c/o BEOZ
University of Maastricht
PO Box 616
NL-6200 Maastricht, The Netherlands
Contact: Dr. Wil H.E. Buntinx (w.buntinx@beoz.unimaas.nl)

R-016
Tizard Centre
University of Kent at Canterbury
Beverly Farm
Canterbury, England CT2 7LZ
Contact: Mandy Twyman (m.s.twyman@ukc.ac.uk)
www.ukc.ac.uk/tizard

RC-017
Academic Department of Psychiatry of Disability
St. George's Hospital Medical School
University of London
Cranmer Terrace
London England SW17 0RE
Contact: Dr. Sheila Hollins (s.hollins@sqhms.ac.uk)
www.intellectualdisability.info

RC-018
Joe Wolfe & Associates
Seville Lodge
Callan Road
Kilkeny, Ireland
Contact: Mr. Joe Wolfe (joew@indigo.ie)
www.jwolfeassociates.com

RC-020
Down Syndrome Association
155 Mitcham Road
London England SW17 9PG
Contact: Elske Schabot (eschabo@downs-syndrome.org.uk)
www.dsa-uk.com

RC-021
San Raffaele Pisana Scientific Institute for Research, Hospitalization and Health Care
Tosinvest Sanità
235, Via della Pisana
Rome, Italy 11063
Contact: Giorgio Albertini (giorgio.albertini.giorgio@sanraffaele.it) or

Carla Albertini (carla.albertini@sanraffaele.it)
www.sanraffaele.it

RC-022
 Research Department
 COPE Foundation
 Bonnington
 Montenotte Cork Ireland
 Contact: Edel Tierney (tierne@cope-foundation.ie)
www.cope-foundation.ie

RC-023
 Unit for Development in Intellectual Disabilities
 University of Glamorgan
 School of Care Sciences
 Glyntaf Campus
 Cemetery Road
 Pontypnnd Wales CF37 4BS
 Contact: Ruth Northway (seal@glam.ac.uk)
<http://udid.weblog.glam.ac.uk>

RC-024
 Centre Medical Jerome LeJeune
 50,avenue Foch
 Paris, France 75116
 Contact: Clotilde Micher (clotilde.micher@cmjl.org)
www.fondationlejeune.org

RC-027
 The Glasgow U.A.P.
 Section of Psychological Medicine
 University of Glasgow
 Academic Centre
 Gartnavel Royal Hospital
 1055 Great Western Road
 Glasgow Scotland G12 0XH
 Contact: Anna Cooper (SACooper@clinmed.gla.ac.uk)
www.gla.ac.uk/departments/psychologicalmedicine/index.html

RC-029
 School of Medicine, Health Policy & Practice
 Institute of Health
 University of East Anglia
 School of Medicine
 Elizabeth Fry Building
 Norwich England NR4 7TJ
 Contact: Peter Langdon (p.langdon@uea.ac.uk)
www.uea.ac.uk

RC-030
 Institute of Special Education & Rehabilitation
 Faculty of Philosophy in Skopje
 University "St. Cyril and Methodius"
 Bull. Krste Misirkov b.b.
 Skopje, Macedonia 1000
 Contact: Dr. Vladimir Trajewski (vladotra@fzf.ukim.edu.mk)
<http://www.fzf.ukim.edu.mk/en/defektologija/index.htm>

RC-031
 Institute for Health Research
 Lancaster University
 Lancaster England LA1 4YT

Contact: Eric Emerson (eric.emerson@lancaster.ac.uk)
<http://www.lancs.ac.uk/fass/ihr/>

RC-033

Foundation for People with Learning Disabilities
 Sea Containers House
 20 Upper Ground
 London, England SE1 9QB
 Contact: Paul Swift (pswift@fpld.org.uk)
www.learningdisabilities.org.uk

RC-034

Intellectual and Developmental Disabilities Unit
 University of Wales - Bangor
 School of Psychology
 Bangor, Gwynedd, Wales LL57 2AS
 Contact: Richard Hastings (iddu@bangor.ac.uk)

RC-036

Stewarts Hospital Research Centre
 Stewarts Hospital Services, Ltd.
 Palmerstown
 Dublin 20 Ireland
 Contact: Anne McCarthy (anne.mccarthy@stewartshospital.com)
www.stewartshospital.com

RC-037

Norah Fry Research Centre
 University of Bristol
 3 Priory Road
 Bristol, England BS8 1TX
 Contact: Dr. Jackie Rodgers (j.rodgers@bristol.ac.uk)
<http://www.bris.ac.uk/norahfry/>

RC-039

Uliazpi Fundazioa
 Portuetxe 53B
 Local 112
 Donostia San Sebastián Gipuzkoa Spain 20018
 Contact: Francisco Mendizabal (pmendizabal@gipuzkoa.net)

RC-041

Specialist Physician Training in Intellectual Disabilities
 Erasmus MC Department for General Practice
 Room FF 326
 P.O. Box 1738
 3000DR Rotterdam The Netherlands
 Contact: Fran Ewals (avgopleiding@erasmusmc.nl)
www.erasmusmc.nl/avgopleiding

RC-042

Vuxenhabiliteringen
 Villavägen 2
 Uppsala, Sweden 752 36
 Contact: Per Erik Johansson (per.erik.johansson@lul.se)
<http://www.internet.hoh.lul.se/lul/hoh/index.htm>

RC-043

White Top Research Unit
 University of Dundee
 White Top Research Unit
 Springfield House
 15/16 Springfield

Dundee, Scotland DD1 4JE
 Contact: Prof. James Hogg (j.h.hogg@dundee.ac.uk)

RC-046
 Special Education Department
 St. Patrick's College
 Drumcondra
 Dublin 4 Ireland
 Contact: Dr. Jean Ware (jean.ware@spd.dcu.ie)

RC-047
 Development and Intellectual Disability Team
 University of Edinburgh
 School of Education
 Holyrood Road
 Edinburgh, Scotland EH8 8AQ
 Contact: Dr. Katie Williams (katie.williams@ed.ac.uk)
www.education.ed.ac.uk

RC-048
 Social Care Institute for Excellence
 1st Floor Goldings House
 2 Hay's Lane
 London England SE1 2HB
 Contact: Tanya Simpson (rrteam@scie.org.uk)
www.scie.org.uk

RC-049
 Akademia Pedagogiki Specjalnej im. Marii Grzegorzewskiej
 ul. Szcz"niwicka 40
 Warsaw, Poland 02-353
 Contact: Prof. Anna Firkowska-Mankiewicz (naukapro@aps.edu.pl)
<http://www.aps.edu.pl>

RC-051
 Aging and Health Centre for Research, Education, and Service Development on Aging People with Intellectual Disabilities (UAU)
 PO Box 2136
 N-2136 Tønsberg, Norway
 Contact: Frode K. Larsen (frode.larsen@nordemens.no)
 Website: www.uau.no
 Research/focal topics: aging, education, research, service development, publishing

RC-052
 LUCAS - K.U. Leuven
 Kapucijnenvoer 35
 Leuven Belgium B-3000
 Contact: Lut Van Hoof (lut.vanhoof@med.kuleuven.ac.be)
www.kuleuven.ac.be/lucas

RC-063
 Centre for Research on Families and Relationships
 Edinburgh University
 23 Buccleuch Place
 Edinburgh, Scotland EH8 9LN
 Contact: Dr. Heather Wilkinson (h.wilkinson@ed.ac.uk)
<http://www.crfr.ac.uk/>

RC-066
 Scottish Consortium for Learning Disability
 The Adelphi Centre, Room 16
 12 Commercial Road
 Glasgow, Lanarkshire Scotland G5 0PQ

Contact: Lisa Curtice (lisa.c@sclid.co.uk)
<http://www.sclid.org.uk>

RC-067

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RC-006

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RC-040
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RC-060

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RC-064

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RC-068

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RC-026

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RC-075

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MIDDLE-EAST

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Meeting of the SIRG Coordination Committee on August 1, 2006

Present: Henny Lantman, Phil Davidson, Tony Holland, Bob Davis , David McConnell, Mike Kerr, Gwynnyth Llewelyn.

Representing the Physical Health, Aging, Psychiatric and Parenting SIRGs

Minutes previous meeting in Taiwan were accepted

Moved Bob, Seconded Phil that minutes accepted with the acknowledgement that Phil Davidson was also present

Review Draft Bye Law to be presented as circulated prior to the meeting by Henny (attached)

Henny talked to this document that was developed by Neil Ross and Henny Lantman
Moved that submit as included seconded Phil and carried

Discussion:

Below the points that were brought up, grouped by issue:

There is a need to clarify the function of the SIRG Coordination committee and its relationship to aspects of ratification of new SIRGs

Recent problems with changes in the SIRG executives and communication and ratification of these changes to IASSID. Issue was highlighted by recent changes in parenting SIRG.

Membership

SIRG's original function was seen as a gathering point for various interest groups within the IASSID and the framework was originally set up with a requirement of membership in IASSID.

Given that the membership ranged between 450 and 700 there was a limited number of SIRGs that IASSID could support.

When new members join there was an opportunity to promote SIRGs that might be relevant to that members interests and it would be an opportunity to get information to that member at that time.

The question of IASSID membership being a requirement of SIG membership was brought up.

IASSID needed to look at accountability of SIRGs to SIRG members and to IASSID itself.

Recently developed and developing SIRGs (eg. parenting and family SIRGs) have different priorities needs including initial support and communication with potential members.

Cooperation

There were a wide range of developmental and organisational differences within the various SIRGs and there are some broad interest groups within the intellectual disability research community without any SIRG representation eg. special education. Often the SIRG's might be driven by an issue that was topical or as a result of activity of some members. As such with some issues there was a tendency to lose momentum over time. Question as to whether this was a good or bad thing. Initial development that happened when SIRG's first created has stalled and that some aspect of the SIRGs are working somewhat independent of IASSID. Danger of only driving force of IASSID is meetings rather than the building of collaborative networks. May be important to work out a reciprocal agreement between SIRGS and IASSID with clearer idea of relative responsibilities. IASSID needs to be in more control the SIRGs structure and function and expected output eg expectations of SIRG's involvement of conferences. One of weaknesses is difficulty in including all SIRG's in this process.

Preparation of Capetown:

Montpellier was far better in approaching the SIRGs and having their input included in the program. He had concern that this was not happening for South Africa committee and there was a need for the SIRG's to be empowered to make recommendations.

Discussion on 4 yearly conference. Including the SIRGs within the program is potentially divisive and there was some merit in using conferences to highlight different themes where SIRGs could contribute to the dissemination of information across the broad spectrum of IASSID membership.

Other remarks on SIRG meetings.

Tony Holland brought up the separate issue of the relationship of the SIRG's to the congresses, the regional and SIRG meetings. Suggestion that a regional representative of the SIRG could be involved in the development of the regional meeting.

Mike Kerr said that SIRGs work more effectively when own activity and not combined with IASSID meeting.

Phil Davidson indicated that there was a priority to have meetings each year for the SIRG's and that sometimes there was conflict in priorities and planning of IASSID

This meeting was seen as a step to deal with some of the issues raised above but was only a start of the process and that there was a need to look at the structure and strategies of IASSID.

Tony Holland felt that a permanent secretariat might facilitate this process and that it needs to be considered.

Phil Davidson said that IASSID needs to support SIRG representation on council by contributing to travel costs.

At the end of the meeting it was resolved to present to council a synopsis of this discussion and the following submission was formulated.

The Meeting felt that it was crucial for the SIRGs development to have an up to date knowledge of those who have enrolled in the specific SIRG and active communication between IASSID and the SIRGs

For this to happen we ask the council to consider providing

- “core secretarial support” as a focus for administration
- Stipends to help cover the basic costs of maintaining the SIRGs eg teleconferences
- Financial support for representation on council

In return the SIRG’s provide the following for IASSID

- Facilitate recruitment to IASSID through the SIRGs
- Contribution to papers, journals, consensus statements, books etc.
- Organisation of SIRG meeting
- Contributions for wider membership within scientific programs eg. presentations not aimed at the SIRG
- Contribute to develop of policy statements
- Professional expertise for advocacy on SIRG related issues

The SIRG groups want direction from council on the question of the relationship of SIRGs and the various levels of conferences eg regional, four yearly congresses

Report of the Special Interest Research Group on Aging and Intellectual Disability (SIRGAID)

IASSID Council Meeting

May 27-28, 2007

Summary of Past Year's Activities

Roundtables. The Special Interest Research Group on Aging and Intellectual Disability (SIRGAID) held its 15th Roundtable in Toronto, Canada on April 26th-29th, 2006. The University of Rochester, located in nearby upstate New York hosted the meetings. The meetings were held jointly with the SIRG on Quality of Life. The University of Toronto and the Ontario Federation for Cerebral Palsy were co-hosts. There were three thematic foci: Health and Aging, Service Policy, and Low Incidence Conditions. 52 people attended the meetings.

The SIRGAID 16th Roundtable will be held in Oslo, Norway on May 30-June 1, 2007. It is being sponsored by the Development Program on Ageing in People with Intellectual Disabilities (UAU) at The Norwegian Centre for Dementia Research. A parallel local congress will take place on May 29-May 30, 2007. Registration figures for this event are strong.

Elections. The SIRGAID elected its 2007-2008 leadership in September 2006. The membership elected Philip Davidson (USA) and Christine Bigby (Australia) as co-Chairs, Philip McCallion (USA) as Treasurer, and Heather Wilkinson (UK) as Secretary. Matthew P. Janicki (USA) will continue as a member of the leadership as Past Chair. Dr. Davidson also will continue to serve as the SIRGAID Council Representative. The membership also elected three At-Large members: Dawna Torres Mughal (USA), Maria van Laake (The Netherlands) and Sunny Kalsy (UK). Dr. Mughal will serve as Newsletter Editor and Dr. Kalsy will assume responsibility for membership activities.

Membership. The IASSID Treasurer reports that we currently have 77 IASSID members who have elected membership in the SIRGAID.

Budget. At its Business Meeting at Toronto, Dr. Mughal reported cash on hand of \$ 5,101.37 anticipated additional revenues of \$800.00, anticipated expenses of \$2,200.00, and an anticipated end-of-year balance of \$3,701.37. The budget was approved.

Plans for Upcoming Year

Planning is underway to prepare a program on Aging and Intellectual Disabilities to be presented at the International Congress in South Africa in 2008. As has been the normal practice, the SIRGAIUD will hold no Roundtable during the International Congress year. There will be a Roundtable in 2009, but a sponsor and venue has not yet been designated. Guidelines for the organization of roundtables have now been

drawn up and endorsed by the executive group and will be discussed at the annual business meeting at the Roundtable in May.

In March 2007, The SIRGAID's first Newsletter was disseminated to all members via e-mail. Dr. Mughal is preparing a second issue.

The Executive Committee will continue its practice of holding bi-monthly Skype meetings. The committee would like the IASSID council to note the difficulties experienced by the SIRGAID in having updated information posted to the IASSID website in a timely manner and request that this issue be addressed.

Submitted – PW Davidson and Christine Bigby, Co-Chairs/Aging SIRG
11 May 2007

Report of Parents and Parenting with Intellectual Disabilities
IASSID Council Meeting
May 27-28, 2007

Summary of Past Year Activities

The Parents and Parenting with Intellectual Disabilities SIRG held its fourth meeting at E-IASSID at Maastricht in August 2006. Thirteen people attended with nine apologies. The meeting expressed its appreciation for the efforts involved in having a Keynote presentation on Parenting with Intellectual Disabilities at the conference and a well attended stream on parenting. Given that the SIRG is relatively small, the quality and quantity of the presentations at each of the IASSID, E-IASSID and Asia Pacific Conferences since the group's inception is quite outstanding.

The SIRG resolved to seek publication of a special issue on Parents and Parenting with intellectual disabilities. Professor G. Llewellyn has approached Professor David Felce and Professor Glynis Murphy and plans are now well advanced with invited authors preparing manuscripts for a Special Issue of JARID on this topic scheduled for later in 2008. The co-editors for this special issue are Professor G Llewellyn, Dr Rachel Mayes and Associate Professor D McConnell.

The SIRG also resolved to prepare a Position Paper on Parents and Parenting with Intellectual Disabilities for consideration by IASSID Council. Associate Professor D. McConnell has assumed responsibility for consultation with SIRG Members and preparing this paper. The Position Paper once approved would also be included in the Special Issue.

Professors R. Traustadottir and G. Llewellyn following conversations with Blackwell Publishing at the conference have prepared in consultation with Dr H. Sigurjónsdóttir and Associate Professor D McConnell and subsequently forwarded to Blackwell's a prospectus for an edited book on Parents and Parenting with Intellectual Disabilities featuring the work of SIRG members.

Plans for Upcoming Year

1. To complete the Special Issue according to the timeline presented to JARID.
2. To complete the Position Paper for forwarding to IASSID Council for their endorsement
3. To plan for the SIRG's first Roundtable at the IASSID Conference in Capetown in 2008.
4. To expend funds to ensure development of Position Paper and support for Roundtable at Capetown in 2008.

Issues or Acting Items

None current

Discussion Points for Council

No current items. The SIRG thanks Council for consideration of SIRG fees disbursement and the subsequent policy and distribution

Financial Statement May 07

Held funds	\$660.00
Disbursed funds May 07	\$513.07

Total: \$1173.07

**Report of Comparative Policy and Practice SIRG
IASSID Council Meeting
May 27-28, 2007**

Summary of Past Year Activities

The first meeting of the comparative policy and practice SIRG was held at the Maastricht European Congress and the Executive committee elected with Jim Mansell (UK) as the Chair, Johannes Schaedler (Germany), Julie Beadle-Brown (UK) as secretary/treasurer and Chris Fyffe (Australia), Chris Bigby (Australia), Eric Emerson (UK) and David Braddock (US) as ordinary members.

It was agreed at that meeting to hold the 2007 SIRG roundtable in Prague, attached to the final conference for the current EU project led by Jim Mansell and Julie Beadle-Brown (among others) and involving other members of the SIRG. It was agreed that Eric Emerson, Julie Beadle-Brown and Jim Mansell would form the programme committee and the Julie Beadle-Brown would work with Jan Siska (Czech Republic) and Judith Klein (Open Society Institute Mental Health Initiative) in order to sort the organization of the roundtable. It was agreed that the first meeting would take the form of topic discussions rather than lots of presentations and would also include a meeting about how the SIRG would operate in the future.

JBB, EE and JM met in December 2006 and agreed the topics for the programme and identified some possible discussants, all of whom subsequently agreed to the role.

The organization of the conference is now complete and registration is now open on the IASSID website.

Membership for 2007 stands at 39.

Plans for Upcoming Year

The main event for next year will be the Prague Roundtable meeting 16th – 17th November 2007. At that meeting, future activities will be discussed and planned.

Issues or Acting Items

None at present

Discussion Points for Council

Representation of the SIRG

Comparative Policy and Practice SIRG Financial statement for 2007.*Expenditure since last report*

Due to the fact that this is the first year of the CCP SIRG there has been no expenditure to date.

Income

Membership fees as of 1st April 2007 amounted to \$648.15.

Registration fees for the Roundtable are being collected by IASSID and will be transferred to the University of Kent before the payment of conference costs are due to the venue in Prague. It is anticipated that no profit will be made from these fees but that fees will just cover the costs of running the Roundtable meeting. However, should there be any profit, this will be added to the SIRG funds and used towards budget item 3 below.

Budget for 2007/2008

In terms of the budget for next year, the CCP SIRG does not have representation on the council of IASSID in the coming year. In addition, registration fees for the first CCP SIRG roundtable in Prague had already been set before SIRG membership income was confirmed.

It is therefore proposed that we use the fees available to us (both from 2007 and from 2008 membership) to do three things:

- 1) To offer two registration fee scholarships/grant for applicants from Eastern European or less developed countries at the SIRG Roundtable in Prague and/or the preceding international conference on Deinstitutionalization and Community Living (approximate cost \$380).
- 2) To contribute towards the costs of a SIRG meeting at the World Congress in Cape Town in August 2008 (to include room hire if necessary and subsidy towards registration fees for the roundtable – arrangements to be discussed at the Roundtable meeting in Prague).
- 3) To help speakers from Eastern European and other less developed countries to contribute to a comparative policy and practice symposium at the World Congress in Cape Town.

Statement prepared by Julie Beadle-Brown 080507

**Report of HEALTH
IASSID Council Meeting
May 27-28, 2007**

Summary of Past Year Activities

Contribution to IASSID Europe conference in Maastricht
Continued publication of SIRG newsletter
Work on International Epilepsy Guidelines
Development and Planning of SIRG meeting in Prato May 2007

Plans for Upcoming Year

Conference in Prato, Italy, May 2007
Completion of Epilepsy Guidelines
Confirmation of SIRG Scientific input to Cape Town 2008

Issues or Acting Items

Nil new

Discussion Points for Council

SIRG Would like early confirmation on planning process for SIRG input into Cape Town 2008



Journal of Policy and Practice in Intellectual Disabilities

*The official journal of the International Association for the Scientific Study of
Intellectual Disabilities*

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Report to Council (May 2007)

Matthew P. Janicki, Ph.D., Editor-in-Chief

- JPPID, established in 2003, is the official journal of the IASSID, and is underwritten through a grant received from the Toinvest Sanità Organization in Rome, Italy. It is co-owned with Blackwell Publishing, which provides editorial support. JPPID is now into its fourth year of publication and is doing well with respect to subscriptions, submissions, and maintaining publication schedules. The work of JPPID is managed by Matthew Janicki, the Editor-in-Chief, and Jenn Hall, JPPID's Editorial Coordinator.

- Last year (2006) we switched over to electronic manuscript submission with Manuscript Central (MC) from Scholar One and this has worked out quite well, as both Jenn and I have become more familiar with MC. We organized four discrete issues, two of which were special issues. The first one was on early intervention and guest edited by Drs. Michael Guralnick of the University of Washington (USA) and Giorgio Albertini of Casa di Cura San Raffaele (Italy) and the second was a special issue of family services practices research guest edited by Dr. Roy Brown of the University of Victoria (Canada). Blackwell organized our acceptance by PsycINFO, the American Psychological Association's indexing service. Blackwell also assigned a new production editor to JPPID, Amanda Martinez, and a senior associated editor, Fiona Williams.

- In 2006, we ran 285 pages, 45 pages over the page budget of 240. In volume 3, issue 1 had 13 articles, issue 2 had 13 articles, issue 3 had 9 articles and issue 4 had 9 articles. Overall we published 43 manuscript articles in 2006. Articles were published from authors in USA (11), Canada (8), Italy (6), Israel (5), Australia and the Netherlands (3), Austria, Sweden, and the UK (2), and Japan (1). We have instituted a control to ensure that we maintain production articles within the page allocation.

- In 2007, we have begun closer scrutiny of the production schedules and submissions due to a reasonable flow of submissions and acceptances of manuscripts. As of the end of May, we have 14 articles under acceptance and an equivalent number under various stages of review. In volume 4, the second issue was a special issue on multiple and profound disabilities, guest edited by Prof. James Hogg of the University of Dunedin in Scotland. This issue ran over the page allocation due to the number of manuscripts submitted and we have made adjustments for a lesser number of pages scheduled for issues 3 and 4. We now have a slight backlog of articles that will take us into 2008. Blackwell has agreed to an increase in the page allocation for 2008 and this should help. On another note, Blackwell has begun to file applications to have JPPID accepted by the major indexing services since we are now on a regular production schedule.

- In 2008, we are planning to regularize our production work to maintain the submission schedule to Blackwell and institute tighter review procedures for manuscripts that are submitted which are poorly written or constructed. In many cases, we had aided the authors by providing editorial suggestions – particularly when the authors' first language was not English. However, with a backlog of manuscripts we will no longer provide this assistance. Also, in 2008, we are planning on a special issue on comparative social policies, guest edited by Prof. Eric Emerson, to coincide in publication with the 2008 Congress.

- *Comments.* The editorial leadership of the journal is running well and is aided in large part by an excellent editorial coordinator (Ms. Jenn Hall) and the editor's proximity to the US offices of Blackwell in Malden, Massachusetts. The adoption of Manuscript Central has helped us manage the submission work load, although we are still working through some bugs evident in Manuscript Central – some of it is due to our inexperience with the program, and some due to the peculiarities of the program. A common challenge is identifying reviewers and obtaining reviews in a timely manner. Manuscript submission is evident at a reasonable rate and our acceptance/ rejection ratio is being tightened. Articles of lesser quality are being rejected or returned for significant revisions at a greater rate than before (when the number of manuscripts per volume was low). A goal in 2008 will be to broaden the editorial board with one or two editors who can help manage the work flow.

Development of IASSID as a Member Organisation

Paper for Discussion

Second Draft, April 2007

Introduction

A number of initiatives affecting membership were taken during the 1990s including introducing individual and research centre membership. Special Interest Research Groups (SIRGs) also came into being at this time. Certain changes followed in terms of the governance of IASSID, including individual members and SIRGs being represented on the Council.

These developments have had a profound and positive impact on IASSID as an Association. Following discussion at the 2006 Council meeting in Maastricht, it was agreed to give consideration to what further development might benefit the Association. This paper discusses a number of the issues raised at that meeting and sets out recommended courses of action for discussion.

Background: Membership, Governance, Structures and Representation

IASSID is a scientific association. It is appropriate for it to develop an active membership of individual scientists who look to it to fulfil a number of functions which support their work. Individual and group (i.e. research centre) members are critical to the vitality of the association. It is their participation which will permit IASSID to be active and provide momentum to its future. However, professional organisations and those representing service users or their families can also become organisational members of IASSID and can be important in ensuring an appropriate emphasis on the application and dissemination of scientific knowledge is maintained.

IASSID is an international association which aspires to be global in reach. It has greater involvement from countries in Western Europe than Eastern Europe, North America than South America, Australasia and the Pacific Rim than Central Asia, and South Africa than the remainder of Africa. It has an English language bias in its membership and business. Given the current under-representation of certain regions and language groups, it is important to monitor the degree of international representation in its governance and activities and to ensure that the Association becomes more internationally representative as it develops.

The current arrangements for constituting the Council of IASSID were agreed at the General Assembly which took place during the 2004 World Congress in Montpellier. A panel model of representation was agreed by which balance of representation was achieved in two respects: international balance with representation of Europe, Australasia, Asia, North America and South America, and balance of membership interests with representation of SIRGs, individual members, research centre members and organisational members.

The Association rules confer rights of representation on Council on individual members and SIRGs. They do not give any rights of representation to an organisation or research centre. Individual members elect their representatives to Council. The number of individual member representatives on Council, currently 5, is set by a formula of 1 representative to every 100 individual members. There were 8 SIRGs in existence when the current Council was formed (there are now 9), of which 5 are represented on Council. The person representing the SIRG is nominated by the SIRG. Two research centres and 8 organisational members are represented on Council. The relatively high

number of organisational members represented reflects historical development; there were even higher numbers on previous Councils. Selection of research centre and organisational member representatives is guided by achieving greater international representation.

In addition to international representation, IASSID has also followed a policy of gender equality and one would assume that this will continue.

- Currently, the 9 member Executive is biased towards Europe (7 members) and North America (2 members). It is biased towards mother tongue English speakers (8 members). The gender balance is 5 men to 4 women.
- The 23 Council members who are not part of the Executive come from 14 countries and are also biased towards Europe (11 members) and North America (6 members). The remaining six members come from Australia (2), Asia (2), South America (1) and the Middle East (1). The balance of English to non-English mother tongue speakers is 10 to 13. The gender balance is 13 men to 10 women. Considering the Council as an entirety (i.e., including the Executive), members come from 24 countries, with a 18:14 male:female ratio and an 18:14 English:non-English mother tongue ratio.
- The 28 officers of nine SIRGs (Ageing, Comparative Policy and Practice, Families, Health, Mental Health, Parenting, PMD, QoL and Ethics) come from only 7 countries, with all but four (1 German, 2 Dutch and 1 Belgian) coming from the UK (9), North America (9) and Australia (6) and although gender balance is good (15:13 male:female), there is a strong bias to English mother tongue speakers (24:4).

The Council is, therefore, the most internationally representative body within the Association, giving some evidence of the effectiveness of the panel representation model employed.

Background: Development of SIRGs

The current development of SIRGs was achieved by backing individuals who came forward with a proposal to form a SIRG. While perhaps little tangible backing was actually given (like most other areas of IASSID activity, SIRG development relied on committed people giving time and energy to make the initiative work), the attitude of the centre was to give SIRG leaders their heads rather than attempt to control or regulate. Such a strategy may well have been sensible as IASSID now has a number of productive groups. However, discussion at the 2006 Council meeting revealed that the arms-length stance taken during early development now felt to some SIRGs like unnecessary distance. Moreover, not all aspirant SIRGs have flourished.

Various aspects of the SIRG - central IASSID relationship have created an impression that SIRGs were not closely bound into the fabric of the Association. These include the emphasis that they must (a) be financially independent of IASSID (often reflected in having separate bank accounts), (b) create their own financial base through raising additional fees from members or by running profitable meetings, (c) use their own finances to meet the expenses of nominated representatives to attend Council meetings, and, (d) continue their programmes of meetings and other work without calling on central financial support. SIRG representatives at the 2006 Council meeting expressed the opinion that the SIRGs ought to be more actively supported and bound in to the Association. At the same time, they thought it legitimate for SIRGs to be more actively managed by the Association. The message appeared to be that IASSID should modify

its laissez-faire approach and develop clearer expectations about what SIRGs do and achieve. Greater support and a more integral role for SIRGs would provide them with opportunities but such a new relationship would also imply greater accountability.

As an interim development, it was thought that the additional fee for members to join SIRGs was a disincentive to their participation, particularly if individuals wanted to become involved in more than one. The 2006 Council meeting decided to raise the general Individual Membership fee by \$20 to provide funding for all SIRGs but to remove all supplementary fees for SIRG membership¹. Members are encouraged to join as many SIRGs as befits their work interests.

Background: Finances

For many years of its existence, the financial underpinnings of IASSID have been fragile. However, the situation has been much improved since the 2000 World Congress. It is still doubtful whether membership subscriptions cover the costs of the running of the Association (i.e., travel and accommodation for Executive and Council meetings). However, income from invested reserves plus an expectation that the World and European Regional Congresses can make profits, result in the overall financial position being currently robust.

IASSID meets the travel and accommodation costs of the nine Executive members for attendance at Executive meetings and Council meetings. It has been increasing the support available to Council members to attend Council meetings. Support offered for the 2007 Council meeting takes account of the location of the meeting and the distance that the Council member has to travel. However, no undertaking is given to cover all costs and the shortfall for some Council members is still likely to be greater than it is for others. It is possible that the Association is being too cautious in moving to meet the full costs of attendance.

The aim should certainly be to reach a position whereby membership subscriptions cover the costs of the routine governance and management of the Association. Rather than increasing fees beyond inflation, the better strategy would be to increase the number of individual, research centre and organisational members (Very approximate costings are given in Appendix 1 for illustrative purposes). As well as generating greater revenue, such an aim would also enhance the more fundamental aim of creating a vibrant network of scientists and researchers who become active in the Association's SIRGs, meetings and other activities.

In addition, the financial reserves of the Association should be available to further its developmental activities. There are recent examples of support being given to promote research in developing countries, to hold meetings in developing countries and to encourage the participation of researchers from developing countries in IASSID activities. However, the challenge is to have a strategic approach which uses hard-earned resources well and which takes account of and balances SIRG proposals for development with central Executive proposals for development.

Governance and management structure

¹ It was also decided that SIRGs that had previously levied a supplementary fee should not be financially worse off than before. If the distribution of the increased membership fee across SIRGs did not provide equivalent income, then additional funds would be allocated from IASSID reserves as a short term expedient. In this way, current forward budgets would be respected.

Individual members and SIRGs are a core constituency of Council and, therefore, integral to the governance of the Association. However, the way that the panel representation mechanism works in practice means that how the Council is determined is rather opaque to those members of the Association who do not have a detailed knowledge of its rules. It is timely for the Association to consider whether it should embark on further reform to establish a model whereby those involved in governance and management are chosen by the membership through a recognised democratic process. However, it is doubtful whether one can do more than set a direction for development before the new Council (i.e., 2008-2012) is constituted. Thus the recommendations which follow are seen as a developmental step rather than an end point.

Recommendations:

1. The panel representation model is retained as the basis for forming the 2008-2012 Council as it fulfils a function of broadening international representation. The model should be extended to include Africa.
2. The current size of Council should be maintained at 30 members.

(Note: a rule change to reduce its size might be considered in order to make the move to covering the full costs of Council members attending the meetings more affordable. However, a lower number would reduce the scope to maximise international representation and the representation of constituent membership communities. Ideally, the financial concerns would be met by increasing all forms of membership, thereby increasing fee income.)
3. The Council would include an Executive which would comprise the four Officers (President, President-elect, Secretary and Treasurer) and a number of Vice Presidents with specific roles to be determined by the President, but selected from among Council members. The Immediate Past president should continue as an ex-officio member of Council and Executive.
4. The Council discuss the roles which Vice Presidents might fulfil and make a recommendation to the President concerning this.

(Note: currently, there are four Vice Presidents with roles which cover SIRG co-ordination, Publications, WHO and International Affairs, and Constitutional Affairs, Awards and Recognition. The VP for Publications is the Editor of the Journal of Intellectual Disability Research. In addition, the Immediate Past President acts as the Association's webmaster.)
5. The trend towards greater democratic accountability to the membership is maintained.
6. There are 26 Council positions not filled by the four Officers (the Immediate Past President is supernumerary). It is recommended that:
 - a) the current formula for the direct election of Council members by individual members is maintained up to a maximum of 8
 - b) each SIRG should be represented by a nominated officer
(Note: the recommendations about SIRG development which follow foresee the number of SIRGs growing to a possible total of about 14)
 - c) the remaining positions should be filled equally by research centre or organisational members so as to maximise international representation
 - d) the officers of SIRGs be elected by individual members affiliated to SIRGs

- e) SIRGs should do everything within their powers consistent with maintaining dynamism and good governance to broaden the international representation among officers.
7. The Editors of JIPPID and JIDR and the IASSID webmaster be supernumerary members of Council should the incumbents of these positions not be ordinarily represented on Council.
 8. IASSID should meet the full costs of Council members attending Council meetings. The expectation that SIRGs cover the costs of their representative attending Council meetings should be removed.

Development of SIRGs

The past strategy of supporting initiative has produced a number of active SIRGs. However, growth has not reflected any end-state picture of how the total subject matter of concern to IASSID might be divided into separate topic areas and, therefore, the nature and number of SIRGs there might finally be. It is one of the criticisms which SIRGs voiced at the 2006 Council Meeting that IASSID had not set out a preferred matrix of SIRGs and sought to establish it.

It is recognised that the success of a SIRG often depends on the enthusiasm and commitment of a few key individuals. One cannot, therefore, guarantee that an attempt to establish a SIRG in an area where there is currently not one will necessarily be successful. Nonetheless, the attempt should probably be made.

The following themes provide a starting point for discussion of end-point SIRG structure (existing SIRGs are asterisked):

- Biology and Biobehavioural Understanding
- Challenging Behaviour
- Mental Health*
- Cognitive, Behavioural and Social Development
- Physical Health*
- Profound Multiple Disabilities*
- Families*
- Parenting*
- Education
- Employment
- Ageing*
- Quality of Life* and Community Living
- Individual Rights (combining Ethics* & Empowerment)
- Comparative Policy and Practice*

Appendix 2 provides greater detail of content areas within these 14 themes.

While the purpose of SIRGs is to focus on a particular subset of concerns, no possible categorisation can remove overlap between them. For example, health is an area of

concern for Physical Health, Mental Health, Profound Multiple Disabilities, Ageing, Quality of Life, Biology and Biobehavioural Understanding, Individual Rights, Families and Comparative Policy and Practice. There are overlaps between Challenging Behaviour, Mental Health, Cognitive, Behavioural and Social Development, and Education. It is important that SIRGs, therefore, collaborate with each other and do not become isolated and narrow. (Note: The Executive did consider what a smaller array of SIRGs with broader remits might look like - see Appendix 3. While, this was not thought to be a good way forward - the longer list above which also respects how SIRGs have developed to date is preferred - it does illustrate the closeness of interests between SIRGs.)

Regional congresses have developed in the last few years so that IASSID now has a major conference most years. Increasingly, SIRGs have had a close involvement in developing the programme within these events by organising symposia. This is a logical development. The World and Regional congresses provide an opportunity for SIRGs to arrange the dissemination of research findings in their areas, perhaps liberating their own meetings for other, more specific purposes. There is still clearly a dialogue to be had about the best way to conceptualise the relationship between the larger, more general meetings and the specific, SIRG focussed meetings. The main function of the large congresses appears to be the presentation and discussion of newly completed research. While other emphases (e.g., roundtable discussions) are possible, the scale of the meetings and the number of parallel sessions tends to inhibit a strategic focus on defined issues. SIRG meetings, however, being smaller may be much more conducive to discussion (e.g., research agendas, methodological applications) and development of strategic agendas.

Recommendations:

1. IASSID should respond to the current impression of unnecessary distance between the central Association and the SIRGs. IASSID should support SIRGs better but also have a view about their activity and direction. SIRGs should become more accountable. It is therefore recommended that:
 - (a) IASSID meets the costs of SIRG business meetings. All SIRGs now receive an allocation of funds to contribute to meeting the costs of running the SIRG. Application can be made for additional funds should this not be adequate.
 - (b) SIRGs should set out work programmes for discussion and agreement by the Council (the period to be covered could be determined by the SIRG, e.g., one year, two years etc.)
 - (c) SIRGs should be able to apply for support from IASSID to be able to carry through elements of their work programmes.
 - (d) SIRGs should describe activities undertaken in their annual reporting to Council
 - (e) Council should agree reasonable expectations for SIRG activity
 - (f) Council should exercise a managerial role in relation to SIRGs, where it judges that the proposed work programme falls well below reasonable expectations or the activities undertaken fall well below the proposed programme
 - (g) The Treasurer and SIRGs should undertake a review of the need for and function of separate SIRG bank accounts (as opposed to identifiable funds in the IASSID main account).

2. Following agreement by Council of end-point SIRG coverage, a Council sub-group should be appointed to work with the Vice President for SIRG co-ordination with the aim to establish and support new SIRGs in areas where they are required but not in existence.
3. SIRGs should arrange joint activities with one or more other SIRGs at least once every four years.
4. Further consideration should be given to the functions of the large world or regional meetings (and the role of SIRGs in contributing to the programmes) and SIRG meetings (e.g., whether the latter are a smaller, more intimate, topic-specific version of the former, or whether they might at times serve a different purpose).

Finance Developments

As recommended above, IASSID should undertake to meet the expenses of Executive, Council and SIRG business meetings through fee income. This will imply the need for the Association and its constituent groups to make concerted efforts to encourage membership growth.

Recommendations:

1. A council sub-group should be appointed to:
 - (a) review the benefit packages for individual, research centre and organisational members²
 - (b) create a virtual membership pack which can be sent electronically to all new members in each category
 - (c) draw up a proposal to increase membership.

² In the case of both group memberships (research centre and organisational), the aim would be to make continued membership financially advantageous without undermining the benefits of individual membership. Benefits could include the right to designate one person as a full individual member, receipt of journals at discounted rates, receipt of newsletter and other electronic IASSID publications, access to member discounted rates for attendance at IASSID meetings for constituent staff/members booked through the organisation/centre.

Appendix 1 Meeting Executive and Council Costs from Fee IncomeCost of Council Meeting

30 people x \$750 per person (\$200 for 2 nights hotel, average \$400 travel, \$100 sundry expenses, \$50 Council dinner) = \$22,500

Cost of 2 Additional Executive Meetings

9 people x \$750 x 2 = \$13,500

Total Cost

\$36,000

Fee Income (full member and research centre member)

\$50 after deduction of \$50 paid to the publisher for JPPID and \$20 for SIRG allocation

Target breakeven membership = 720

Appendix 2 SIRG Themes and Content Areas

<u>Biological and Biobehavioural Understanding</u>	Genetics Syndromes Biobehavioural processes Behavioural Phenotypes Brain Research/Neurotransmitters Risk Factors for ID Developmental and Behavioural Neurotoxicology
<u>Challenging Behaviour</u>	Challenging Behaviour Forensic Issues Psychological Intervention & Other Therapies
<u>Mental Health</u>	Mental Health Diagnosis/Assessment and Classification Systems Psychopharmacology Psychological Intervention & Other Therapies
<u>Cognitive, Behavioural and Social Development</u>	Adaptive Behaviour Cognitive Development Communication and Language Early Intervention Social Skills/Impairment Autism Down's Syndrome
<u>Physical Health</u>	Physical Health Medical Intervention/Medication/Dentistry Sensory and Physical Disabilities Epilepsy
<u>Profound Multiple Disabilities</u>	Profound Intellectual Disability Sensory and Physical Disabilities Epilepsy Assistive Technology
<u>Families</u>	Early Counselling and Adjustment Family Experience Family Supports Family Lifecycle Siblings Ageing Carers Parents with ID
<u>Parenting</u>	Parents with ID
<u>Education</u>	Early Intervention/Pre-school Provision Schooling College Transition
<u>Employment</u>	Transition Employment Day Occupation Supports Careers Retirement

Ageing

Ageing and Health Status
 Functional Decline
 Lifespan Transitions
 Retirement
 Death and Dying/Palliative Care

Quality of Life and
 Community Living

Quality of Life Assessment
 Quality of Life Supports/Determinants
 Home Life/Residential Supports
 Community Integration/Inclusion
 Leisure
 Personal Relationships and Sexuality
 Self-determination
 Material circumstances
 Person-centred Planning
 Vulnerability, Abuse, Protection
 Spirituality

Individual Rights

Values and Ethics
 Genetic Screening
 Law and Civil Rights
 Advocacy and Self-advocacy
 User Views/Participation/Empowerment
 Gender
 Culture and ethnicity
 Ethics of Research

Comparative Policy and Practice

Epidemiology
 Policy and Service Patterns
 Achievement of Strategic Change
 Cost-effectiveness
 Service Management and Quality Assurance
 Staff Training and Professional Development

Appendix 3 Alternative Clustering of SIRG coverage

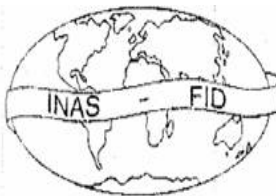
- **Aetiology, Health and Psychopathology**
 - to include: Biological and Biobehavioural Understanding, Physical Health, Mental Health, Challenging Behaviour, Forensic Issues, Ageing, Nursing, Palliative Care, Environmental Hazards

- **Behavioural, Cognitive and Social Development**
 - to include: Behavioural Development, Cognitive Development, Communication, Education, Down's syndrome, Profound Multiple Disabilities

- **Family Life**
 - to include: Families, Parenting

- **Adult Life**
 - to include: Comparative Policy and Practice, Quality of Life, Community Living, Employment, Social Inclusion

- **Civil Rights**
 - to include: Ethics, Empowerment, Law



Report to the INAS-FID membership on athletes with intellectual disability and the 2008 Beijing Paralympic Games

It has appeared that there is a need among the membership for a résumé and for updated information on the actions taken by INAS-FID for the inclusion of athletes with intellectual disability in 2008 Beijing. This report begins in November 2004 when the IPC General Assembly assigned IPC the task to actively direct a process by which mutually (for IPC and INAS-FID) acceptable eligibility and verification systems are developed. The report does not include the actions taken from 2001 to 2004 which led to the inclusion of a small number of athletes in 2004 Athens, on a demonstration basis. However, at some places reference is made to occurrences from before 2004.

INAS-FID member organisations should feel free to forward this report to whoever they think appropriate.

The report includes:

Fact sheet July 2006 (distributed to membership last August)
pages 2 through 5

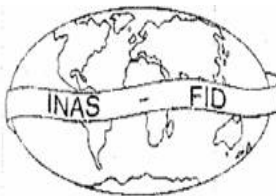
Report of a meeting IPC/INAS-FID 23 August 2006
pages 6 through 10

INAS-FID presentation before IPC Governing Board 25 November 2006
pages 11 through 15

Letter IPC 27 November 2006
page 15

Next steps
page 15

Jos Mulder
President
January 2007



Fact sheet

on the systems for determining eligibility of athletes with intellectual disability to participate in the 2008 Beijing Paralympics and on the IPC Governing Board decision of 24 June 2006.

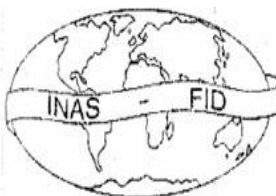
1. November 2004 the IPC membership decided that the IPC should actively direct a process by which mutually (for IPC and INAS-FID) acceptable eligibility and verification systems are developed.
2. For that, and in the beginning of 2005, a so called General Group was formed, made up of the Chairman of the IPC Sport Science Committee, the IPC Medical and Scientific Director, the INAS-FID Eligibility Adviser and the Director of SUH (where the INAS-FID Secretariat is located). Later, an expert from the Leuven University (Belgium) joined the Group.
3. April 2005 the IPC Governing Board decided to include in the Beijing programme slots for the participation of athletes with intellectual disability in the sports of Athletics, Swimming and Table Tennis, pending the development of mutually acceptable eligibility and verification systems.
4. November 2005 the IPC membership stressed the need for the involvement of the IPC Sports concerned in the process. The membership further decided that access to full medal events in Beijing should be granted in case the first part of the process is completed, that is the establishment of mutually acceptable “general eligibility criteria”. The membership agreed that the second part of the process, that is the establishment of “sport specific eligibility criteria”, is moved until after Beijing.

The “general eligibility criteria” are for determining whether an athlete meets the criteria for intellectual disability (following the standards developed by international scientific and professional organisations) and for identifying the impact of intellectual disability on sport (following the Sport Information and Consequences Questionnaire, SIC-Q).

The “sport specific eligibility criteria” are for indicating whether there should be additional and varying requirements per sport.

5. June 2006 the General Group presented its report to the IPC Governing Board. The report included a Research Report (50 pages printed on neutral paper) and a Summary Report (11 pages printed on paper with the IPC name and logo). The Summary Report indicates that the first part of the process has been completed, the second part not. The relevant lines in the paragraph Executive Summary read:

The accompanying Research Report provides sufficient evidence to suggest that INAS-FID has developed a general eligibility process, as follows:



Criteria	Met
Impact of Intellectual Disability on Sport Performance	Yes
Determination of 'Minimum Handicap'	Yes
Protest Procedures	Yes
Sport Specific Criteria	No

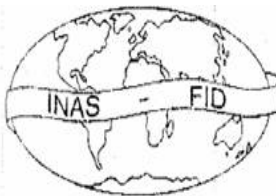
6. With regard to the involvement of the IPC Sports concerned a line in the paragraph Sport Involvement reads:

The below Sports have been included in the research project at varying levels since January 2005 and have provided direction as to how sport specific criteria may be developed in the future.

After that, the Sports of Athletics, Swimming, Table Tennis and Rowing are listed and names of those who have acted as contact persons.

7. Some further quotes from the Summary Report:

- a. Much of the progress made to date has been due to the commitment and dedication of members of the General Group and others integrally involved in the process, including the Sports. This has contributed to a collaborative approach to the issues and has taken research in the field of classification to a new level (quote from Executive Summary).
- b. As the IPC Governing Board considers the question at hand it is important to remember that the research that has been conducted is extensive and that the model implemented can have significant benefits to other sports on the Paralympic programme. It is also worth noting that when evaluating one sport or disability group it should be conducted while acknowledging the current classification environment and the scientific merits of the classification systems of all sports (quote from Executive Summary).
- c. Recalling that most athletes included in the research had intensively been involved in their sport for 7 or more years, these findings point to the enduring implication of applying sport skills in their sport that are inherent when someone has an intellectual disability (quote from paragraph Impact of Intellectual Disability on Sport Performance).
- d. It is worth noting that IQ scores are inadequate for fully understanding the dynamic relationship between the various factors that determine sports proficiency in relation to intellectual disability. Interestingly, research demonstrates that when investigating whether top athletes – based on their sport performance – would have higher IQs than those who are not ranked no significant differences were found between ranked and unranked athletes on IQ scores (quote from paragraph Determination of Minimum Handicap).
- e. The verification of athlete registration information and the resolution of Protests at competitions are managed by the INAS-FID Accreditation Committee. Appendix 1 details the role of the INAS-FID Accreditation Committee This procedure is comparable to those in other sports on the Paralympic programme,



allowing an athlete the right to both Protest and Appeal any decision made, while enabling Protests to be managed on-site at the competition (quote from the paragraph Protest Procedures).

- f. Throughout the research period considerable progress has been made in developing and understanding of the implications of intellectual disability across a number of sports (particularly in Athletics, Swimming, Table Tennis and Basketball). However, the development of sport specific criteria is an ongoing process. While fully appreciating the desire for closure and an end to this process as soon as possible, fixed timelines for developing a sport-focused system of classification raise several concerns from a method and process perspective. The scientific process is one of inherent uncertainty as it cannot be pre-judged where the data might lead (full quote of the paragraph Sport Specific Criteria).

8. A quote from the chapter Status of the Report in the Research Report reads:

Second, it should be clear that this report is about eligibility to enter a competition with an open class. Consistent with the eligibility criteria and the underlying basis of the impairment, there is no provision in the general eligibility requirements for dividing athletes with intellectual disability into more than one class (i.e. there is no sub-classification or segmentation of athletes within the intellectual disability group).

This statement is then followed by a reasoning in relation to the over 500 different forms of cognitively based impairments and in relation to the concept of elite sport.

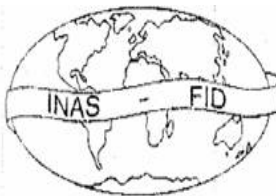
9. A quote from the chapter Conclusions of the Research Report reads:

From this evidence it is clear that athletes with intellectual disability are unable to engage in equitable competition with non-disabled athletes and this holds independent of, for example, level of intellectual impairment and years in training.

10. In spite of this positive report the IPC Governing Board, on 24 June 2006, decided that athletes with intellectual disability may not participate in Beijing.

11. On 26 June 2006 the IPC wrote to INAS-FID, giving reasons for the decision. On 30 June 2006 INAS-FID wrote to the IPC, asking for further clarification and information. On 11 July 2006 the IPC wrote to INAS-FID in reply.

12. In its letters the IPC gives as reasons for the decision that
 - a. sport specific eligibility criteria still must be developed;
 - b. the general eligibility system does not achieve required standards;
 - c. the SIC-Q is open to subjectivity (coaches involvement);
 - d. the on-site verification is an administrative process only;
 - e. the opinions of the Sports are negative;
 - f. the cutoff score for IQ should be 70, not 75.



13. INAS-FID's position on these subjects is that

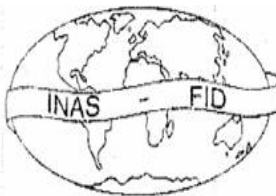
- a. it was agreed that the issue of sport specific criteria was moved until after Beijing;
- b. the IPC has not made clear in which way the INAS-FID systems are of a lower standard than systems for other disability categories; this is the reverse of what the Summary Report of the General Group says (see 7 b above);
- c. the IPC is re-opening discussions that were concluded in April 2005 when the SIC-Q was accepted as an integral part of the Athlete Registration Package, at which time no reservations on its reliability were made, just the reservation of later refinements if deriving from research findings. With regard to the risk of subjectivity because of the involvement of the coach it should be noted that the SIC-Q came into being following a meeting with the IPC Medical Officer and the IPC Technical Officer late 2002 in Bonn, the IPC Technical Officer stressing the importance of the views of the coach;
- d. the IPC starts again repeating its wish for the on-site assessment of an athlete's eligibility in case of a protest, whereas this is in conflict with the internationally recognized requirements for the assessment of intellectual disability which are that such assessment can only be made by a national expert, in the country of the athlete, in the social, cultural and linguistic environment the athlete is used to. An athlete cannot be re-assessed at a competition venue;
- e. INAS-FID has asked for copies of the Sports letters. This was refused. The negative opinions of the Sports are surprising. They are in conflict with statements in the Summary Report of the General Group (see 6 above).
- f. Also on the IQ cutoff score it looks as if the IPC wishes to escape from agreements made in April 2005 with new reasonings that, from documents exchanged at the time (letters General Group, INAS-FID, IPC), clearly appear to be false.

14. The overarching problem is that the IPC has difficulties in understanding the specific nature of the concept of intellectual disability. In the case of an athlete with a physical disability the IPC relies on the judgement of a medical or para-medical officer, and in the case of an athlete with a visual impairment on the judgement of an ophthalmologist. However, in the case of an athlete with intellectual disability the IPC is not prepared to rely on experts in the field but prefers to follow its own, non-expert, opinions. Moreover, the advices of the General Group are ignored.

15. In the foregoing INAS-FID could not do anything else but refer to "the IPC".

However, we are aware that there are many individuals within the IPC circle who have a good understanding of the specificity of the concept of intellectual disability and who are prepared to follow the advices of experts in the field. Towards them we apologize for our general way of speaking.

July 2006
 Jos Mulder
 President INAS-FID



Meeting held on 23rd August 2006 at the Hilton Hotel, Manchester (UK) Airport, from 11.00 to 13.15 hrs.

Present:

- Sir Philip Craven, IPC President
- Xavier Gonzalez, IPC CEO
- Graham Arthur, lawyer employed by IPC
- Jos Mulder, President INAS-FID
- Bernard Atha, President INAS-FID Europe

SUMMARY

The meeting was friendly but to the point.

After much debate INAS-FID accepted an offer from the IPC President to make a presentation to persuade the IPC Governing Board to reverse its decision of 24 June 2006. This will be at the next IPC Governing Board meeting, 23 to 26 November 2006 in Kuala Lumpur.

If (and it was agreed to underline the word if) the decision is reversed, previously made agreements on numbers of athletes and “tailored qualification systems” will be honoured.

This gives every supporter of athletes with intellectual disability time to write to the IPC Governing Board Members, to their Members of Parliament, to their Ministers of Sport, to well known sports people, and make them aware how unfair the ban is. Please send us copies of your letters.

Remember that some of the IPC Governing Board members will have voted in favour of athletes with intellectual disability. We do not know who voted for or against. It may have been a secret vote. We simply do not know.

A full report of the meeting is given below.

24 August 2006

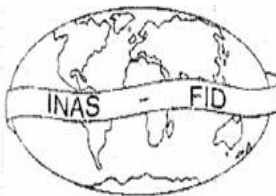
Jos Mulder, President INAS-FID

Bernard Atha, President INAS-FID Europe

FULL REPORT

Phil Craven welcomed all to the meeting and invited INAS-FID to lead the discussion.

Jos Mulder thanked the IPC President for agreeing to the meeting. He said that the aim of INAS-FID is to have the decision of the IPC Governing Board to continue the ban on athletes with intellectual disability reversed. As the IPC President is very influential he has the power to persuade the IPC Governing Board to change its decision. It was not known to INAS-FID whether the vote in the IPC Governing Board was unanimous or the decision was by a majority. INAS-FID would like to think it was a narrow majority. Jos Mulder then presented a document with the following text



Quote

Claim to participation Beijing

WHEREAS

- a system for the registration of athletes with intellectual disability who meet the criteria for participation in the 2008 Beijing Summer Paralympic Games is in place
- the system has been approved by a group of experts appointed by IPC and INAS-FID
- the system forms an integral part of the Athlete Registration Application Form version April 2005

INAS-FID CLAIMS THAT

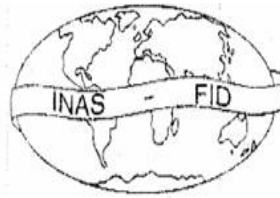
1. athletes with intellectual disability who are registered for eligibility with INAS-FID on the basis of the Athlete Registration Application Form version April 2005, have the right to qualify for full medal events in the 2008 Beijing Summer Paralympic Games
2. the IPC shall allocate slots for the participation of qualified athletes in class 20 for Athletics, class 14 for Swimming and class 11 for Table Tennis
3. the number of slots shall be as decided by the IPC Governing Board at its meeting of April 2005 (“pending eligibility to compete”) whereof the number of Swimming slots shall be the number as in Sydney, as suggested by the IPC CEO in a meeting of him with the IPC Medical and Scientific Director and the INAS-FID President immediately after the IPC Governing Board meeting
4. for qualifying for Beijing athletes with intellectual disability as meant in paragraph 1 shall have the right to participate in IPC qualifying competitions
5. in addition to the arrangement as in paragraph 4, and as far as necessary, tailored qualification systems are established as per the e-mail message of 17 January 2006 from the IPC Medical and Scientific Director.

23 August 2006

Unquote

Phil Craven said he could only persuade his colleagues if he was sure the INAS-FID case was right. He felt the IPC Governing Board would need new evidence if it were to change its decision.

The IPC letter of 26 June 2006, in which the reasons for the IPC Governing Board decision are given, was discussed.



IQ cutoff score

INAS-FID said that in bringing under discussion again the IQ cutoff score, IPC deviates from its agreement of April 2005. Xavi Gonzalez said that the agreement had a preliminary nature and was meant as a basis for further research. Jos Mulder replied that the letter of 20 April 2005 with which the General Group presented its findings to IPC, and IPC's response of 28 April 2005 clearly indicate that the IQ cutoff score was not subject to further research but was a definitive agreement. Xavi Gonzalez advised that, although there was some discussion on it in the IPC Governing Board meeting, the IQ cutoff score was not an issue on which the Board's decision was based. Instead, he said, the decision was based on three other main reasons:

- the possible subjectivity of the SIC-Q because of the involvement of the coach
- the protest procedure
- the advices of the Sports.

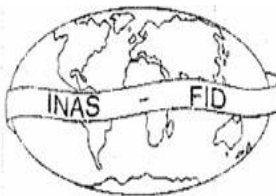
SIC-Q

Jos Mulder clarified how the SIC-Q came into being. This was at a meeting of IPC and INAS-FID officers late 2002 in Bonn after the closing of an IPC Executive Committee meeting. It was agreed there to establish a questionnaire (later named Sports Information and Consequences Questionnaire, SIC-Q). At the time the IPC Technical Officer stressed the importance of including the views of the coach. Bernard Atha said that possible subjectivity does play a role in many classification issues within the Paralympic movement. It may not be a reason for rejecting the SIC-Q.

Protest procedure

INAS-FID has stated in its letter of 30 June 2006, which was a response to IPC's letter of 26 June 2006, that it cannot meet IPC's wishes for an on-site assessment of an athlete in the case of a protest against the athlete's eligibility. According to the international standards for the assessment whether an individual meets the criteria of intellectual disability, an assessment can only be made by a national professional (eg psychologist) and in the social, cultural and linguistic circumstances the individual is used to. This is not possible at an event. Bernard Atha said that if the procedures presented by INAS-FID (ie a review of the documents of the nationally made assessment) does not satisfy IPC, any challenge based on eligibility could be treated like a drug test. If a challenge is made against an athlete with intellectual disability, another national test could be undertaken at the expense of the party in the wrong. Results could be reported and medal consequences dealt with the same way as in the case of a drug test outcome, which is post the event.

Phil Craven said this was the first time this position has been put to the IPC. It is a new factor that has to be considered. He also said that it is a fundamental principle in IPC that national classifications can be verified internationally. Jos Mulder said that he was surprised of this comment. INAS-FID has always stressed that an assessment on intellectual disability cannot be done on-site. He referred to INAS-FID's previous reports to the IPC Executive Committee.



Bernard Atha added to this that if the IPC would wish to keep athletes with intellectual disability out of Paralympic Games all they need to do is insist on a protest procedure on eligibility at the event. Such a procedure is impossible and would therefore automatically exclude athletes with intellectual disability.

Advices of the Sports

Xavi Gonzalez informed that also the Sports did not believe that athletes with intellectual disability should be entitled to compete in IPC sanctioned events. INAS-FID responded that the report of the General Group (made up of experts appointed by IPC and INAS-FID) came to an opposite conclusion, namely that the previously agreed conditions for participation in Beijing are met. Before INAS-FID could have a view on the advices of the Sports it would have to see their letters.

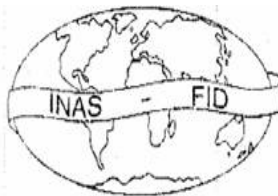
JEVC

During the discussion on IPC's letter of 26 June Bernard Atha mentioned the possibility of establishing again an IPC/INAS-FID Joint Eligibility Verification Committee for the verification of the eligibility of athletes with intellectual disability to Beijing. Such JEVC has worked well in the case of athletes with intellectual disability to Athens. This idea was not elaborated further.

Jos Mulder said that a reverse of the IPC Governing Board decision is a matter of urgency, mainly because 2007 is a year of qualifying competitions for Beijing and entries for such competitions are to be made well in advance. He asked for a decision within a few weeks. Phil Craven responded that there was no way in which he could agree to that request. Such a decision has to be made by the IPC Governing Board at a formal meeting. Its next meeting is from 23 to 26 November 2006 in Kuala Lumpur. If INAS-FID would wish that, he would be prepared to put the INAS-FID appeal on the agenda for that meeting. He felt however that new information would be required to achieve a change. He also said that the numbers of athletes and the timely qualification cannot be a reason for an urgent decision. If (and it was agreed to underline the word if) the IPC Governing Board decision is reversed the previous made agreements on the numbers of athletes and on "tailored qualification systems" shall revive and be honoured. This was put by Xavi Gonzalez in words like (not verbatim): "this will never be an issue".

Jos Mulder and Bernard Atha then conferred and on their return to the meeting it was agreed that INAS-FID would make an appeal to the IPC Governing Board at its November meeting on the understanding that if the decision is reversed the numbers of athletes and the "tailored qualification systems" as detailed above in paragraph 3 and 5 of INAS-FID's claim, are retained. On advice of Xavi Gonzalez it was accepted by INAS-FID that numbers depend on NPCs choosing to include athletes with intellectual disability in their delegation.

Note for the INAS-FID membership, not discussed in the meeting: In agreeing with an appeal Jos Mulder and Bernard Atha took into account the advices of lawyers that all internal opportunities for appeal must be used before INAS-FID can refer itself to a German Court or can request that IPC and INAS-FID refer themselves to the CAS (Court of Arbitration in Sport).



With regard to a copy of the draft minutes of the IPC Governing Board meeting of 24 June 2006 and to a copy of the letters of the Sports, Phil Craven said that he would see what he could do. He stressed that for the letters of the Sports he would need the approval of the Sports since the letters were submitted to the IPC Governing Board in a confidential manner. When Jos Mulder expressed surprise of the confidentiality of the letters Xavi Gonzalez indicated that their critical content, in essence, was on the SIC-Q and the protest procedure, as discussed in this meeting.

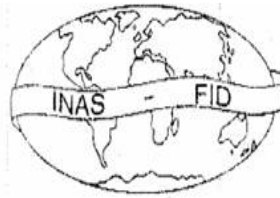
Jos Mulder informed of the name of the law firm advising INAS-FID and of the name of the solicitor in its The Hague office and its Düsseldorf office, the latter being a CAS arbitrator himself. He wondered whether it would be useful if an INAS-FID lawyer and an IPC lawyer sit together and evaluate legal aspects. This idea was not taken up by IPC.

Graham Arthur asked that the appeal to the IPC Governing Board be not called an appeal which has legal meanings including matters like due process and discovery of documents. It could open the door to legalistic issues. Bernard Atha responded that INAS-FID is happy to call it a presentation to persuade the IPC Governing Board to reverse its decision of 24 June 2006.

It was agreed that IPC and INAS-FID would each inform their membership about this meeting as they think appropriate.

After mutual thanks for the way discussions were held the meeting was concluded.

A copy of this report has been sent to the IPC CEO.



INAS-FID presentation before IPC GB, 25 November 2006, Kuala Lumpur

Handout

In this handout numbers and headings are similar to those on the power point slides. Texts are in most cases more elaborated.

2. Thanks

Thank you, Mister President, for the opportunity given to me to address the IPC Governing Board at this meeting.

3. Sydney

At the 2000 Sydney Paralympic Games able bodied athletes posed to have an intellectual disability and participated in the Games. The administrative systems in INAS-FID were not in order. Athletes with intellectual disability were banned from IPC sport events and INAS-FID was required to bring its administrative systems in order.

4. Criteria

The INAS-FID eligibility criteria in effect for Sydney were well described in the IPC Media Release of 27 November 2000: “Only athletes whose IQ was tested to be approximately 70 to 75 or below, who have limitations in two or more adaptive skill areas such as communication, self-care, home-living or functional academics, and who acquired their condition before the age of 18, are eligible to compete in Paralympic events for athletes with an intellectual disability”.

5. IPC Report 2001 on Sydney

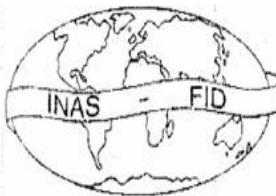
In the 2001 “Report of IPC on INAS Evaluation Matrix” the assessment details of each athlete with intellectual disability who participated in Sydney were listed. Those who did not meet the criteria described in the previous slide were required to be re-tested. Those who met the criteria were not required to be re-tested. It is worthwhile mentioning that the IPC applied the IQ 70-75 bandwidth.

6. General Group 2005

In the beginning of 2005 a so called General Group was formed, made up of IPC and INAS-FID experts. On 20 April 2005 the Group reported to IPC and INAS-FID. The Group proposed to definitively replace the bandwidth of 70-75 by a clear cutoff score of 75 as only a first step in the assessment process. It also proposed to approve the SIC-Q as the current system for identifying the impact of intellectual disability on sport, subject to later further improvement based on research outcomes. The Group’s proposals were put into a revised Athlete Eligibility Application Form. The form was approved by INAS-FID and IPC in their letters of 22 April and 28 April 2005.

7, 8 and 9. Letter IPC 28 April 2005

The relevant parts in the IPC letter of 28 April 2005 read:



“Please be advised that the IPC approves the revised form with the following comments:

1. It is agreed that the revisions to this form are an interim step towards a mutually agreed eligibility and verification system. Any findings from the forthcoming research regarding the impact of intellectual disability on sport performance will be included at a later date in the Athlete Eligibility Application Form, if appropriate.
2. Consideration is given to creating a ‘closed list’ of internationally recognised and professionally administered IQ tests to ensure the reliability of the information provided in the initial phase of establishing eligibility”.

10. Closed list

At its meeting of 29 August 2005 the General Group investigated the possibility of creating a ‘closed list’. The Group concluded that a ‘closed list’ does not meet the requirement of taking into account cultural context. In different places in the world different tests are validated, but always against the same internationally recognised requirements.

11. Consequently

As a consequence there was

- a definitive agreement on using an IQ cutoff score of 75 as a first step in the assessment process, not subject to further research and
- an agreement on using the SIC-Q as the current system for identifying the impact of intellectual disability on sport, subject to later further improvement based on research outcomes.

12. IQ

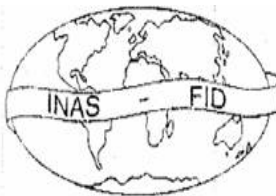
In the previous slides I have given attention to the IQ score discussion. However, it should be noted that experts in the field of intellectual disability would regard this as giving too much attention to IQ. An IQ score is not seen as absolute. IQ testing is not the only instrument for identifying intellectual disability. Over time the assessment of intellectual disability through adaptive behaviour scales has become important as well. This is part of the INAS-FID systems.

13. SIC-Q

The Sports Information and Consequences Questionnaire (SIC-Q) is a tool for identifying the impact of intellectual disability on sport performance. We were informed that the IPC Governing Board has concerns on the reliability of outcomes of the SIC-Q because of the involvement of the coach. However, it should be noted that in IPC’s letter of 28 April 2005 no reservation on the involvement of the coach was made, just the reservation of later further improvement based on research outcomes. It should also be noted that the SIC-Q came into being following a meeting with the IPC Medical Officer and the IPC Technical Officer late 2002 in Bonn, at which time the IPC Technical Officer stressed the importance of including the views of the coach.

14 and 15. Protest procedures

With regard to Protest Procedures the IPC is stating that INAS-FID, in the past, agreed with on-site assessment of athletes. INAS-FID has responded that it has not made such promise. The discussion derives from the decisions of the 7/8 December 2001 IPC General Assembly.



Decisions INAS-FID has promised to comply with. One of the decisions was “That the IPC Protest Procedures for Classification and Eligibility that are applied universally at the Paralympic Games and IPC Championships shall include athletes with intellectual disability”. IPC and INAS-FID have taken the 2001 decision as a decision that, of course, takes into account the specific nature of intellectual disability, the assessment of which may only be made in the country of the athlete concerned and in the cultural, language and social circumstances the athlete is used to. Otherwise outcomes will be not reliable.

16. Protest procedures

INAS-FID consulted in 2002 with the IPC Medical Officer and in 2004 with the IPC Sports of Athletics, Nordic Skiing, Swimming and Table Tennis on Protest Procedures, in all cases based on an on-site review of original assessment documents via online consultation of databases and files. Evidence of what I am saying here is in the IPC Medical Officer’s advice of 5 November 2002 and in the e-mail correspondence with the IPC Sports as included in INAS-FID’s report to the IPC Executive Committee of 2004.

17. General Group report 2006

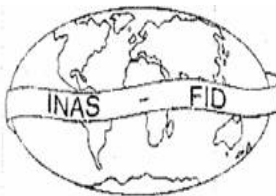
In 2006 the General Group completed its report to the IPC Governing Board. The Group concluded that all conditions for the inclusion of athletes with intellectual disability in Beijing were met. The Group reported, through the IPC Medical and Scientific Director, that the IPC Sports concerned were involved in the process. The Group also reported that the Protest Procedure presented “is comparable to those in other sports on the Paralympic programme”. As an overall judgement the General Group gave as its opinion that “the research that has been conducted is extensive and that the model implemented can have significant benefits to other sports on the Paralympic programme”.

18. Improvement of systems

In view of the establishment of sport specific criteria (an “after Beijing” requirement) INAS-FID is collaborating with the Leuven Research Group and the IPC Sport Science Committee. In October the Leuven Research Group conducted a research programme at the INAS-FID World Basketball Championships in Yokohama (Japan). With this, INAS-FID hopes to demonstrate that it is prepared to work on the further improvement of its systems based on outcomes of scientific work and research. However, in the mean time its athletes may not be excluded from Paralympics. After all, within the Paralympic movement it is recognized that for athletes of other disability categories classification systems need to be improved. For that, a project running over several years is on its way. In the mean time the athletes concerned were not excluded from Paralympics.

19. Protest procedures again

At a meeting in Manchester on 23 August 2006 with the IPC President and the IPC CEO INAS-FID offered an additional commitment in an effort to solve the Protest Procedures issue. It proposed, in case the on-site (online) review of original assessment documents and files does not satisfy, that the athlete is re-assessed upon her/his return home and that in case of non-eligibility, procedures as in the case of a doping offence are applied. I herewith put that proposal before the Governing Board.



20. JEVC

At the meeting in Manchester INAS-FID also expressed understanding for IPC's wish to have "clean" (in the sense of eligibility) Paralympic Games. It therefore proposed a revival of the Joint Eligibility Verification Committee (JEVC). Such JEVC worked well for Athens and it could work again for Beijing. The JEVC should be made up of IPC and INAS-FID representatives and should review the assessment documents of athletes going to Beijing, in addition to the verifications carried out before by the National Eligibility Committees with the endorsement of the NPCs and the verifications by the INAS-FID Secretariat at SUH. I herewith also put this proposal before the Governing Board.

21. Request

INAS-FID requests the IPC Governing Board to

- include athletes with intellectual disability in Athletics-, Swimming- and Table Tennis events in Beijing on the basis of the IPC/INAS-FID Athlete Eligibility Application Form as advised by the General Group (i.e. version April 2005)
- accept INAS-FID's offer for a nationally conducted re-assessment of an athlete in case, at the time of a protest, an on-site (online) review of original assessment documents and files does not satisfy
- participate in a Joint Eligibility Verification Committee for an extra review of the assessment documents of athletes going to Beijing.

22. Third party

If the involvement of a third party is necessary, IPC and INAS-FID could agree on making the issue subject of a procedure in the Court of Arbitration for Sport (CAS). A last resort for INAS-FID is a procedure before a German Court. However, we would not wish this.

23 and 24. German Court

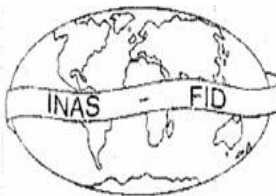
INAS-FID is aware of its membership duties. It does not want to aggravate the dispute unnecessarily and would not like to claim anything groundless. It therefore has asked for the advice of German experts on sports law on a procedure before a German Court. The opinion of these experts is that the INAS-FID case is a good case and that it fulfils all the strict requirements under German law with regard to Admissibility, Jurisdiction, Applicability of German Law, Standing to Sue and Substantive Law. However, we stress this again, we would not wish a procedure before a German Court.

25. CAS

If the involvement of a third party appears to be inevitable we propose to agree on a CAS procedure. The CAS is *the* platform for the sports family to solve disputes. One of the advantages of a CAS procedure is that it creates no negative publicity. As you very well know there are several kinds of procedures in the CAS. The applicable kind of procedure to be decided by IPC and INAS-FID.

26. Request again

However, we hope that a CAS procedure is not necessary and that the IPC Governing Board is prepared to meet our request as detailed above in paragraph 21.



27. Athletes

The ongoing dispute between IPC and INAS-FID since 2000, seriously affects athletes with intellectual disability who were not involved in any wrong doing themselves. Their Paralympic sports career is interrupted for already six years which is extreme in the world of sports. We ask the IPC Governing Board to take this into account in its decision making.

28. In closing

INAS-FID feels it is running out of time. NPCs are already making preparations for the composition of their squads to Beijing. Therefore, I would appreciate receiving an indication of how the Board would like to respond to my requests before my departure from Kuala Lumpur, which is at 6 PM today.

29. Thanks

Thank you very much for your time and for your attention to this matter.

Jos Mulder
President INAS-FID

Letter IPC 27 November 2006

In this letter the IPC CEO confirms the decision taken. The relevant part of the letter reads as follows.

Quote

I hereby officially confirm to you that the IPC Governing Board, following your presentation on behalf of INAS-FID, unanimously approved the following statement:

“After receiving the presentation of INAS-FID, the IPC Governing Board noted that no new material and no new information had been provided by Jos Mulder. The IPC Governing Board reconfirms the decision taken at its meeting of June 2006, in Lausanne.”

Unquote

Next steps

INAS-FID is advised by the international law firm Bird & Bird. Its attorneys at law Wouter Pors (The Hague) and Martin Schimke (Düsseldorf) are working for INAS-FID on a pro bono basis. INAS-FID is consulting with them on next steps. The INAS-FID membership will be kept informed.

Academy Responses and Proposals - March 2007

Report to IASSID Executive

Introduction

This report covers the period from December 2006 to March 2007. It deals with the implementation of the recommendations and requests from the Executive of IASSID and also explains some of the developments that have been necessary to ensure the major plan for an academy is put into operation. There are also several suggestions from the new Academy Council on which we would like IASSID Executive comment and/or agreement. At this point a course proposal form has been developed for the selection and development of courses (See below). Please note this has been developed and aspects already used in discussions with Gare Fabila, Mexico.

Recommendations regarding the Academy Structure

- 1) It has been recommended by the academy council that the name of the council should be **Academy on Education, Training and Research- IASSID**. This suggestion has come from several members of the Academy.. The rationale for

Comment [KM1]: Are we the IASSID Academy..... or the Academy..... IASSID ?

this is that the Association is a scientific research organization and the aim of the Academy is to disseminate through its courses up to date research and practice.

2) It is recommended that the title of the chair should be Director and Chair of the Academic Council.

New member to Academy Council

Dr (Lisa) Kuo-Yu Wang, Department of Social Welfare, National Chung-Cheng University, Chia-yi, Taiwan, has accepted an invitation to join the Academy council.

Four developments have occurred in relation to the proposed course venues.

1. Feedback from Dr. Janiki on the visit to Chile suggests that an arrangement for courses in Chile at the present time would probably not be viable at this time owing to doubt about possible arrangements.

Comment [KM2]: Might need to explain this more precisely

2. I have e-mailed Glynis Murphy to suggest meeting in March to discuss course(s) around the IASSID Conference in South Africa.
3. An opportunity has arisen to run courses in relation to Singapore and the South Asian conference on intellectual disabilities run by IASSID and with DSI as co-supporters. This seems a very appropriate venue for courses and has been much supported by Dr. McVilly and Dr. Matt Janiki in terms of their initial visits to Singapore. The chair of the Academic Council has had some preliminary

discussions in Singapore, and has had some preliminary discussions with the past chair, Dr. Balbir Singh and current president, Jo Mills of Down Syndrome International, who are in favour of supporting this aspect of the project. It is suggested that this is very good example of the way in which IASSID and DSI can cooperate under their joint agreement. There have also been some initial e-mail discussions with Bee Hong Tan, Director, of the Social Service Training Institute in Singapore which sponsors and funds courses. She has invited the Academy to examine their course interest areas and propose collaboration.

From the Academy's perspective the courses at this stage are viewed as being ones for personnel who may be participants at the conference. Dr McVilly is arranging further discussions in relation to the Academy involvement and IASSID.

Recommendation

The planning for this is obviously at an initial stage, but the Council would ask for endorsement of this particular development.

4. Opportunities have also arisen for the development of courses in Mexico with direct liaison with Gare Fabila who is a member of IASSID and is in a key position in Mexico to arrange such courses. She has been visiting workshops in Canada in which the director of the Academy has been involved, and she has specifically requested particular courses. A preliminary proposal is now being developed on the lines of the document attached below on the understanding that this will be raised with IASSID

Executive for their backing and support. It is suggested by the Academy Council that this is a good opportunity to trial such courses which will involve at least one member of IASSID as well as the opportunity for the director of the Academy to be a major participant in the program. This will help in the general design development and trialing of the documentation and process that needs to be carried out as well as course presentation. The issue of language has been discussed. Simultaneous translation seems possible and is being explored. All tables, figures and content summaries will be translated in advance. This service can be provided through Mexico.

It is anticipated that Nehama Baum who is a member of 3 SIRG's of IASSID might also participate in this course. The possible dates of these workshops would be somewhere between October and January/February 2008.

Detailed costing has not yet taken place but proposed presenters will prepare material with the committee and present at no cost. Accommodation, meals and facilities will, we understand, be at no charge. The major cost will be travel as forecast in our first report to the IASSID Executive.

Recommendation

This is recommended for Executive's endorsement.

5. There has been discussion of the recognition that would be given to students who attend any Academy course. This is seen as critically important in developing countries as it gives organizations and students recognition and support. It is suggested the Academy should recommend a certificate of attendance to IASSID for each student completing the course. The name and place of the course, name of the student should be included on the certificate along with the date. It has also been suggested the certificate could also include an indication of who conducted the course (and their qualifications), the hours of study involved, list the key learning outcomes (competencies) and if the course included any form of examination of knowledge gained or test of competency attained as a consequence of involvement in the course. This may make the certificate rather long ,but an official transcript containing some of these details along with the certificate would probably be desirable. The signatures of the President of IASSID and the Director and Chair of the Academy should be appended.

If the Executive, IASSID agrees with such an approach we suggest the certificate should be drafted by the Council and forwarded to the executive of IASSID for their consideration along with a sample transcript.

Recommendation. Once a course is approved and completed an Iassid/Academy certificate should be given to each completing student.

Below is a proposed outline for procedures and content in relation to Academy course development.

Respectfully submitted

Roy I. Brown PhD

Director and Chair

International Academy on Education & Training in Intellectual

Disabilities (IASSID)

See Below for attachment.

Academy Council IASSID

Course Proposal Form

PART 1

Preliminary information

Name(s) and affiliation of proposer(s)

Organisation(s) likely to be involved

Site proposed for course

Address of primary correspondent

Postal

e-mail

Telephone

Fax

Type of course being proposed along with tentative title

The reasons for requesting a course of this nature

Types of participant to be involved. (by employment and level of qualification and experience)

Anticipated number of participants

Preliminary outline and brief proposal including main elements.

Names, addresses, qualifications and employment of at least 3 members in the host country who are recommended to the Academy Council as members of the organizing committee. Attach brief CV

Development of the sub-committee to the Academy council for the design and development of course once the outline has been generally approved. Such a committee should be made up of 2 or 3 members from the local community plus representation as

determined by the academic council. This will normally be at least one member of the academy council plus other relevant members of IASSID, frequently from a relevant SIRG.

Part 2

Role of the sub-committee

Curriculum content: 2 types of information to be provided

1) The curriculum to be covered, which should be done in dot point format with headings and sub-headings. The curriculum should include a clear statement of the learning outcomes (e.g., knowledge or competencies) to be achieved by participants as a consequence of their enrolment in the course. These could be either theoretical in nature or applied.

2) The method(s) of delivery should be described in terms of onsite, distance learning, theory or practicum content

3) Proposed date for the course

4) Number of Participants

Arrangements for the course.

These will include the extent to which the local community and organizers of the course can provide support so that the programmed can be run and administered at a cost effective level. The items to be addressed are as follows:

Lecture /workshop - space

Lecturing aids. These might include blackboard, whiteboard, note books

Power Point, overhead projector, CD player, video equipment.

General description of the space to be provided; whether small side rooms are available for group discussion

Location of the space

Whether visits to local centres and agencies are to be included; if so, provide details

The language in which the course is to be delivered

The availability of translation facilities

It is requested that these facilities are provided cost free to the academy as far as this is possible. Where it is not possible, a detailed presentation will be required to see to what extent outside funds may be required.

The above should include arrangements for the course lecturers and tutors. This will include:

1. How accommodation will be arranged and paid for,
2. The arrangements for meals and how they will be paid for,
3. The cost of transportation to the lecture site, both external such as airfares and local internal transportation within the country.

It is understood that the agency requesting the course may not be able to cover all these funds, in which case outside sources will need to be considered.

Teaching of the course and evaluation

Name of instructors proposed for the course. Once this is completed, the Academy will require relevant CV's and will seek the availability of the person to undertake the instruction. Where a developing country is concerned, the academy will try to arrange for cost-free instruction.

Evaluation of the Course

It is expected that all academy IASSID courses will be evaluated at the immediate conclusion of the course. This evaluation will include:

1. A questionnaire response from each participant, which will be mailed to the director of the academy,
2. Written commentary from the designers of the course and the participating agencies. Such evaluation will include the extent to which the course has met its aims,
3. The extent the facilitators and instructors presented material,
4. The value of the course to the services and agencies concerned, as well as to the participants.
5. Participant and lecturer satisfaction or otherwise with the local conditions and presentation facilities and travel arrangements
6. The cost effective nature of the course
7. Recommendations in all areas for improvement but underlining the highlights of the course which were most valuable.

Evaluation and commentary from the instructors will be also sought in terms of the arrangements that were made. This may be supplied by the instructor at the conclusion of the course in dot point format.

NOTE:

- 1. Specific aims of the course in relation to the population attending and the needs of services or agencies within the country concerned. These will be specific criteria against which course delivery will be evaluated*
- 2. Lecturers conducting courses on behalf of the IASSID Academy will be asked to provide a master copy of their instructional material to the Academy for the purposes of maintaining an accurate record of material presented. However, any intellectual property rights pertaining to the material will remain vested with the*