



International Association  
for the Scientific Study  
of Intellectual Disabilities

# Council Meeting

August 1 & 2, 2006

Maastricht

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**ATTENDANCE - August Council Meeting  
As of JULY 28, 2006**

<b>NAME</b>	<b>OFFICE</b>	<b>MEETING CONFIRMED</b>
Felce, David	President	YES
Murphy, Glynis	President-Elect	YES
Janicki, Matthew	Treasurer	YES
<b>Timmons, Vianne</b>	<b>Secretary</b>	<b>Regrets</b>
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	YES
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	YES
Heller, Tamar	Council	YES
Hollins, Sheila	Council	YES
Jacobson, Ulla	Council	
Kerr, Mike	Council	YES
Levy, Joel	Council	REGRETS
<b>Malbran, Maria</b>	<b>Council</b>	<b>REGRETS</b>
McVilly, Keith R.	Council	YES
Ouellette-Kuntz, Helene	Council	YES
Reinders, Hans	Council	
<b>Strutz, Frank</b>	<b>Council</b>	<b>REGRETS</b>
Suemitsu, Shigeru	Council	
Verdugo, Miguel	Council	YES
Vlaskamp, Carla	Council	YES
Wang, Lisa	Council	YES

**AGENDA**  
**IASSID COUNCIL MEETING**  
**MAASTRICHT**  
**Tuesday, 1 August, 2006 - 12.00-18.00**  
**Crowne Plaza Hotel**  
**Wednesday, 2 August, 2006 - 9:00 - 14:00**  
**RADAR**

1. Commencement and Roll Call
2. Previous Minutes and Matters Arising
3. President's Report
4. Treasurer's Report
  - Finance Committee Report
  - Membership Committee Report
  - Financial Arrangements with Blackwell
  - Travel Reimbursement Policy
5. Secretary's Report
6. Collaborations
  - WHO
  - Other Associations
7. SIRG & Affinity Group Reports & Financial Statements
8. Constitutional Affairs (S. Kealy)
9. Conference Reports and Updates
  - Asia-Pacific (L Wang)
  - Europe (H. Lantman de Valk)
  - Sud America (P. Walsh)
  - 2008 Congress & African Working Group (G. Murphy)
10. 2012 World Congress Venue
11. JPPID Editor's report
12. Website Report
13. Publications Committee
14. International Course
15. Marketing
16. Other Business

**IASSID Council Meeting  
June 11, 2005  
Howard International House  
Taipei, Taiwan**

***NOTE: The minutes provide a summary of the discussion and hopefully main points are covered.***

**Attendance:**

Phillip Davidson, Robert Davis, Ilana Duvdevany, David Felce, (Chair), Matt Janicki, Stephan Kealy, Mike Kerr, Henny Van Schrojenstein Lantman de Valk, Keith McVilly, Glynis Murphy, Patricia Noonan Walsh, Helene Ouellette-Kuntz, Trevor Parameter, Hans Rienders, Neil Ross, Shigeru Suemitsu, Vianne Timmons (Recorder), Lisa Wang

**Observers:** Jos Mulder, Lorraine Glidden

**Regrets:**

Anthony Holland, Giorgio Albertini, Monica Bjorkman, Jan Blacher, Fabrizio Fea, Richard Hastings, Ulla Jacobson, Joel Levy, Maria Malbran, Robert Scholack, Frank Strutz, Miguel Verdugo, Carla Vlaskamp

**Meeting Opened at 9:05 am**

**1. Introductions**

Council members introduced themselves. David Felce thanked Lisa Wang for organizing the conference and meeting. David Felce recorded the Council's sympathies for Sheila Holland who is experiencing a difficult time.

**2. President's Report**

The President referred to the President's Report that went out to Council members. One went out independently and one with the newsletter. David Felce asked for feedback from Council members.

Keith McVilly mentioned that he received the information and it was effective in keeping him informed and he felt he was aware on the activities of IASSID and that he was well prepared for this meeting.

David Felce took a minute and reviewed the content of his February letter.

Honorary Council members are to be placed on the listserv for Council. Stephen Kealy will send the list to Vianne Timmons to include in all correspondence.

For the South Africa Congress in 2008 Stephen Kealy recommended setting up an action plan to seek out sponsorships. Keith McVilly recommended that if we identify people in our respective countries we should look at a form letter from David Felce seeking sponsorship. Mike Kerr suggested that IASSID set up a process of identifying sponsorship selection so that we can inform potential sponsors. David Felce mentioned there was approximately 150 waived registrations at the France conference in 2004.

Bob Davis suggested that we look at sponsorship for regional conferences.

Stephen Kealy moved and Lisa Wang seconded the acceptance of the President's Report.

### 3. **Treasurer's Report**

#### Finance Committee Report

Matt Janicki passed around the finance report for January 1<sup>st</sup> – December 31 2004. The balance is plus \$15, 566.76. He then reviewed the Pass Throughs Funds, primarily the money transferred to SIRGs. He presented a summary of the Statement of Reserves.

The 2005 budget was presented. Phillip Davidson asked that the term Landing Funds be changed to Development Funds.

The 2005 Income and Expense Statement was reviewed. Mike Kerr asked why the SIRGs have to ask for their funds. Matt Janicki stated that some SIRGs do not have bank accounts that are active. Matt Janicki mentioned that he does send a note to the SIRGs letting them know how much each SIRG has in reserve. Trevor Parameter asked if the SIRGs were submitting financial reports. Matt Janicki said that he did not receive them. By-law 5.2 states that the SIRGs **must** provide the Treasurer with an annual financial statement. Phillip Davidson stressed that it was important for the financial statements be placed with the Treasurer for accountability purposes.

Bob Davis stated that Henny Van Schrojenstein Lantman de Valk developed a document that stated that IASSID was not responsible for debts incurred by SIRGs.

Philip Davidson suggested that the SIRGs should have their yearly budgets vetted by the Treasurer of IASSID. **Matt Janicki asked that Henny Van Schrojenstein Lantman de Valk, as Vice President responsible for SIRGs, look into this issue (SIRGs posting budgets and financial statements of SIRGs with the Treasurer of IASSID) and legal liabilities.** Keith McVilly supports central reporting and accountability. Matt Janicki mentioned that his financial report only reflects money collected centrally, not money collected by

SIRGs. He affirmed the need for SIRGs reporting their budgets to IASSID Treasurer.

This document is to be treated as a confidential document.

#### Agreement with Blackwell

Matt Janicki passed around the agreement with Blackwell Publisher. IASSID does not own JIDR. We do not get revenues from the journal but we get the benefit of distributing it to our members. In September 2004 we met with a representative from Blackwell to see if there was a better financial arrangement. The conclusion was the current arrangement is beneficial to IASSID members.

#### Travel Reimbursement Policy

Matt Janicki distributed a travel and expense reimbursements policy. David Felce indicated that there is an intent to try to fully support the costs of running this organization and the \$500 travel stipend for Council members is a move in that direction. Mike Kerr asked for consideration of pooling the \$500. to fully support individuals who do not have support to attend Council meetings. Keith McVilly asked about the relationship with national organizations such as ASSID. **Matt Janicki asked Keith McVilly to put on paper a framework for cooperation of national organizations with IASSID. David Felce stated that Executive will review this at its next meeting.**

David Felce thanked Matt Janicki for the report and all his hard work as Treasurer.

Patricia Noonan Walsh moved and Lisa Wang seconded acceptance of the Treasurer's Report.

Neil Ross distributed the IASSID Congress 2000 and IASSID 2004 statements. The registration fee in 2000 was \$400 (US) and \$520 (EUROS) in 2004.

#### Membership Report

Matt Janicki distributed the membership update and reviewed the document. There are 517 members. In 2004, there was 763 members; the increase is due to the Congress. 2003 is a more accurate comparison and we are up in membership numbers from 2003. David Felce stated that as we get more organized, and organize regional meetings; people will find it advantageous to join.

There was a discussion of the national association membership, 20 paid up and 14 non paid. If a national association has not paid in the last few years they are dropped. Lisa Wang spoke about the challenges with her national association. Matt Janicki stated that all Lisa Wang needs to do is check with her Association

to see if they want to remain a member. If they do not, she can approach another organization.

Keith McVilly asked if the national organizations have a seat on Council. Stephen Kealy indicated that every organization is asked for a nomination for Council before Congress. The election committee prepares a slate of nominations for Council. The representation of individual members has been increased to one for every hundred members. Once appointed to Council you represent yourself not the organization that nominated you. The Council needs to ensure a wide geographical representation. Lorraine Glidden asked if there would be a report back to national organizations regarding the status of the nominations. Stephen Kealy indicated that we may have been remiss in reporting back regarding the outcome of the elections and also the process to the organizations. Lorraine Glidden mentioned that we may want to revisit at the process.

Glynis Murphy indicated that we should have Frequently Asked Questions on the website. Bob Davis stated there may need to be a separate means of communication with the Associations. Keith McVilly indicated that information on IASSID is not widely understood at the national organizations. Trevor Parameter supported Keith McVilly and felt that we have to carefully handle the relationships.

Matt Janicki stated that we have 36 research centers paid up and 20 non renewed. Matt Janicki expressed concern about the non renewals. Patricia Noonan Walsh suggested informal contact may increase renewals. Bob Davis suggested that we include a link to research centre websites as an incentive.

Henny Van Schrojenstein Lantman de Valk recommended family and partner membership as a possibility.

Helene Ouellette-Kuntz moved and Keith McVilly acceptance on the membership report.

Phillip Davidson asked if policies passed should be posted. Stephen Kealy suggested that policies are attached to the by-laws. David Felce referred this item to later on the agenda.

#### **4. Secretary's Report**

##### Logo

Keith McVilly asked what the meaning of the original logo was. The majority of Council members (11 members) indicated that they supported the logo change. There was significant discussion around the logo.

The second point is whether we go with the logo suggested #1 in the newsletter. Lorraine Glidden suggested that we use the rays from the original logo with iassid

in the centre. Council asked for a show for support for logo 1 (6), 6 against. David Felce will secure more design work. Mike Kerr asked that the next vote should be final in identifying a logo. Stephen Kealy asked about using the logo used in France at the Congress.

Helene Ouellette-Kuntz suggested that we identify what we want the logo to represent before we go to a graphics creation. Bob Davis suggested that we also distribute the letterhead with the logo. Hans Rienders indicated that we need to ensure that we should identify the purpose of the logo. Matt Janicki stressed that we need to move the logo forward. Mike Kerr suggested any ideas to David Felce by the 1<sup>st</sup> of July. **Trevor Parameter agrees to develop a logo and have it to David in the next two weeks. Glynis Murphy will have a selection to David Felce in two weeks.** Trevor Parameter is asking that the three original logos distributed at Council stay in the mix. **Stephen Kealy asked that David Felce write to the graphics department at UPEI and thank them.**

#### Web CT

Keith McVilly suggested that Web CT is a great teaching tool. Keith McVilly suggested there be a link on the main website. Neil Ross indicated there is a calendar on the IASSID website. Neil Ross indicated that most of the information is on the IASSID website. He suggested that we try Web CT for a year and see if it gets used more than the website.

## 5. Collaborations

#### WHO

Patricia Noonan Walsh discussed the background of IASSID's relationship with WHO. The Executive in March agreed that IASSID continue the relationship with WHO. In April, Dr. Saxena wrote Patricia Noonan Walsh and asked for a workplan for the next three years. Patricia Noonan Walsh distributed the letter that she sent regarding the proposed workplan. Dr. Saxena wrote back and indicated that he was available for consultation. Trevor Parameter provided some history of the relationship. David Felce stressed that we apply ourselves to work we are able to undertake.

Bob Davis indicated that people with ID have third world health outcomes. The SIRGs, in particular the Health SIRG, is very interested in working with WHO. Bob Davis asked about the Association's expertise in developing world health issues. David Felce indicated that this will be reflected in the workplan. Patricia Noonan Walsh stated that we may want to develop a symposium, looking at developing country health issues, in Capetown with WHO representation.

Lisa Wang suggested we look at the attendees for the Taipei conference who may have expertise with health in developing countries. Mike Kerr thanked Patricia Noonan Walsh for promoting the relationship. Mike Kerr supported the wording of Patricia Noonan Walsh's letter. He also supported Bob Davis connecting with

the SIRGs. Bob Davis mentioned the UN convention around the rights for people with disabilities. Patricia Noonan Walsh is aware of the convention. Patricia Noonan Walsh wants to ensure that IASSID is not just a name on the NGO list of WHO. She wants to ensure IASSID has a role. Phillip Davidson indicated that the biggest payoff for this organization is bringing the voice of people with disabilities to the WHO health discussions. A number of the SIRGs have identified the same issues as WHO. Phillip Davidson asserted the need for modest workplan and suggested that Patricia Noonan Walsh write the SIRG leadership and ask for their interest in working with WHO. Phillip Davidson suggested that advocating for research in Africa in healthy outcomes should be broadened to the African region.

**Council voted to endorse preparation of the workplan with WHO by Patricia Noonan Walsh.**

#### Other Associations

IASSID signed an agreement with International Society for Augmentative and Alternative Communication Association (ISAAC). There is discussion with Down Syndrome International. David Felce will follow up with Alzheimer's International. European Association of Service Providers also approached IASSID for an agreement.

The Academy of Mental Retardation is discussing its future. David Felce suggested that the Academy may wish to look at the agreement with ISAAC.

## **6. SIRG Reports**

Henny Van Schrojenstein Lantman de Valk presented on the meeting of the SIRGs held on June 10<sup>th</sup>. She brought up two issues:

The fee structure: Can the fees be reorganized to have one fee to join all SIRGs and therefore provide incentives? David Felce indicated that the wording is permissive; you don't have to have a fee. Bob Davis brought up the point that IASSID should encourage membership in SIRGs. There are members that have areas of interest that cut across a number of SIRGs. Do we need to rethink how we charge for multiple memberships? You end up charging your most active members and it serves as a disincentive for people to join multiple SIRGs. Mike Kerr spoke out in support of Bob Davis. Mike Kerr feels there should be no charge for SIRGs. They should raise their own funds for activities.

Glynis Murphy asked what proportion members of IASSID are members of SIRGs. Matt Janicki thought there is approximately a third. Phillip Davidson indicated that this is a complicated matter, he does not agree with Mike Kerr's proposal. The aging SIRG supports the \$20.00 fee. The money is used to support

the roundtable on aging that has been held for the last 14 years. SIRG gets the service of the Treasurer of IASSID in collecting the fees. IASSID depends on the SIRGs and therefore this requires further discussion. Matt Janicki indicated that there is no requirement to collect fees from SIRG members.

David Felce mentioned that there should be a plan for SIRGs as an organization. David Felce highlighted that we don't have a formal policy on approval of new SIRGs. Is there a limit on new SIRGs? Do we need a policy on ending SIRGs? **David Felce proposes that the current leadership of the SIRGs come to an agreement with Henny Van Schrojenstein Lantman de Valk's facilitation.**

Bob Davis brought up the issue of legal liability. **Matt Janicki will explore whether the current insurance will cover SIRGs.**

A number of SIRG reports have been tabled. The Parenting SIRG asked for space at IASSID 2006 in Europe to have a keynote on parenting. Henny Van Schrojenstein Lantman de Valk referred this to the program committee of Europe 2006. Glynis Murphy indicated she will be writing the SIRGs regarding the program in Capetown. **SIRG reports will be posted on Web CT.**

SIRG reports not yet tabled: Families, Forensics, Quality of Life, Aging

Phillip Davidson noted that the 15<sup>th</sup> roundtable on aging will be in June 2006 in Toronto.

## **7. Conference Reports and Updates**

### *IASSID Asian-Pacific (Lisa Wang)*

The program book was distributed to Council. It is printed in English and Mandarin. There are 400 registrations. The VIP is the Deputy Prime Minister. The Minister of Interior in charge of Social Welfare will also be attending. Lisa Wang gave out 21 travel awards to participants which came to over \$11 000 US (list distributed). She recommends travel grants for any additional regional conferences.

David Felce asked Lisa Wang to provide a statement of income and expenditures. This would help with future conference planning.

Bob Davis congratulated Lisa Wang on her excellent organization and suggested that there may need to be a system of mentoring from one conference organizing group to another.

*IASSID Europe (Henny Van Schrojenstein Lantman de Valk)*

Sponsorship is being worked on. Sponsorship is being sought to support participants from Eastern Europe. The call for proposals will be on the website by July.

Hans Rienders asked about the policy of participation of people with intellectual disabilities. Henny Van Schrojenstein Lantman de Valk indicated that there was no policy developed yet. Hans Rienders recommends explicit policy on how people with intellectual disabilities can be included. Trevor Parameter recommended that the self advocacy groups need to take this initiative. This conference is about research and we need to educate the self advocacy groups. Hans Rienders reiterated that IASSID Europe 2006 needs an active policy to ensure education of the self advocacy groups. The policy needs to be intentional, encouraging people who are involved in research telling their stories. Keith McVilly recommended space in the program on advocacy research. Henny Van Schrojenstein Lantman de Valk will follow up on these suggestions. David Felce indicated that people with disabilities in France were frustrated when their sessions were completed. Glynis Murphy reminded Council that there was a call for accessible abstracts in France. Helene Ouellette-Kuntz suggested a specific day which people with disabilities are invited and a special program be developed. Bob Davis described a conference where presenters were asked to do a presentation and then a plain language presentation. It was very successful. David Felce has been encouraging the Citizenship and Empowerment group to develop their own program within the conference. Maybe as scientists that are interested in being inclusive we should organize specific sessions that run through the program which are inclusive and of interest to people with intellectual disabilities. The same issue is relevant to service providers. Lisa Wang deliberately planned specific sessions for parents, service providers, self advocates with translation in IASSID Asian-Pacific.

*IASSID South America (David Felce)*

Miguel Verdugo is looking at Santiago for 2007. Maria Malbran is looking at southern Brazil.

*IASSID/AAMR North American (Matt Janicki)*

There is a large meeting being organized for May3-5<sup>th</sup> in Montreal in 2006. There are a number of symposiums being organized by IASSID for this conference. Matt Janicki is encouraging any additional symposiums to be organized by IASSID members. The conference theme is Inclusion.

David Felce suggested that IASSID needs to establish a procedure for regional conferences connected with IASSID. He suggested that there should be a sub-committee from Council set up to work with the regional organizers. Glynis Murphy is concerned about the work load and suggests that the Council recommend a lead mentor from Council be identified to work with regional

planning committees. **This will be discussed at the Executive meeting in November.**

## **8. Procedure for Selecting World Congress Venue**

Neil Ross is responding to a request from David Felce to set up the procedure to select World Congress Venue. He distributed a one pager of a proposed procedure and presented an overview.

David Felce feels strongly that mentoring is required and therefore the Committee is made up of the President and Past President because they participated in organizing Congresses. Glynis Murphy supports the proposal and suggested adding Eastern Europe. Trevor Parameter spoke in support of the proposal. Phillip Davidson asked how the sites were selected previously. Neil Ross indicated that IASSID was approached by the conference sites. Matt Janicki suggested that fiscal implications be added to the procedure along with the potential for fund raising. Helene Ouellette-Kuntz asked how important the local organizing committee is? David Felce replied that the local organizing committee was important in relation to specific issues such as organizing study tours, volunteers etc.. Bob Davis suggested that the previous site selection should inform the future selection.

Stephen Kealy moved and Henny Van Schrojenstein Lantman de Valk seconded acceptance of the policy.

David Felce asked Council members for their opinion on the 2012 conference. South America 6 votes, Eastern Europe 5, Canada 3, and one for Stockholm, Australia and Mexico.

## **9. International Course**

Matt Janicki provided a history of the proposal for an international course on intellectual disabilities. Giorgio Albertini brought this proposal to the Executive. Matt Janicki was assigned coordination on behalf of the Executive. Tosinvest and IASSID would develop a four year time frame for this project with a review in 2008. Matt Janicki mentioned the option of setting up an Academy that vets proposals for training programs under the IASSID name.

Glynis Murphy indicated that crediting courses may be a challenge at some institutions. Hans Rienders asked why we would take this on? Matt Janicki indicated that the initial proposal was to provide training for people in areas where they do not have ready access. Phillip Davidson stated that the idea is morphing, complex. Phillip Davidson felt that there was a risk in taking on delivering courses but the Academy idea seems more manageable. This requires more planning. Bob Davis asked about a market for this? Ilana Duvdevany

wondered who would take these courses. Helene Ouellette-Kuntz suggested that IASSID take a role in facilitating credit transfer. Mike Kerr asked how IASSID will credit courses? David Felce recommended SIRG involvement in this initiative. We want to disseminate knowledge as a scientific organization and running courses does facilitate knowledge impact. David Felce suggested that we may wish to set out the curriculum and put a call out for interest. Stephen Kealy suggested that effort should be put on the structure of IASSID before we add another layer. Bob Davis suggested rather than a course could SIRG have a working roaming seminar group. Keith McVilly feels this is an important area to pursue, he suggested tapping into e-learning.

## 10. JPPID

### Editor's Report

Matt Janicki distributed the Editor's Report and a flyer with a call for papers. Matt Janicki reviewed the content of the Editor's Report. Matt Janicki recommended an additional \$2000. for editorial expenses. Bob Davis asked about the potential to generate monies from the journal. Matt Janicki indicated that revenues should be seen in 7 or 8 years. Stephen Kealy moved and Henny Van Schroyen Lantman de Valk seconded \$2000 to be allotted to JPPID for editorial support.

## 11. Marketing

Matt Janicki is asking Council for ideas in generating interest in membership and journals. Lorraine Glidden recommended electronic bundling. Blackwell does do this bundling.

Keith McVilly recommends partnering with national organizations. Many have journals that we could set up reciprocal arrangements. **This will be placed on the Executive agenda.** David Felce pointed out an inconsistency with the ISAAC agreement and the National Associations relationship. Keith McVilly recommended a memo be prepared that presents potential agreement with the Associations. Matt Janicki will check with Blackwell and whatever is developed would be placed it on the web site. Mike Kerr stated that IASSID is a complex organization and with new energy we should look at new partnerships. **Keith McVilly recommended the membership committee look at interaction with national associations. Keith McVilly will take the lead on this.** Bob Davis recommended a formal induction for new members.

## 12. 2008 Congress Program Committee Report

Glynis Murphy provided an overview of the plans for the 2008 Congress. In the Capetown venue there is not enough room to run 20 parallel sessions. This will

be revised to 16 parallel sessions and increased poster presentations. The format will be similar to France's Congress. There will be papers from African delegates all the way though and the last day will focus on Africa. Glynis Murphy has a proposed draft budget with the total cost 498, 178 Euros. The revenue 589,000 Euros. The registration fee is 500 Euros and a reduced registration for 300 delegates. There was a suggestion that we should have a set registration with bursaries rather than a reduced registration fee.

### African Working Group

IASSID will put in 30 000 Euros for a research fund. On the registration form there is a request for a donation for research funds of 35 Euros. The African working group highlighted the challenge of attracting delegates, sponsorships and research funds. Over the next few months the working group is asking for any contacts that Council members have. **Glynis Murphy will send out a form to be filled in by Council members.** Glynis Murphy is asking Council members to think about potential researcher funders. **Glynis Murphy will have a sponsorship information sheet prepared and it will be placed on the web site.** Matt Janicki wondered if Patricia Noonan Walsh could make contact with WHO for sponsorship. Matt Janicki is recommending that IASSID contact universities and research centres country by country so that they feel that they are part of the process. Glynis Murphy indicated that she will need some secretarial support. Patricia Noonan Walsh suggested that international offices in the universities in the African region be approached. Patricia Noonan Walsh also suggested approaching African graduates from our universities. Phillip Davidson stated that the term Africa refers to the continent. He suggested the use of the term African Region which encompasses islands and other areas. The Fogerty Centre funds international research around the world and make funds available to institutions that partner with institutions in developing countries. There are Fogerty Centres in Africa. This may be a special outreach that IASSID may wish to undertake. Phillip Davidson encouraged IASSID to approach Fogerty Centres and seek a relationship with them. Phillip Davidson volunteered to approach the Fogerty Centre.

Hans Rienders expressed a concern that attendees would not stay until the last day. Hans Rienders is recommending that there would be a program throughout the congress rather than a focus on the last day. Glynis Murphy indicated that the local organizing committee recommended the last day (Saturday) focus on South Africa to facilitate local involvement.

Stephen Kealy mentioned that we need to be approaching our own countries about sponsorship. There needs to be a booklet put together with people targeted to do specific action. Stephen Kealy indicated that 3 years comes along quickly.

Mike Kerr suggested approaching International Health Disparity event which will be scheduled later this year. The organizing of this event is just emerging. Matt Janicki asked if IASSID could be a partner in this event.

Trevor Parameter indicated that the two greatest challenges with people with intellectual disabilities will be IV/Aids and poverty. Patricia Noonan Walsh will keep this in mind when approaching WHO. Mike Kerr recommended approaching the World Bank for support.

Glynis Murphy recommended a program committee meeting at 11:30 am June 12<sup>th</sup>.

### **13. Website Report**

Neil Ross distributed the statistics on the web sites hits. The daily visits are 244. Neil Ross recommend that if Council wants the website redesigned it should happen quickly. If Council has any suggestions for the website please be specific and provide details to Neil Ross. If there are mistakes please copy the text into a word document and correct it. Keeping the website accurate is a collective effort. Neil Ross has been working on raising a sponsorship for the website. He has received a donation of 400 Euros. Mike Kerr commended Neil Ross on the website. Phillip Davidson complemented Neil Ross on his personal responsiveness to Council member's input.

### **14. Report from the Publication Committee**

Tony Holland distributed a report to Council members.

### **15. Future Research Plans and the Goal to Develop a SIRG in Sports Research.**

Jos Mulder thanked the Council for allowing International Association for Sport for People with Intellectual Disabilities (INAS-FID) to speak to Council. INAS-FID was established in 1986 in order to give a platform for people with intellectual disabilities to compete under international rules. There is 87 national members who are part of INAS-FID. INAS-FID has been negotiating with the International Para-Olympic Committee (IPC) for membership criteria. INAS-FID is looking at research on the link between intellectual disability and sport. Trevor Parameter is seeking Affinity membership for Intellectual Disability and Sport Performance. There is a questionnaire developed for coaches to assess the relationship between intellectual disabilities and sport performance. There needs to be more research in sports performance and intellectual disability not only in the context of the Para-Olympics but in all sports performance including special Olympics. Trevor Parameter is also supporting the nomination of experts to sit on eligibility committees. Participants require a psychological assessment to determine that they have intellectual disabilities. There is a challenge in getting the psychological assessments.

A proposal will be coming forward seeking membership as an Affinity Group or a SIRG. Bob Davis indicated there is overlap with the health SIRG. Trevor Parameter agreed there is overlap. Patricia Noonan Walsh supports this approach as there are significant research funds available in Ireland in sports performance. Mike Kerr invited this group to join the Health SIRG if there is a challenge getting numbers for a SIRG application. In INAS-FID the interest is on performance at the elite level. Trevor Parameter will discuss this with the Health SIRG. Jos Mulder will work with Trevor Parameter at the procedures around establishing an Affinity Group or SIRG.

Keith McVilly suggested an article for the next newsletter. Trevor Parameter wrote the national associations. Trevor Parameter will send Neil Ross something for the website. There are around 50 nations that participate in sport. Jos Mulder asked if a list of IASSID national organizations could be made available. David Felce agreed to distribute information to our national organizations rather than making the list available. David Felce suggested that there could be an insert placed in the journals seeking interest.

Glynis Murphy wondered if sports psychology departments have been approached. She also suggested going through the national psychological associations.

Hans Rienders suggested that IASSID indicated that this discussion fits into the broader policy development around the formation of SIRGs. Henny Van Schroyen Lantman de Valk will look at this.

## **16. Other Business**

Keith McVilly indicated that AASID now has a 7 year meeting schedule. If there is any interest in holding a meeting in Australia please contact AASID. The invitation is extended out to the SIRGs also.

### Awards

Stephen Kealy distributed information around criticism around award selection. Stephen recommended a more structured approach to the award selection. He recommended using regional meetings to honor younger researchers. **Stephen Kealy will bring a proposal to the November Executive meeting.**

## **Meeting Adjourned**



## International Association for the Scientific Study of Intellectual Disabilities

### President's Report to Council 2006

August, Maastricht

Reviewing the highlights of the year is as usual very heartening:

1. First and foremost, Lisa Wang organised and staged an excellent Inaugural Congress of IASSID-Asia Pacific in June, 2005. There was a strong scientific programme from the region, the venue and hospitality arrangements were of the highest quality and all aspects of presentation were utterly professional. The Congress was completely successful in its aim to bring together researchers from the region and provide a forum for exchange of their work. The congress abstracts are being published in the *Journal of Policy and Practice in Intellectual Disabilities*.
2. Henny Lantman, Marian Maaskant and Wil Buntinx have equally well organised the Second IASSID-Europe Conference, which we look forward to over the next few days. About 430 papers will be presented by 340 presenters. Registration has been strong and it looks like we will be at maximum capacity again. The conference abstracts are published in the *Journal of Applied Research in Intellectual Disabilities*.
3. SIRG meetings are an established part of the annual calendar too. The Aging SIRG met in Dortmund last year and in Toronto this April. The Physical and Mental Health SIRGs held their second joint meeting in Melbourne last September. The Profound and Multiple Disabilities SIRG met in Bruges in October. The Quality of Life SIRG also met in Canada earlier this year, and the Employment Affinity group organised a Roundtable in April in St Petersburg.
4. The Quality of Life SIRG sponsored a special issue of the *Journal of Intellectual Disability Research* (2005, **49**, 695-811), following the example two years ago of the Family SIRG and their double issue on family research (2003, **47**, 215-399). A number of the plenary addresses from the World Congress in Montpellier were published in the *Journal of Applied Research in Intellectual Disabilities* (2005, **18**, 279-344).
5. We have agreed a new logo. This logo may be used for all IASSID meetings (e.g., regional and SIRG conferences). Please check with the Executive whether it is appropriate to use the logo for other purposes (e.g., meetings involving IASSID through participation of its officers or the officers of SIRGs).

6. We signed a new agreement of co-operation with the *International Society for Alternative and Augmentative Communication* and we have made a similar agreement of co-operation with *Down Syndrome International*.
7. The finances of the Association are still in a good state. It was important that the Asia-Pacific Conference broke even. IASSID provided a grant to support scholarships, but otherwise Lisa Wang produced a cost neutral budget. Our thanks go to Lisa for her tremendous local fund raising effort which underpinned this.
8. Clearly, as the number of IASSID events increases and we advance our truly worldwide identity, then the demand from countries in Eastern Europe, Asia, Africa and South America for support to attend our meetings will increase. Any suggestion from Council Members or SIRGs on how to broaden the base of our attempts to gain sponsorship for delegates from developing countries to attend our meetings would be greatly appreciated.
9. We will have our second planning meeting in Cape Town for the 2008 World Congress in August. We are still keen to use the Congress in Cape Town as a means to promote our field throughout Africa. The Africa research fund is being launched.
10. As I reported last year, a procedure is now in place for IASSID to assess proposals for publications which will carry IASSID endorsement. Any suggestions for publications which IASSID may wish to commission would be appreciated.
11. Our agreement with the WHO has been renewed. IASSID will support the WHO's development of an international atlas on intellectual disabilities where it can. Tangentially related to this, Eric Emerson is leading an editorial team to produce a special issue of the *Journal of Policy & Practice in Intellectual Disabilities* on "Intellectual Disability Policy and Practice in Low and Middle Income Countries".
12. We had a constructive meeting in Montréal in May to further plans to hold a meeting in Chile next year in collaboration with the Pan America Health Organization. A human rights lawyer in Santiago, Soledad Cisternas Reyes, has agreed to be a local organiser. Miguel-Angel Verdugo is playing a key role for IASSID alongside Patricia Walsh and Matt Janicki.
13. IASSID was well represented as co-sponsor of the International Summit for the Alliance on Social Inclusion in Montréal in May, with members organizing symposia and presenting papers. The meeting was a great success.
14. Keith McVilly, Trevor Parmenter and Matt Janicki are making advance arrangements with colleagues in Singapore for the Second Conference of IASSID-Asia Pacific.

My sincere thanks go to everyone who has contributed to IASSID's activities in 2005/6.

David Felce  
President

## Meeting of IASSID Council

Maastricht, the Netherlands - 3 August 2006

### Report to Council

#### Background

WHO has agreed formally to continue its relationship with IASSID. IASSID organizes a world congress every four years (Montpellier 2004, Capetown 2008); European region conferences (Dublin 2002, Maastricht 2006); and a regional conference in Southeast Asia (Taipei 2005, Singapore 2009). Building on a preliminary event in Buenos Aires (July 2003), IASSID now wishes to develop its presence in South America and welcomes active collaboration with the Pan American Health Organization (PAHO) to test the feasibility of a regional conference in South America in 2007.

#### Activity 2006

On 15 March, Matt Janicki and I met three PAHO officials at their headquarters in Washington DC: -

Jose Luis Di Fabio, Area Manager, Technology and Health Services Delivery  
Javier Vasquez, Human Rights Specialist, Area of Technology and Health  
Services –Legal Affairs  
Enrique Vega Garcia, Regional Advisor on Aging and Health

They were very positive about active collaboration between PAHO and IASSID, notably in raising awareness and understanding of the needs of people with intellectual disabilities in the South American region.

It was agreed that we share interest in, first, *human rights* among people with intellectual disabilities. It was noted that in many countries, people with intellectual disabilities are deprived of liberty and civic participation through permanent guardianship laws, and are often incarcerated in large psychiatric institutions. Sterilization is a further threat. A second domain is how best to promote healthy lives and *healthy aging* among people with intellectual disabilities. In each of these complex areas, it seems that IASSID might offer expertise and share knowledge with those charged with making policy on behalf of people with intellectual disabilities throughout countries in the region.

#### Proposed conference

A conference organized by IASSID and PAHO in Santiago, Chile in early September 2007 was discussed: -

- (a) The timing is suitable for PAHO in advancing recommendations through its structures of governance and internal timetable;

- (b) September is springtime, and the start of the academic year;
- (c) Chile is now reforming its guardianship laws;
- (d) There is a new President in Chile and a climate of change;

At PAHO's suggestion, we made contact with Soledad Cisternas Reyes, a human rights lawyer who has been involved in advancing the UN Convention. Soledad obliged us by traveling to Montréal to attend the Summit on Social Inclusion from 2-5 May 2006. The Executive of IASSID met with her there to discuss initial plans for an event in Santiago in September 2007. A target audience of about 250 persons was agreed. These talks were especially fruitful thanks to the translation support that Miguel-Angel Verdugo provided.

### **Current plans**

IASSID will team up with colleagues on Santiago, Chile, to hold an IASSID-Sud America conference in Santiago after mid-September 2007.

A survey of many colleagues has yielded a list of about 30 individuals throughout South America who have become very interested in participating in this meeting.

Thematically, as recommended by PAHO, we plan to focus on human rights and disability, but the meeting will be designed to highlight service models and governmental policies toward disability.

Plans are proceeding to develop ministerial support within Chile and to involve a range of voluntary and charitable organizations involved with human services and social welfare. PAHO has agreed to be involved, and Patricia is working to connect with local PAHO officials in Santiago.

MJ is willing to represent IASSID at a September 2006 meeting at PAHO if this is appropriate and we shall both be meeting with our Chilean colleagues in January 2007 to discuss the logistics and program planning for the September conference.

---

**Patricia Noonan Walsh**

Vice-President on International Organizational Affairs



# International Association for the Scientific Study of Intellectual Disabilities

Treasurer  
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## Report on Membership - 2006

### 1. Individual Memberships

As of the end of July 2006, there are 455 paid or otherwise recognized active individual members in good standing with IASSID – a decrease of 63 members from 2005. 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

The statistics for individual members are shown below.

*Applications for membership can be made via the internet at [www.iassid.org](http://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.*

#### 2001-2006 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 have 455 members	(63 loss of members)

#### 2003-2006 Member Category Stats<sup>1,2</sup>

2003	FU - 383	AS - 34	SJ - 17	AM - 9	
2004	FU - 481	AS <sup>3</sup> - 26	SJ - 25	AM - 13	
2005	FU1 - 154	AS <sup>3</sup> - 3	SJ - 9	AM - 10	
	FU2 - 275				
2006	FU1 - 95		SJ - 3	AM - 11	PO - 5
	FU2 - 285				
2003	FN - 70	PJ - 1	PN - 3	RC - 14	
2004	FN - 145	PJ - 7	PN - 3	RC - 21	
2005	FN - 9	PJ - 7	PN - 8	RC - 22	ST - 19
2006	FN <sup>4</sup>	PJ - 4	PN - 6	RC - 32	ST - 11

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

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

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

<sup>4</sup>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
<b>2006</b>	390 - 88.0%	49 - 11.1%	1 - <1%	3 - <1%
<b>2005</b>	438 - 88.7%	50 - 10.1%	0	6 - 1.2%
<b>2004</b>	658 - 93.2%	45 - 6.4%	0	3 - 0.4%
<b>2003</b>	389 - 84.7%	69 - 14.8%	1 - <1%	1 - <1%
<b>2002</b>	248 - 67.9%	116 - 31.7%	1 - <1%	0

EFT = Electronic Funds Transfer

## Timing of Membership Payments for 2004, 2005, and 2006

	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
<b>2006</b>	11.5%	13.4%	24.7%	20.1%	14.9%	7.2%	4.8%	2.2%	1.2%
<b>2005</b>	0.04%	17.2%	28.8%	19.2%	14.4%	8.5%	7.4%	2.0%	2.0%
<b>2004</b>	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.

☞ 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

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email or whose email addresses have proved faulty.

### **Payment Forward**

7 are paid to end of 2007

### **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 have paid for the JIDR for 2006

### **JPPID Subscribers**

478 had JPPID included in their membership fee for 2005  
443 had JPPID included in their membership fee for 2006

616 were given gratis subscriptions for 2004<sup>6</sup>  
7 had paid for JPPID for 2004

## **2. Association Memberships**

Currently, we have **17** national associations as paid-up members and **16** which have 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 16 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 2006, we have **49** paid-up Research Centers, and **12** which have not renewed. In 2005 we had **36** paid-up Research Centers and **20** which did not renew. Of the 2005 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. To date, we have had only one Research Center formally disengage from IASSID and that was due to its research program folding.

The list of current, paid Research Centers can be found on the IASSID website and on Appendix B.

*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 1 August 2006*



## **Appendix A Paid-up Affiliative National Organizations of IASSID**

American Association on Mental Retardation  
Asociacion Espanola para el Estudio Cientifico del Retraso Mental  
Association of University Centers on Disabilities  
Australasian Society for the Study of Intellectual Disability (ASSID)  
BILD - British Institute of Learning Disabilities  
Deutsche Interdisziplinäre Gesellschaft zur Förderung der Forschung für Menschen mit geistiger Behinderung e.V.  
Down Syndrome Association (Singapore)  
Finnish Association on Mental Retardation  
G. Allen Roeher Institute  
Japanese Association for Study of Developmental Disabilities  
MAMH - Medical Aspects of Mental Handicap  
National Federation of Voluntary Bodies  
Polish Association for Persons with Mental Handicap  
Psychopedicka Spolecnost  
Royal College of Psychiatrists  
South African Association for the Scientific Study of Mental Handicap  
Svenska Lakarforeningen for Omsorgs - och Handikappmedicin

## **Appendix B Paid-up Staff-Based Research Centers and Organizations**

Academic Department of Psychiatry of Disability  
Akademia Pedagogiki Specjalnej im. Marii Grzegorzewskiej  
Australian Family & Disability Studies Research Collaboration  
Beach Center on Disability  
CEMEDIPP  
Center for Disability and Human Development  
Centre for Disability Studies  
Centre on Intellectual Disabilities  
Centre for Developmental Disabilities Studies  
Centre for Research on Families and Relationships  
Centre de réadaptation Lisette-Dupras  
Centre for Developmental Disability Health Victoria  
Department of Social Welfare

Department of Psychiatry  
Developmental Disabilities Research & Education Group  
Division of Disability Studies  
Down Syndrome Educational Trust  
Down Syndrome Research Foundation  
Foundation for People with Learning Disabilities  
Governor Kremers Centrum  
Institute of Special Education & Rehabilitation  
Institute of Applied Human Services  
Institute on Community Integration  
Institute for Health Research  
Laboratoire de Recherche Interdepartementale en Deficiences Intellectuelles  
LUCAS - K.U. Leuven  
Matheny Institute for Research in Developmental Disabilities  
Neurodevelopmental Psychiatry Services  
Nippon Care-Fit Service Association  
Norah Fry Research Centre  
Research Department COPE Foundation  
San Raffaele Pisana Clinic  
Schiefelbusch Institute for Life Span Studies  
School of Medicine, Health Policy & Practice  
Services de Réadaptation L'Intégrale  
Special Education Department  
Stewarts Hospital Research Centre  
Stímulo Centro de Estimulación y Desarrollo Neurocognitivo A.C.  
Strong Center on Developmental Disabilities  
Tizard Centre  
Toby & Henry Battle Developmental Centre  
Uliazpi Fundazioa  
Unit for Development in Intellectual Disabilities  
VAV - Norwegian Centre for Dementia Research  
Victoria Dual Disability Service  
Waisman Center  
Welsh Centre for Learning Disabilities  
White Top Research Unit  
Young Adult Institute, Inc.

## **Report to Council - August 2006**

### **Ad Hoc Study Group on Establishing an International Training Academy**

#### ***Subject:***

Proposal to Establish an International Academy on Education and Training in Intellectual Disabilities

#### ***Summary:***

Council asked for an evaluation of the prospect of IASSID establishing a global training and education component designed to aid workers and countries in conducting research and in better understanding intellectual disabilities and empirically based practices for providing services. A working group was convened and input was drawn from many sectors. The group recommends that Council authorize the establishment of an International Academy on Education and Training in Intellectual Disabilities that would vet proposals for training programs sanctioned by IASSID, be authorized to accept grants and other funds to commission or conduct direct training, prepare educational curricula and pay faculty, and oversee certification of participants in IASSID sanctioned training programs. The working group recommends that the Academy be set up with an executive faculty senate of nine persons, one of whom would be designated the Director-General, and receive a working budget of at least 10,000 Euros per annum for a five-year trial period. It is also recommended that an evaluation should be conducted by Council in 2012 for viability and continuation.

#### ***Background***

At its meeting in Maastricht, the Netherlands, on 19 March 2005, the IASSID Executive Committee was presented with a proposal to establish a mechanism for organizing and delivering a series of “international courses” on intellectual and developmental disabilities by Council member Dr. Giorgio Albertini. Dr. Albertini explained the interest of his host organization, Tosinvest Sanità, to underwrite and support such a venture and asked if IASSID would be interested. The Committee voted to pursue the matter and asked that a feasibility study be undertaken. Dr. Matthew Janicki, IASSID Treasurer, was asked to undertake the administration of the study.

To organize and evaluate the potential for such an endeavor, Dr. Janicki convened two *ad hoc* working group meetings, one in San Juan, Puerto Rico on 19 April 2005 and another in Witten-Bommerholz, Germany on 19 May 2005. The key outcomes from these meetings, and selective input from IASSID members who did not attend the meetings, included the following:

At the first meeting in San Juan, the group dealt with the idea of a singular course and noted that:

1. A course would need a strong administrator to oversee the various activities and functions and to coordinate the content.

2. Courses would be better suited to specialty topics of 2-3 days duration rather than a week long course on a range of topics. This would help draw attendees and would limit days that attendees must be absent from their place of employment.
3. The course needs to be arranged around topics that may be derived from a needs assessment.
4. There need be learning objectives that drive the content of each course and that each course needs to follow a general prescribed outline. Most likely such courses would be organized in conjunction with a local university or IASSID research center.

At the second meeting in Witten-Bommerholz, the discussions went further and moved toward how to administer such courses and what should be the role of IASSID in international education. The meeting's participants recommended that:

1. A singular course should run 3-5 days at each location, using both core and locally secured faculty, with English as the primary language (but subject to modification under select conditions). The course would be designed to be an intensive and would offer from 35 to 45 classroom hours of instruction.
2. The course should offer certification credits that would be organized by a local partner (university, medical or other association) as dictated by national law or regulation of the host country or by an IASSID accreditation body. Participants would also receive a Certificate of Attendance or Completion issued by IASSID.
3. Participants should be persons from the country or region, or international registrants, pre-qualified to register for the course.
4. Course content should be (1) a standard curriculum of an overview of developmental disabilities, and (2) detailed segments, depending on the make-up of the participants or the design of the presentation content.
5. Courses should be offered at the rate of 1-3 per year, depending on the locale and registrant demand. Courses might be set up to offer general introductory material once a year and then one or two specialized content areas per year.
6. With respect to the administration of such courses, IASSID should create an Academy on Intellectual and Developmental Disabilities as the host for the course(s). The Academy could also organize wrap-around mini-courses that would be pull-outs from the main curriculum and these mini-courses would be offered at the periodic IASSID regional or special interest group meetings, as well as at the quadrennial Congress.
7. An ad hoc Secretariat for the Academy/International Course should be set up and IASSID would need to provide or find some entity to provide logistical and secretarial aid.

8. That the curriculum and course content would be designed by the faculty of the Academy. Provisional appointments to the faculty would be drawn from a solicitation of interest among IASSID members. These members would be charged to design the curriculum and framework for the course process and content, with learning objectives and broad suggestions for student reading materials and presentation content. The faculty would then be involved with pilot testing the course and in overseeing the operation of the Academy. Permanent appointment of faculty to the Academy would be made by the IASSID Council.

9. IASSID should agree on a four-year timeframe to develop, pilot and manage the course to test out the process and content of course materials. A management team would be charged and empowered to carry forth with the course over a determinant period of time. This period would be used as a feasibility measure of the Academy, both from a financial and organizational point of view. The whole process would be reviewed in 2008 by IASSID Council at its annual meeting and a decision made on its viability and continuance.

On 11 June 2005, the IASSID Council at its meeting in Taipei, Taiwan was presented with a summary of the collective work to date. A number of issues were raised about the practicality and viability of such an endeavor and additional study was requested.

One recommendation of Council was that the construct of this effort move away from thinking about how IASSID might be a purveyor of courses or workshops and move toward formulating how IASSID might compose and organize a comprehensive “Academy on International Education in Intellectual Disabilities” to serve as an overseer of such courses. The thinking was that rather than getting IASSID in the business of organizing and managing courses, with its attendant costs and staff workloads, IASSID and its constituent parts would be better served by promoting the offering of courses and creating a means to vet and coordinate training and education offerings in the constituent countries.

The working group was thus charged to examine how such an Academy might be structured and operate. The notion was that an organization, university, or group of individuals might first create a course, select the faculty, and locate a venue for the presentation of a specific course. The course’s principals would then apply to IASSID for sanction to offer the course using IASSID’s name and aegis. To apply, the course principals would have to provide information on the course content, the faculty (with C.V.’s), the learning objectives, the business plan for the offering, the nature of the expected participants, any credits or certifications offered, and venue plans for review and approval by the “Academy.” Council also felt that under some circumstances, such a course might become part of IASSID’s offerings and offered directly by IASSID - say via a specific request by national health or social welfare authorities, the World Health Organization (or similar international bodies), or as a result of the receipt of a grant from a foundation or similar organization.

Dr. Janicki was asked to continue the work on the “Course” and its practicalities. To

broaden the input, a Listserv was set up in February 2006 and IASSID members were asked to volunteer to become a virtual planning committee. Some 50 members responded to the call for volunteers and the discussion process was set up and carried out over a period of three months. (A listing of the group is provided in Appendix A.) To start the discussion and advisement process, the following questions were posed:

1. How do we go about creating this “Academy” and who should be invited to be the organizing faculty?
2. What will be the role of this “Academy” and how will the faculty function?
3. What guidelines can the “Academy” issue to help the applicants and to maintain control over the quality and integrity of the courses approved to be offered under its auspice?
4. What will be the financial arrangement with the approved courses?
5. How will the “Academy” be managed?

As the discussions progressed, it was suggested that a survey be undertaken of the offerings currently available around the world. IASSID member Nancy Jokinen volunteered to head up a study group to solicit and assemble this information; she was aided by Joan Sheppard. She concluded that there was substantial interest in this initiative and had a record of numerous contacts made in connection with the task. In her report, she provides (1) a synopsis of issues and ideas that were raised by her contacts and which may be useful in further discussions of the IASSID Academy group; (2) a list of nine multinational / international courses and 16 other courses and one video; and (3) two accompanying documents that contain example course details. Her report is found in Attachment B.

### *Considerations*

The expanded working group’s discussions lead to a wealth of useful suggestions, among them were the following points:

- The Academy might sponsor international conferences, technical assistance visits to encourage local development, provide training materials, and facilitate linkages from local countries and organizations to international organizations.
- Web or CD-based education is often much more feasible and inexpensive, and costs can be easily recouped. Both of these options (web-based or CD-based education, and a review of existing resources) would be useful in developing countries. An important caveat, however, is the importance of access to a “real person”— either via face-to-face or via online interaction. Research regarding student satisfaction with and achievement in distance learning is clearly demonstrating that overall satisfaction and performance are related to instructor availability and feedback, accessibility to reliable technology and other resources, and a maintaining a sense of social inclusion within the on-line learning process.
- Some researchers and practitioners in directive positions would find English-language

materials or courses useful, but many practitioners and even researchers would be less willing, or unable, to use materials/courses in English only. In certain developing countries, such as India, this may be less of a problem, but for Latin American countries, there will be a great need for materials in Spanish (and, in a few cases, Portuguese and French).

- Courses need to be at all levels and special attention needs to be given to the needs of developing countries.
- The Academy should become an international accrediting body, with the IASSID Academy setting the standards for accreditation of workers who are entering the field.
- As an accrediting body, IASSID should assess particular topics for courses that are under-represented, and then provide crucial information to determine what content is needed to be critically addressed and help prioritize course development.
- Courses could be developed in module format. This would allow completion in isolation, but also the opportunity to complete a series of courses that could result in being awarded a combined certificate.
- When putting together a course, one has to take into account the huge diversity in cultures and especially of the social structures in the world and thus course activities should reach the potential users in their own languages.
- Most pure theoretical subjects can be taught and learned on a distance education basis. While in the moment practical experiences are a part of the program (as they should be), local supervisors are mandatory. Combining those two modes of learning will prove to be more productive.
- Relevant partners would be educational institutions, service and care providers, accreditation bodies and public administration. However, training activities should be done in person, with local trainers and local budgets.
- The Academy could provide help to other countries by having faculty willing to come locally and having a ready set of seminars or courses. The Academy should have and be able to provide expert lecturers willing to travel and provide course materials on site. The Academy could also help by stimulating research locally and supporting collaborative initiatives.
- Consideration should be given to setting up sub-work groups to take on particular curriculum development tasks, using one of two fundamental approaches. One is to think of the different groups that need education and fill in the curriculum needs for each of the groups. The other is to begin with the categories of curriculum content and then determine the curriculum needs for each group.

- The IASSID academy should promote research and data gathering, mentoring groups of professionals to build their own research, and publishing the results electronically for the profit of all workers around the world. The IASSID Academy should set up several partnerships with NGOs and federations to sustain research activities and training activities beneficial to both sides of the developmental gap.
- A long-term vision of the IASSID academy development would be targeting, at first, the most developed countries in the underdeveloped world and then proceed to the others as local resources are identified. All courses and workshops for low income and developing countries should be run at affordable costs.

### ***The Recommendations***

¶ Establish an IASSID *International Academy on Education and Training in Intellectual Disabilities*, made up of a faculty governance committee of nine eminent persons experienced in providing broad-based international education, eight of whom would be appointed by the President and one, the Director-General, would be nominated by the President and appointed by Council. Persons appointed to the academic governance must be free of any conflict of interest with institutional or organizational training activities. The Council should set up a designated oversight responsibility within the IASSID Executive.

¶ Charge the *Academy* faculty governance committee with establishing the parameters and activities of the *Academy* during its first year, with the Director-General reporting back to Council at its 2007 annual meeting (and then annually) on the activities of the *Academy*. Provide for a five-year activities period, with annual reviews and with a final review to be held by Council at its 2012 annual meeting and determination on whether to continue the *Academy*. Suggested activities would be to develop standards for courses, support and provision of collaborative education and training with existing national institutions and international organizations, securing collaborative agreements with other training resources, and applying for grants for education and training activities. Accomplishments would be measured by range of courses offered, numbers of persons trained, educational curricula affected, and productive changes in national policies toward people with intellectual disabilities.

¶ Allocate a sum of 10,000 Euros in the first year for the administrative functions of the *Academy*, limited to reimbursement of expenses for the faculty for meeting, communicating and conducting other relevant administrative activities, awards for course development, translation expenses, and support for the Director-General.

¶ Charge the *Academy* to target activities that are collaborative and which focus on aiding countries considered to be developing market economies.

*Attachment A* – Members of the ad hoc working group

*Attachment B* - Report of subcommittee on international courses

## **Appendix B. Members of the ad hoc working group**

James Acquilano  
Giorgio Albertini  
Betena Allen  
Trudy Arentz  
Robin Atwood  
Diane Baxley  
Anne Botsford  
Roy Brown  
Thomas Buckley  
Kristin Van Burm  
Letizia Cartagena  
Diego González Castañón  
Chris Conliffe  
Stuart Cumella  
Philip Davidson  
Laraine Glidden  
Joan Earl Hahn  
Meindert Haveman  
Tamar Heller  
Dana Henning  
Matthew Janicki  
Nancy Jokinen  
Henry Kwok  
Maria van Laake  
Jane McCarthy  
Phil McCallion  
M.M. Meijer  
Joav Merrick  
Donna Torres Mughal  
Karen Nankervis  
Aldred Neufeld  
Trevor Parmenter  
Elizabeth Perkins  
Jelle Reynaert  
Leslie Rubin  
Bob Schalock  
Kate Scorgie  
Justine Joan Sheppard  
Peter Sturmey  
Ryo Takahashi  
Sarah Tallapragada  
Tor Rynning Torp  
Jennifer Torr  
Annapia Verri  
Lisa Wang  
Germain Weber  
Heather Wilkinson  
Luk Zelderloo

## **Attachment B - Report of Subcommittee on International Courses**

To: Matthew P. Janicki  
From: Nancy S. Jokinen  
Date: June 15, 2006

### **Task**

To compile a listing of multi-national or international courses being offered (or having been offered) in the area of intellectual disabilities for an IASSID work group.

The information collected was to include:

- Course Name • Country/Countries of Origin • Course Affiliations • Topic
- Language • Course content • Target Audience • Format • Cost
- A note on feasibility for international or multi-national use
- Contact Information

### **Assistance:**

Joan Sheppard provided assistance in searching for courses.

### **Method**

- Requests for information were posted on the IASSID Academy and other listservs
- Queries were made through personal contacts
- Contacts were made to authors of current publications
- Internet search

### **Summary of Findings**

There was substantial interest in this initiative and numerous contacts made in connection with the task. This summary provides (1) a synopsis of issues and ideas that were raised by people and may have influenced the findings or be useful in further discussions of the IASSID Academy group; (2) a list of 9 multinational / international courses and 16 other courses and one video; and (3) two accompanying documents that provide course details.

### **Issues / Ideas:**

1. What interpretation is given to the word “course”? The definition and use of the word “course” varies internationally and is in contrast to alternatives such as program, workshop or training. There are many people for instance that provide training or workshops on an international level.

2. What distinguishes multinational / international courses from other courses? It was suggested that most courses draw on international literature and research for course content. Further, content is enhanced by an instructor’s international experience. Finally, many university-based courses are available to international students.

3. Courses may be highly pertinent to the study of intellectual disability although not specific to intellectual disability (e.g., courses on social role valorization, inclusive education, human rights, and theoretical models of disability).

4. A propensity for some universities and countries to broaden the scope of disability rather than be disability specific (e.g., disability studies versus study of intellectual disability).

5. In developed / high income countries, there are many universities that offer disability study programs; some have specific programs designed for the study of intellectual disability particularly at the graduate level. No attempt was made to catalogue these here.

6. Collaborative efforts and partnerships exist between universities within countries and across countries. Some of these include partnerships with NGOs. Tapping into these networks might be invaluable in pursuing the IASSID Academy initiative.

7. T. Saraswathi Devi (Sarah), Lebenshilfe Association, Visakhapatnam, India suggested that internship arrangements would be viable opportunities to build relations between different countries and could enhance research and study of intellectual disability.

### Course Lists

The courses are presented in two lists; an international/multinational listing and another list of courses that appeared to have a national or regional orientation. I have included information on all the courses that people took the time to submit. This provides a glimpse of some of the offerings available on courses pertaining to intellectual disability and the differing formats used, but is obviously not a comprehensive listing, particularly on any specific national level. Details of the courses are provided in the accompanying documents and course numbers correspond to the page number of the respective document to ease locating details.

Overall, there were 9 international or multinational courses identified as specific to intellectual disability and identified in this search (although we note that there are more that did not self-identify). These are briefly listed below.

- No courses were found with links to Africa.
- One indicates international work being conducted in South America (#1).
- Course information pertinent to the Asia-Pacific area is limited despite email contacts to Japan, China, Thailand and Bangladesh. Connections between the University of Sydney and Singapore (#s 4 & 5) were found as well as with mainland China (#6). Few details were found on a course (#9) promoted by the Asia-Pacific Development Center on Disability (APCD) and this may warrant further investigation.

#### International Courses:

##### **A Basic One Year Training Course in Intellectual Disability** (Spanish, Portuguese)

- The ITINERIS Foundation, Lic. Andrea Aznar y Dr. Diego González Castañón
- Latin America, for: direct staff, professionals or self-advocating families.

##### **On-Line Programme in Down Syndrome** (English)

- Down Syndrome Research Foundation (DSRF) in affiliation with LIDC, Simon Fraser University. Several instructors are based at DSRF and have links with Universities in Canada and Australia.
- For frontline personnel, rehabilitation counselors, professionals, parents

##### **Intellectual disabilities and dementia** (English)

- School of Social Welfare, University at Albany
- For U.S. and European graduate students

##### **Diploma in Developmental Disabilities** (English)

- Centre for Developmental Disability Studies (CDDS) and the Social Service Training Institute (SSTI) of the National Council of Social Services (NCSS) in Singapore
- For professionals, direct care workers, teachers, teacher assistants

##### **Certificate program on autism spectrum disorders (ASD)** (English)

- NSW Australia: Autism Association (ASPECT), Social Service Training Institute (SSTI) of the National Council of Social Services (NCSS) in Singapore and the Faculty of Education & Social Work at the University of Sydney
- For professionals including Teachers, Teacher Assistants

**Graduate Program in Developmental Disabilities (Grad Cert , Masters and Masters Honours) (English)**

- Faculty of Health Sciences at the University of Sydney
- For graduate students from Australia, Singapore & Mainland China
- 

**Dysphagia Management in Adults and Children with Developmental Disability (English)**

- Justine Joan Sheppard, Nutritional Management Associates,
- For allied health professionals and educators
- 

**An Internationalised Approach to the Psychiatry of Intellectual Disability (English)**

- Monash University & King's College
- For medical professionals and graduate students

**A course on Intellectual Disability, required support and interventions to address the needs of persons with intellectual disability, including Down syndrome (language unknown)**

- Centre for Disability in Development (CDD) and Asia-Pacific Development Center on Disability (APCD)
- For development and disability organizations and also for individuals

Other Courses:

**Australia:**

- 1.MPM5206 Psychiatry of Intellectual and Developmental Disabilities - Monash University
- 2.CMH2005 Dual Disabilities, Monash University
- 3.Postgraduate Course in Psychiatry, New South Wales Institute of Psychiatry
- 4.Introduction to Developmental Disability, Monash University
- 5.EDUC6087 Developmental Disabilities, Newcastle University

**Canada**

- 6.Education Training Package in Developmental Disabilities, University of Western Ontario

**European Initiative:**

- 7.European Certificate Course on Disability Studies, University of Ghent, et al.

**Ireland:**

- 8.Certificate of Higher Education in Health & Social Care (Learning Disabilities), Course G556UJ, University of Ulster

**Italy:**

- 9.Disability in developmental age, University of Siena
- 10.Human Rights and disability, University of Padova, et al.
- 11.Mental health promotion and quality of life in adults with intellectual disability - University of Florence
- 12.Italian Course ECM for doctors and nurses, PAVIA

**United States:**

- 13.2<sup>nd</sup> Annual Developmental Disabilities Health Care Update: Focus for Primary Care Providers, Swedish Medical Center, et al.
- 14.Assessment & Analysis of Severe & Challenging Behavior, Institute for Applied Behavior Analysis

15. Leadership in the Non-Profit Disability Organization  
16. SE 101 Introduction to Intellectual and Developmental

**Video:**

17. Healthcare Scenarios in Developmental Disability Medicine

I trust the IASSID Academy group will find this summary and listing of courses in part interesting and that it will generate some further discussions. If you have any questions or comments, please contact me.

Nancy Jokinen, MSW/RSW  
PhD Candidate, University of Calgary

## Section B - National or Regional Courses

**Course Name: MPM5206 Psychiatry of Intellectual and Developmental Disabilities**

*Country/Countries of Origin*  
Australia

*Course Affiliations*  
• Monash University

*Topic*  
• See course synopsis

*Language*  
• English

*Course content:*

- an elective subject in a Master of Psychological Medicine
- a series of interactive seminars based upon learning modules.
- **Synopsis:** Historical, philosophical, ethical, humanitarian and legal issues in the lives and care of people with intellectual/developmental disabilities; epidemiology of intellectual/developmental disabilities; intellectual/developmental disability within the family life cycle, in society and across the lifespan are covered. Psychiatric disorder in intellectual/developmental disability is also examined in detail.

*Target Audience*  
• Postgraduate; open to medical practitioners.

*Format*  
• online education.

*Cost*

*A note on feasibility for international or multi-national use*  
• is designed to meet the needs of psychiatry trainees in the state of Victoria but could be adapted for international students

*Contact Information*  
• Submitted by Dr Jennifer Torr, Senior Lecturer Centre for Developmental Disability Health Victoria ([Jenny.Torr@med.monash.edu.au](mailto:Jenny.Torr@med.monash.edu.au))

**Course Name: CMH2005 Dual Disabilities**

- Unit in a community mental health postgraduate diploma

*Country/Countries of Origin*  
• Australia

*Course Affiliations*  
• Monash University

*Topic*  
• Intellectual disability and mental illness

includes substance use and mental illness so is not pure ID.

*Language*

- English

*Course content:*

- **Synopsis:** This unit deals with two major disabilities associated with mental health problems: intellectual disability and substance misuse. Topics include aetiology of intellectual disability, epidemiology of mental illness in intellectual disability, manifestations of mental illness in the intellectually disabled, management issues for the intellectually disabled, substance use, harmful use, addiction, dependence and other definitions, determinants of substance use and abuse, substance use and precipitation of mental illness, motivational intervention, models of change and harm minimisation in the area of dependency, and HIV and substance misuse.

*Target Audience*

- mental health clinicians

*Format*

- distance education

*Cost*

*A note on feasibility for international or multi-national use*

- This unit is potentially available for international students although the content was not developed with an international audience in mind so it may be ethnocentric. The unit is combined with drug and alcohol use and mental illness which may not suit some in the ID field.

*Contact Information*

- Submitted by Dr Jennifer Torr, Senior Lecturer Centre for Developmental Disability Health Victoria ([Jenny.Torr@med.monash.edu.au](mailto:Jenny.Torr@med.monash.edu.au))

**Course Name: Postgraduate Course in Psychiatry**

- Currently not being offered.

*Country/Countries of Origin*

- Australia

*Course Affiliations*

- New South Wales Institute of Psychiatry

*Topic*

- Psychiatry and intellectual disability

*Language*

- English

*Course content:*

*Target Audience*

- psychiatry trainees

*Format*

- CD-ROM based with local tutors.

*Cost*

*A note on feasibility for international or multi-national use*

- It could possibly be resurrected if there was enough interest. The point is that it is a fully developed unit.

*Contact Information*

- Submitted by Dr Jennifer Torr, Senior Lecturer Centre for Developmental Disability Health Victoria ([Jenny.Torr@med.monash.edu.au](mailto:Jenny.Torr@med.monash.edu.au))

**Course Name: Introduction to Developmental Disability**

Note: This is currently unavailable as an accredited RACGP CPD item due to the requirement to be re-accredited for the 2005 - 7 RACGP triennium. Due to the relatively small numbers of people electing to complete this subject in the past it has been decided to devote our efforts to develop material for the increasingly more popular on-line education format.

*Country/Countries of Origin*

- Australia

*Course Affiliations*

- Monash University

*Topic*

- Developmental disability

*Language*

- English

*Course content:*

Comprises 5 short course 10-hour modules. These modules are:

- How GPs Manage Complex Problems in People with Intellectual Disability
- Causes of Developmental Disability
- Working with Services for People with Developmental Disability
- Communicating with People with Developmental Disability
- Problem Behaviours in People with Developmental Disability

*Target Audience*

- General Practitioners.

*Format*

- Distance Education Training
- This subject can still be offered as post graduate education for further private study purposes.

*Cost*

*A note on feasibility for international or multi-national use*

- could be offered internationally

*Contact Information*

- submitted by Dr Jennifer Torr, Senior Lecturer Centre for Developmental Disability Health Victoria ([Jenny.Torr@med.monash.edu.au](mailto:Jenny.Torr@med.monash.edu.au))

**Course Name: EDUC6087 Developmental Disabilities**

- Graduate Certificate and the Masters levels in Disability Studies course.

*Country/Countries of Origin*

- Australia

*Course Affiliations*

- Centre for Special Education and Disability Studies School of Education, Newcastle University

*Topic*

- General, see course content

*Language*

- English

*Course content:*

- Overviews a number of common developmental disabilities, examines the social, emotional and physical health issues of these disabilities, and critically analyses contemporary approaches to the support of individuals with a disability.
- Other courses may be applicable but do not specify ID/DD in title or course content.

*Target Audience*

- Undergraduate and graduate students

*Format*

- Distance learning only

*Cost*

*A note on feasibility for international or multi-national use*

From personal contact made April 25, 2006

- Our course readings draw heavily on the international literature and the cultural specificity of disability is acknowledged in our course materials. However, given that the international literature in this area is dominated by a handful of countries I believe you'll find that our program and the programs of most other educational institutions reflect this dominance.

*Contact Information*

[Ian.Dempsey@newcastle.edu.au](mailto:Ian.Dempsey@newcastle.edu.au)

[http://www.newcastle.edu.au/faculty/education-arts/post\\_grad\\_brochures/Disability%20Studies.pdf](http://www.newcastle.edu.au/faculty/education-arts/post_grad_brochures/Disability%20Studies.pdf)

**Course Name:** Education Training Package in Developmental Disabilities

*Country/Countries of Origin*

- Canada

*Course Affiliations*

- Collaborative Effort of the universities of McMaster, Ottawa, Queen's, Toronto & Western Ontario, Canada

*Topic*

- Health related

*Language*

- English

*Course content:*

*Target Audience*

- Medical Undergraduates

*Format*

<http://www.psychiatry.med.uwo.ca/ddp/mededucation/titlepage.htm>

*Cost*

*A note on feasibility for international or multi-national use*

- Provincial but provides links to international resources

*Contact Information*

**Course Name: European Certificate Course on Disability Studies**

- September 3-11, 2005

*Country/Countries of Origin*

- European initiative

*Course Affiliations*

- University of Uppsala, Sweden; University of Halle, Germany; University College Dublin, Ireland; University of Exeter, United Kingdom; University of Valladolid, Spain; Norwegian University of Science & Technology Trondheim, Norway; and University of Ghent, Belgium.

*Topic*

- Disability in the broad sense

*Language*

- English

*Course content:*

- theoretical models, European policy and research methods

*Target Audience*

- Graduate students from European universities that are part of the network

*Format*

- week long intensive held on site at University of Valladolid, Spain

*Cost*

- Students without a grant - 250 Euro.

*A note on feasibility for international or multi-national use*

- Funding for the intensive course was provided through the SOCRATES program
- 21 students from various countries participated
- Following the initiative, Patricia Noonan Walsh (Dublin) and a colleague from the University of Ghent have been in discussion about the feasibility of a joint Master's program in Disability Studies organized by Dublin & Ghent.
- It would take the broader approach to disability studies versus a focus on specifically on intellectual disability.

*Contact Information*

- Information provided by Patricia Noonan Walsh

**Course Name: Certificate of Higher Education in Health & Social Care (Learning Disabilities), Course G556UJ**

*Country/Countries of Origin*

- Ireland

*Course Affiliations*

- School of Nursing, University of Ulster

*Topic*

- Learning disabilities

*Language*

- English

*Course content:*

- 6 modules from: Fundamental Issues in Learning Disabilities (NUR116J4); Enhancing communication with people who have learning disabilities (NUR117J4: Level 1) New Styles of Community Based Services for people with learning disabilities (NUR423J4: Level 2); An Introduction to Relationships and Sexuality in Learning Disability Services (NUR571J4: Levels 2/3); Approaches to Challenging Behaviour with people who have learning disabilities (NUR 440J4: Level 2/3); An Introduction to Research (NUR 301J4: Level 2); Health Promotion in Professional Practice (HEP 307J1: (Level 2)

*Target Audience*

- Staff who have recently joined learning disability services or longer-serving staff who wish to update their training; Staff of mainstream health and social services who wish to develop their knowledge of learning disabilities; Voluntary workers and others interested in pursuing a career in this field.

*Format*

- E-learning using WebCT with support of a personal tutor and the opportunities to interact with colleagues from other services and settings while taking the course.

*Cost*

- Approximately £198 per module

*A note on feasibility for international or multi-national use*

- We have designed some e-learning materials that are accredited at our university with local students in mind. However they could be accessed from any where in the world but they have not been written with other countries in mind. Roy McConkey.

*Contact Information*

- Professor Roy McConkey. School of Nursing, University of Ulster, Newtownabbey, N. Ireland BT37 0QB.  
[r.mcconkey@ulster.ac.uk](mailto:r.mcconkey@ulster.ac.uk)  
Tel: 028 90 36 88 89

**Course Name: Disability in developmental age**

*Country/Countries of Origin*

- Italy

*Course Affiliations*

- University of Siena

*Topic*

- Various topics related to intellectual disability – see course content

*Language*

- Italian

*Course content:*

- The course deals with disability in developmental age, the difficult parenthood, the evaluation of autism and pervasive developmental disorders and their rehabilitation, mental retardation and neurological disorders during childhood, functional and sensory deficit, learning and behavioural disability, the transition between school and job.

*Target Audience*

- Medical, Psychologists, Pedagogisti, Technicians and Professionals of the Riabilitazione (Fisioterapisti, Logopedisti, Ortottisti, Audioprotesisti, Technicians of the Riab. Psychiatric, etc), Teaching, Educators, Ass.Sociali and the other candidates he are in possession of one of following tito them:  
1) Bachelor in all the disciplines (old ordering),  
2) Bachelor of first and according to level (new ordering);  
2) Diploma rilasciato from Fine Schools Directed to Special University or recognized from the University and tito them equipollenti.

*Format*

- BEGINNING RUN Settembre 2006
- specialistici seminaries + one introductory, for total 140 hours
- 9 Weekends: friday (pom.), saturday int day

*Cost*

- REGISTRATION TAX  
1000 euro in two installments

*A note on feasibility for international or multi-national use*

*Contact Information*

- For further information on the course tel. to the 335/406039 or to write to [franzgrasso@tin.it](mailto:franzgrasso@tin.it) - Dr. Fat Francisco; see also

<http://www.disabili.com/content.asp?Subc=13343&L=1&idMen=598>

**Course Name: Human Rights and disability**

*Country/Countries of Origin*

- Italy

*Course Affiliations*

- University of Padova.
- Disabled Peoples' International - European Region (DPI-Europe)
- Italian federation for the overcoming of handicap (FISH)
- Italian national council on disability (CND)
- European center of Excellence Jean Monnet of the University of Padova
- Region of the Veneto Councillorship to the social Political

*Topic*

- Human rights in the cares of the persons with disability

*Language*

- Italian

*Course content:*

- history of social treatment of people with disability; an international focus on human rights of people with disability; European Union and European Council's politics for the rights of people with disability ; UN and disability; international instruments for the safeguarding of human rights; human rights and social inclusion of people with disability; the operative sectors; the role of the organizations for people with disability; social services based on human rights and local and regional politics; University and disability.

*Target Audience*

- Civil employees, managing, administrators of local and regional agencies; Professionals of not governmental/ governmental organizations, social cooperatives; Volunteers of the associations for the protection of the rights of the persons with disability and their relatives; Educators and makers of the scholastic world and extra-scholastic

*Format*

- The Course is articulated in 4 modules: international vision of the human rights of the persons with disability; regional instruments of protection of the human rights; human and social inclusion; human and disability: the Italian political and the territorial services.
- The Course carries out in the period February-June 2006 and previews 90 hours of lessons and 30 hours of seminars and workshops. The obligatory minimal frequency is of 70%. The Course has a value of 12 credits formed to your university.

*Cost*

- Tax of registration Euro 608,50.

*A note on feasibility for international or multi-national use*

*Contact Information*

- Director of the Course: Mark Mascia, University of Padova, see:

[http://www.centrodirittiumani.unipd.it/a\\_formazione/corsivv/agg\\_0506.asp?menu=formazione](http://www.centrodirittiumani.unipd.it/a_formazione/corsivv/agg_0506.asp?menu=formazione)

**Course Name: Mental health promotion and quality of life in adults with intellectual disability**

*Country/Countries of Origin*

- Italy

*Course Affiliations*

- University of Florence, Faculty of Medicine & Surgery

*Topic*

- proposed to supply acquaintances advanced in the field of the problematic ones psicopatologiche of the subjects with *Disability Intellettiva* and of methodical of appraisal, treatment and promotion of the mental health and of *Quality of Life* of the same ones.

*Language*

- Italian

*Course content:*

- The course deals with intellectual disability in a life-span point of view and it deals with quality of life, in particular it concerns clinical aspects. thematic main of the course they are:
- History of the concept of Mental Deficiency, Delay Mentale and Disability Intellettiva; Concepts of handicap and difficulty of participation; Systems classified you of the Disability Intellettiva; The concept of "life span"; Concepts of identity, to inhabit and job; The concept of Quality of Life
- Aspects epidemiologists of the Disability Intellettiva; Genetic aspects; Neurological aspects; Aspects of infantile Neuropsichiatria; The double diagnosis: relationship between Disability Intellettiva and psychiatric diagnosis; Instruments of appraisal of the Disability Intellettiva; Instruments of appraisal of disturb psychiatric in the Disability Intellettiva; Psicofarmacologici Treatments; Psicoterapeutici Treatments; Therapies not convenzionai; The services for the Disability Intellettiva
- - Instruments of appraisal for the qualification of Disability Intellettiva-Instruments of appraisal of the Quality of Life - The abilitative levers - Psicopedagogici treatments - The working insertion - The job with the family - The integrated therapeutic plan.

*Target Audience*

- Post Bachelor course; admitted to the Course graduated in Medicine and the Surgery, Psychology and Sciences of the Education

*Format*

- 50 hours of Didactics articulated in 30 hours of frontal lessons, 6 hours of mailing-lists, 4 hours of round table and 10 hours of training.
- it will be carried out from 4 February to 27 May 2006.

*Cost*

- 650 euro

*A note on feasibility for international or multi-national use*

*Contact Information*

<http://www.med.unifi.it/segreteria/didattica/perfezionamento/default.htm>

**Italian Course ECM for doctors and nurses**

**DAY ON THE DISABILITA**

**18 Saturdays November 2006 College S. Caterina from Siena Via S. Martino, 17/A - PAVIA**

**PRELIMINARY PROGRAM**

Hours 8.30 OPENING OF THE JOBS *S. Perlini – and. Frisian*

**THE SESSION: Patient and Institution** Moderator: *M. Melazzini*

Hours 9.00 – 9.30 **The needs and the rights of the patient with disability** *M. Melazzini*

Hours 9.30 – 10.30 **The motoria and neuro-motoria disability: the problem of the prescription of the aid from a technical-legislative point of view** *M. Arena, And. Nembro*

Hours 10.30 – 11.00 **The appraisal and quantification of the motoria disability**

*G. Sandrini, M. Bartolo*

Hours 11.00 – 11.15 ARGUMENT

Hours 11.15 – 11.30 COFFEE BREAK

**II SESSION: The intellettiva disability: the problem of the diagnosis** It moderates: *G. Sandrini*

Hours 11.30 – 12.00 **Neurological aspects clinical** *To. P. Verri*

Hours 12.00 – 12.30 **The genetic diagnosis** *Or. Zuffardi*

Hours 12.30 – 12.45 ARGUMENT

Hours 12.45 – 13.45 PAUSE LUNCH

Hours 13.45 – 14.30 **The psicometrica appraisal** *V. Destefani, To. Cremante*

Hours 14.30 – 15.00 **Aspects doctor-lawyers** *To. Riva*

Hours 15.00 – 15.20 **The disabile and the world of the job** *C. Gremita, N. V. Mennoia*

Hours 15.20 – 15.30 COFFEE BREAK

**III SESSION: L' attendance to the disabile patient** Moderators: *G. Belloni and. Frisian*

Hours 15.30 – 16.15 **The clinical management hospital territory** G. Belloni, G. It admires - P to you. Brizzi  
Hours 16.15 – 16.45 **Professional role dell ' nurses** S. Quattrocchi  
Hours 16.45 – 17.15 **Role of the voluntary service associations** C.Torselli  
Hours 17.00 – 17.30 CLOSING OF THE JOBS G. Belloni – and. Frisian  
Hours 17.30 – 18.00 QUESTIONNAIRE

#### **MODERATORS AND RELATORI**

G ADMIRES TO YOU. – *General medicine doctor*  
BELLONI G. – *Provincial Order of the Medical Surgeons and the Odontoiatri of Pavia*  
BRIZZI P. – *general medicine Doctor*  
CREMANTE TO. – *IRCCS “ Mondino ” Pavia*  
DESTEFANI V. – *IRCCS “ Mondino ” Pavia*  
FRISIAN AND. – *IPASVI Pavia*  
GREMITA C. – *ASL Pavia (Service ambient Prevention and emergency of job)*  
MELAZZINI M. – *IRCCS “ Maugeri ” Pavia*  
MENNOIA N.V. – *University of Pavia*  
NEMBRO AND. – *To.Or. Pavia*  
ARENA M. – *ASL Pavia*  
PERLINI S. – *Provincial Order of the Medical Surgeons and the Odontoiatri of Pavia*  
QUATTROCCHI S. – *ASL Rho*  
RIVER TO. – *IRCCS Policlinico “ S. Matteo ” Pavia*  
SANDRINI G. – *IRCCS “ Mondino ” Pavia*  
TORSELLI C. – *ANFFASS Pavia*  
VERRI TO. P. – *IRCCS “ Mondino ” Pavia*  
ZUFFARDI OR. – *University of the Studies of Pavia*

#### **Course Name: 2<sup>nd</sup> Annual Developmental Disabilities Health Care Update: Focus for Primary Care Providers**

- **April 8, 2006**
- **Seattle, Washington**

#### *Country/Countries of Origin*

- United States

#### *Course Affiliations*

- Swedish Medical Center, Division of Developmental Disabilities/ADSA/DSHS and the Developmental Disabilities Council

#### *Topic*

- Health care

#### *Language*

- English

#### *Course content:*

- PDF brochure received and available
- Indicates up to date information on complex medical needs (e.g. common health issues, differential diagnosis, mobility issues in aging, screening and assessment of men & women's health issues, sleep disorders, and osteoporosis)

#### *Target Audience*

- Practitioners in the field of Family & General practice, Pediatrics, Psychiatry, Psychology and allied health professionals

#### *Format*

- One day workshop

#### *Cost*

- \$90 U.S. for Physicians; \$60 for Other health care professionals; Free for Residents, Fellows and Medical Students

*A note on feasibility for international or multi-national use*

*Contact Information*

- Gene McConnachie, Ph.D.  
Field Services Psychologist  
Region 4 DDD N46-6 1700 E. Cherry St.  
Seattle WA, 98122  
(206)568-5718

**Course Name: Assessment & Analysis of Severe & Challenging Behavior  
Los Angeles, July 23 - August 5, 2006**

*Country/Countries of Origin*

- United States

*Course Affiliations*

- Institute for Applied Behavior Analysis

*Topic*

- A rationale for nonaversive behavioral support.
- Behavioral assessment and functional analysis.
- Ecological manipulations for behavior change.
- Positive programming for durable results.
- Focused nonaversive strategies for rapid control.
- Emergency management within a non-aversive framework.
- Limitations of the nonaversive model.
- Identification of positive reinforcers.
- Assuring staff consistency in service implementation

*Language*

- English

*Course content:*

- advanced, competency-based training practicum

*Target Audience*

- psychologists, behavioral consultants, resource specialists and other qualified professionals

*Format*

- Summer Institute. Training activities will include supervised, field based practicum assignments, feedback sessions, lectures, reading and writing assignments, practice exercises, follow-up telephone consultation and evaluation

*Cost*

- \$4095.00 US — Includes tuition, shared accommodations for 14 nights, materials (see list of provided materials below), local transportation to and from training sites, access to word processing staff, follow-up telephone consultation, hosted social events

*A note on feasibility for international or multi-national use*

- Previous participants have attended from Australia, Canada, Great Britain, Greece, Ireland, Malta, New Zealand, Norway, Spain and the U.S.

*Contact Information*

- John Marshall, Director of Professional Training Services
- Institute for Applied Behavior Analysis
- PO Box 5743 • Greenville, SC 29606-5743 USA
- Toll Free (US & Canada): (800) 457-5575
- TEL: (864) 271-4161 • FAX: (864) 271-4162
- e-mail: jmarshall@iaba.com

**Course Name: Leadership in the Non-Profit Disability Organization**

*Country/Countries of Origin*

- United States

*Course Affiliations*

- University of Illinois Chicago

*Topic*

- It focuses on enhancing the ability to run an organization to facilitate better quality services

*Language*

- English

*Course content:*

- The topic is discussed from a broader sense than just US to take in discussion of systems in Australia, England, Ireland and Germany, and Romania.

*Target Audience*

- University students

*Format*

*Cost*

*A note on feasibility for international or multi-national use*

*Contact Information*

- Information submitted by Cindy Haworth, [chaworth@comcast.net](mailto:chaworth@comcast.net)

**Course Name: SE 101 Introduction to Intellectual and Developmental Disabilities**

*Country/Countries of Origin*

- United States

*Course Affiliations*

- Instructor is affiliated with Teachers College, University of Columbia
- UniversalClass.com

*Topic*

- The course covers I/DD and its history, definitions, causes, prevention, and intervention.

*Language*

- English

*Course content:*

- There are 40 lesson objectives cited on the website for this course.

*Target Audience*

*Format*

- Online course

*Cost*

- \$30.00 US

*A note on feasibility for international or multi-national use*

*Contact Information*

<http://home.universalclass.com/i/crn/3564.htm>

**Other Educational Materials submitted:**

1. **Video available from the CDDHV**

<http://www.cddh.monash.org/products-resources.html>

**Healthcare Scenarios in Developmental Disability Medicine**

This interactive DVD introduces users to Jacqui, Colin, Sara and Geoff. Through video scenarios you will learn about their lives and how their developmental disability affects them. A medical consultation with each person highlights particular issues in the healthcare of people with developmental disabilities. An accompanying knowledge base, extensively illustrated with images and personal stories, provides an overview of developmental disabilities, explores general issues in healthcare, communication strategies, mental health and illness in people with intellectual disabilities and the experiences of families and carers.

- submitted by Dr Jennifer Torr, Senior Lecturer Centre for Developmental Disability Health Victoria  
([Jenny.Torr@med.monash.edu.au](mailto:Jenny.Torr@med.monash.edu.au))

-30-

## Agreement for cooperation between

DSI - Down Syndrome International

The Sarah Duffen Centre, Belmont Street, Southsea, Portsmouth, PO5 1NA England  
and

IASSID – International Association for the Scientific Study of Intellectual  
Disabilities

PO Box 870, Rockport, ME 04856 USA.

1. DSI and IASSID share a common focus on the rights of individuals with disabilities, and a commitment to promote scientific research in this field and advocate for quality of life internationally;
2. DSI and IASSID agree to offer a number of benefits to each other's members;
3. DSI and IASSID agree to advertise each other's main events in their publications and website;
4. IASSID members can purchase DSI materials such as books, etc., at the same reduced price as DSI members; IASSID members can take a subscription to the DSI Newsletter etc at the same reduced price as DSI members, by ordering from the publisher (DSRF), using the DSI website link or [www.dsrf.org](http://www.dsrf.org).
5. DSI members can purchase IASSID materials such as books, etc. at the same reduced price as IASSID members; DSI members can take a subscription to Journal of Policy and Practice in Intellectual Disabilities and the Journal of Intellectual Disability Research (JIDR) at the same reduced price as IASSID members;
6. IASSID members can attend the biennial DSI International conference at the same membership price as DSI members;
7. DSI members can attend the quadrennial IASSID international congress at the same membership price as IASSID members;
8. DSI and IASSID, respectively, will appoint a liaison to each others governing boards and, when appropriate, to relevant committees;
9. IASSID will maintain a Special Interest Research Group (SIRG) within IASSID on the subject of Down syndrome within the SIRG guidelines set by IASSID; members of DSI will be eligible, under this agreement, to be members of this SIRG under the same provisions as members of IASSID.
10. The DSI Secretariat and treasurer (or their named representatives) and the IASSID secretariat and treasurer (or their named representatives) will collaborate to set up a system to allow for checking of cross-membership.

11. The respective Presidents and/or senior officers of IASSID and DSI shall be eligible to attend each others world congresses free of fees as long as they attend in their official capacities as invited participants in the programs.

This agreement shall in effect when signed by both senior officers of DSI and IASSID, shall be reviewed at least biennially by the respective governing bodies, and shall be in effect until rescinded by one or both of the organizations.



DSI President

12<sup>th</sup> July, 2006

Date

Balbir Singh



IASSID President

21<sup>st</sup> June, 2006

Date

David Felce

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

## **June 2006**

### Past Activities

The Special Interest Research Group on Aging and Intellectual Disability held its 14<sup>th</sup> Roundtable and Annual Meeting in Dortmund, Germany on May 17<sup>th</sup> through 19<sup>th</sup>, 2005. It was organized by Dr. Meindert Haveman. Approximately 34 SIRGAID members attended the meetings. The themes included Health Outcomes, Death and Dying, and Social Aspects of Aging with ID. A parallel conference was held on the 20<sup>th</sup> of May attended by over 75 local providers and University faculty. Four members of the SIRGAID gave presentations.

The SIRGAID 15<sup>th</sup> Roundtable was held in Toronto, Canada on April 26<sup>th</sup>-29<sup>th</sup>, 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 designated Oslo Norway as its venue for the 16<sup>th</sup> Roundtable, to be held May 20-22, 2007. It will be sponsored by the Development Program on Ageing in People with Intellectual Disabilities (UAU) at The Norwegian Centre for Dementia Research.

The current officers continued in leadership, including Philip Davidson and Christine Bigby as co-Chairs, Dawna Torres Mughal as Treasurer, Heather Wilkinson as Secretary, and Matthew P. Janicki as Past Chair. Dr. Davidson also continued to serve as the SIRGAID Council Representative.

### Membership

Dr. Dawna Mughal, our Treasurer reports that we currently have 36 IASSID members who have paid their \$20 SIRG dues for 2006.

### 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, although discussion recommended caution in adopting a spending plan that overestimated dues revenues. There was strong sentiment to limit travel expenses of Officers attending IASSID sponsored events without substantial sharing of costs with IASSID.

Submitted – PW Davidson, Co-Chair/Aging SIRG  
15 June 2006

Report of SIRG on Families  
IASSID Council Meeting  
AT E-IASSID, Maastricht, August 2006

**Summary of Past Year Activities**

The Families Research group of IASSID remains active and involved with IASSID. Highlights of activities of the last year or so include:

- (1) Two meetings of the Families Research group, at the Gatlinburg Conference 2005 and 2006. Members in attendance represented most regions of the U.S.; there was representation from Wales and the U.K. as well.

The goal of the 2005 meeting was to discuss the number of symposia to submit to the Maastricht meeting, since we had been told that presentations would be limited. We considered invited symposia, as well as a more general call for papers. At the 2006 meeting, we discussed the upcoming Special Issue of JIDR (see below), and confirmed plans for Maastricht. Laraine Masters Glidden provided a report of the first Asia Pacific IASSID Conference.

- (2) In response to the overwhelming interest in families research, among IASSID members and the field of ID at large, the JIDR Editors (Tony Holland, Editor; Jan Blacher & Chris Oliver, Associate Editors) and Editorial Board approved a second Special Issue on the topic. As in the first issue, the call for papers for the current one (co-edited by Richard Hastings, Ann Turnbull, & Bruce Tonge) has resulted in a large number of submissions – too many for one issue. Accepted papers that do not make it into the Special Issue will appear in regular issues of JIDR.
- (3) Membership of the Families SIRG continues to be strong, and we have maintained a mailing list of 110.

**Plans for the Upcoming Year**

Families SIRG plans include:

- a) maintenance of an active membership with ongoing and active email communication
- b) continue to solicit papers on families for JIDR and other journals associated with IASSID
- c) a feature on families research highlights from Maastricht in Jan Blacher's "Research Reflections" column for *Exceptional Parent* magazine
- d) plans to attract even more cross-cultural research on families, and more cross-country collaboration

- e) plans to assure families research representation and highlights at the IASSID meeting in Cape Town

**Issues or Action Items for Council**

The Families SIRG would be delighted with more communication and involvement with the Executive body of IASSID. Conversely, the Families SIRG would like to better inform the IASSID Council and Executive of the SIRG's active research agenda. While the Families SIRG has prominence in the JIDR arena, it might be well to include Special Issues on Families in JARID and/or JPPID.

This summary of Families SIRG activities is respectfully submitted by Jan Blacher, C-Chair, Families SIRG.

**Families SIRG:**

*Co-Chairpersons: Jan Blacher, Professor and Faculty Chair,  
Graduate School of Education, University of California, Riverside  
Chris Hatton, Institute for Health Research, Lancaster University*

*Secretary: Malin Olsson, Gotenborgs Universitet Psykologiska Institutionen*

*Treasurer: Richard Hastings, Professor of Psychology, School of Psychology,  
University of Wales, Bangor*

**Report of Health SIRG  
IASSID Council Meeting  
August 1 and 2, 2006**

Prepared by Professor Mike Kerr 20<sup>th</sup> June 2006

**Summary of Past Year Activities**

The SIRG held a major conference on Health Issues hosted and funded by The Centre for Disability Health Victoria and held in Melbourne Australia. This was a great success and consolidated the position of the SIRG as a leading player in disability Health.

The SIRG published a Key report into the disparity in health experienced by people with an intellectual disability:

Scheepers M, Kerr M, O'Hara D, Bainbridge D, Cooper S-A, Davis R, Fujiura G, Heller T, Holland A, Krahn G, Lennox N, Meaney J & Wehmeyer M (2005) Reducing health disparity in people with an intellectual disability: A report from Health Issues Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *J of Policy & Practice in Intellectual Disabilities*, 2(3/4), 249-55.

The SIRG continues to produce regular newsletters and have teleconferences of the board

**Plans for Upcoming Year**

The SIRG will hold a joint roundtable on medical student education with MAMH at the Maastricht meeting

The SIRG will hold a business meeting in Maastricht

SIRG members are developing Guidelines for the management of epilepsy and other guidelines have been mooted

Initial plans are in place for a SIRG conference to be held at Monash University premises in Tuscany in 2007 on the theme of standards and guidelines for Intellectual disability health

**Financial statement**

**IASSID SIRG Financial Statement**

Please provide the following information by July 10, 2006

1. Name of SIRG **Health**

2. Name of person completing report

**Vee Prasher**

3. Contact information of person completing report

a. Postal address **Greenfields, Monyhull, Kings Norton, Birmingham  
Uk b30 3QQ**

b. Telephone & Fax **0044 121 449 2293**

c. Email **vprasher@compuserve.com**

4. Statement of Holdings

*Check as appropriate:*

SIRG is holding funds

a. Amount of funds held by SIRG as June 1, 2006 \$3621.00

b. Name and address of bank or institution holding funds NatWest Bank Kings  
Heath Birm

c. Name of person responsible for maintenance and disbursement of funds  
vprasher

d. Name of person(s) responsible for auditing disbursement and receipt of funds  
vprasher/mike kerr

e. Date of last audit of funds (i.e., review of bank statement by responsible SIRG  
officer) jan 2006

SIRG is not holding any funds

IASSID is holding SIRG funds

a. Amount of SIRG funds held by IASSID as of June 1, 2006

5. If the person responsible for managing the funds will change during 2006-07,  
please provide name of the new person responsible for funds

6. Please list sources of income for the SIRG

SIRG dues collected by IASSID and SIRG

Revenue from Roundtable and/or other meetings

Donations

Grants, awards, etc.

### **Issues or Acting Items**

The SIRG would like to aim for a position of no extra fee payable to join a SIRG and for SIRGs to be centrally funded by IASSID

The SIRG would like consideration of more clear cut input into the health aspect of IASSID meetings.

### **Discussion Points for Council**

As above

## **Report on the Mental Health Special Interest Research Group**

### **IASSID Council Meeting**

**Maastricht, August 1<sup>st</sup> and 2<sup>nd</sup> 2006**

The MH-SIRG was a co-sponsor with the Health SIRG of a conference held in Melbourne, Australia in September 2005 organised by Professor Bob Davies. The conference was well attended with days allocated to the themes of mental and physical health.

Members of the MH-SIRG attended a meeting of the World Psychiatric Association (WPA) at the invitation of Professor Luis Salvador to establish a formal link between the recently formed section of the WPA on intellectual disabilities and the MH-SIRG, and co-hosted meetings on ID and mental health.

At the AGM of the MH-SIRG held at the Melbourne meeting Tom Cheetham (Canada) was formally appointed as the new treasurer. Anna Cooper and Tony Holland agreed to continue as co-chairs.

At the AGM plans were considered for the future work of the MH-SIRG. It was noted that for many countries there was a lack of expertise available to assess and treated psychiatric disorders as they affect people with intellectual disability. It was proposed that the MH-SIRG should organise a workshop to consider the training in ID of psychiatrists and psychologists in particular. It was agreed that this would be scheduled for 2007. Venue to be determined. It was noted that the position paper prepared by the MH-SIRG was on the IASSID web-site. There was some discussion about whether further position papers would be helpful. It was noted that there were special editions of JIDR that focus on this issue.

The next meeting of the MH-SIRG would be held as part of IASSID Europe in August 2006 in Maastricht.

Tony Holland

June 2006

**Report of SIRG Parents and Parenting with Intellectual Disabilities  
IASSID Council Meeting  
At E-IASSID, Maastricht August 2006**

**Summary of Past Year Activities**

The Parents and Parenting with Intellectual Disabilities SIRG held their third meeting at the first Asia Pacific IASSID Conference in May, 2005 in Taipei.

Although the Parenting SIRG did not formally mount a Parenting stream at this conference there were several presentations primarily from Australia on parenting for people with intellectual disabilities. These presentations attracted good audiences and a great deal of interest from attendees.

The Parenting SIRG held an informal meeting with attendees including Professor Hans Reinders to discuss, in particular, the symposia for the IASSID Europe conference in Maastricht in 2006. The meeting agreed to approach the Chairs of the E-IASSID conference with a proposal to have parenting as a keynote topic. The meeting also agreed to actively pursue several symposia building on the topics agreed at Montpelier.

The Executive Committee of the Parents and Parenting with Intellectual Disabilities SIRG is as follows:

Chair: Professor Gwynnyth Llewellyn, Australia  
Deputy Chair: Dr David McConnell, Australia  
Secretary/ Treasurer: Professor Peter Vietze, USA  
Executive members:  
Dr Sue McGaw United Kingdom  
Dr Marie Gustavsson Holstrom, Sweden  
Dr Jytte Faureholm, Denmark  
Professor Rannveig Traustadottir, Iceland  
Professor George Singer, USA

The Parenting listserv has again been of benefit to members. Up to date information is regularly shared by this list serv about events in member countries. For example, the development and implementation of the Australian National Strategy for Parents with Learning Difficulties; the release of the UK Report, *Finding the Right Support?* prepared by our colleagues at the Norah Fry Research Centre, University of Bristol.

**Plans for Upcoming Year**

1. To ensure good representation at E-IASSID at Maastricht in August, 2006.
2. To explore opportunities for cross country collaboration and particularly in areas identified as critical concerns and noted above in summary of past year activities.
3. To attract additional members to the SIRG and to promote our activities by way of the Parenting Listserv and the SIRG's website attached to the IASSID website.

4. To ensure ongoing and timely reporting of member's activities worldwide and in particular to announce new publications, research and development activities and policy issues or development and public media attention to parents and parenting with intellectual disabilities.
4. To identify appropriate ways to effectively utilize additional SIRG membership fees including for example student sponsorship for presentations at IASSID conferences.

### **Issues or Acting Items**

To further streamline pathway between IASSID Council and the SIRG to ensure timely relay of IASSID members indicating their interest in the Parents and Parenting SIRG to the Secretary/ Treasurer to ensure that interested parties have full access to SIRG activities.

### **Discussion Points for Council**

1. The SIRG requests an update on the progress of new and streamlined pathways of communication from the IASSID Executive to the SIRG's as discussed by the incoming President in Montpellier. The SIRG continues to experience difficulty in getting timely information about the membership base and subscriptions due to the SIRG.
2. The SIRG is keen to be informed about the Council's strategy, timeline and process in publishing books on the area of interests of the SIRGS. It would be helpful for example if there was an identified plan and timeline so that SIRG members could mobilize their efforts to work towards an outstanding international publication in a timely and orderly way.
3. The SIRG is also keen to be informed about the strategy in place to secure special editions of the *Journal of Policy and Practice in Intellectual Disabilities*. It may be helpful for example to have a schedule of special editions with SIRG's signing up well ahead of time to coordinate a special edition in their area of expertise and interest.

## **Report on the SIRG *Profound Intellectual and Multiple Disabilities (PMD)* 2005-2006**

### **Board**

The SIRG PMD board is constituted as follows:

Chair : Loretto Lambe (UK) and Carla Vlaskamp (NI)  
Chair elect and secretary : Bea Maes (Bel)  
Treasurer : vacancy , (seat temporarily taken over by Bea Maes)  
Past chair : Han Nakken (NI)

Members:

- Mary Arnold (USA)
- Anne Brown (UK)
- Care Fabila (Mex)
- Barbara Fornefeld (Ger)
- Mats Granlund (Swe)
- Paul Pagliano (Aus)
- Knut Slåtta (No)
- Jenny Whinnet (UK)
- Sui Sone (Japan)

### **Activities June 2005 –June 2006.**

#### ***Terminology***

Although in the 12<sup>th</sup> World Congress of 2004 there was an impressive number of presentations on planning, executing, and organizing education, health care, and support for individuals with ‘PMD’, it was not absolutely clear, if the speakers were talking about the same ‘group’ of persons. As a number of different terms were used to describe the target group, it may very well be that different (sub)groups were being referred to. This brings us to the urgency for an international agreement on a general accepted classification, which will facilitate communication and prevent misunderstanding. As the term Profound Intellectual and Multiple Disabilities is the term most widely used and accepted, we decided to favor this term over the term Profound Multiple Disabilities.

#### ***Round Table***

A Round Table invitational conference was held in Brugge, Belgium, in October 13-15 th. Two broad topics were chosen as key topics for the conference:

- (1) quality of service provision and support in community services and families, with special attention to staff attitudes, skills, working methods and training
- (2) procedures and evaluation of educational and developmental programs and activities and of (pseudo)treatment programs and methods

As part of the Invitational conference, which was attended by members from the UK, Scotland, Sweden, Ireland, Japan, Germany, Belgium and the Netherlands, the

contribution of our SIRG to the 2nd European IASSID-conference at Maastricht (the Netherlands) was discussed. As the program committee had already decided that there will be 4 symposia under the theme 'PMD', topics and our contribution was discussed. Convenors were designated for each symposium. In each symposium there will be 4 presentations.

### ***Newsletter***

In the beginning of 2006, our sixth Newsletter was sent to all our members. The newsletter also included the request to fill in a so-called 'membership card'. The members were also brought up to date on the development of a website.

### ***Web-site / E-mail***

The SIRG information can be found on the web-site of the IASSID under [IASSIDoffice@aol.com](mailto:IASSIDoffice@aol.com), SIRG, Profound Multiple Disabilities. The information on this web-site has recently been revised.

Next to the information on the IASSID website, another website is up and running, on <http://www.sirgpmd.be>. On this website, our 'mission statement' can be found. An important part of this website is the 'membership card'. With these cards, vital information on members is gathered and can be used to facilitate contact between members. In the sections 'announcements' and 'reports', information on e.g. recent research projects is stated. This website needs further development but will hopefully grow to an interactive site that can run next to the regular IASSID website.

### ***International Masters***

Members from the Netherlands, Belgium, Germany and Scotland have started an initiative on the development of an International Masters. After initial contact by e-mail, a meeting was organized in Cologne, Germany, in March 2006. It was decided upon that we would start with the development of preliminary modules. The group will meet again in August 2006.

### ***Colloquium for young researchers***

At the round table conference, a suggestion came forward to organize a colloquium for young researchers. This idea has been worked out steadily but surely by Colin Griffiths in close cooperation with some board members. Arrangements have now been made, and the colloquium will be held in August 1<sup>st</sup> -2<sup>nd</sup> at Maastricht.

### **Financial Statement**

The report on the financial statement was completed by Bea Maes. This report is attached.

Groningen, 3<sup>rd</sup> July  
Carla Vlaskamp, chair.  
Bea Maes, secretary and treasurer.

**Attachment: Financial Statement**

Name of SIRG: Profound Intellectual and Multiple Disabilities (PMD)

Name of person completing report: Bea Maes

Contact information of person completing report:

University of Leuven, Vesaliusstraat 2, 3000 Leuven, Belgium

Tel. 00-32-16326224 Fax 00-32-16325933

[Bea.Maes@ped.kuleuven.be](mailto:Bea.Maes@ped.kuleuven.be)

Statement of Holdings

SIRG is holding funds

SIRG is holding 212,55 € on June 1, 2006

KBC Bank Steenokkerzeel, Van Frachenlaan 9, 1820 Steenokkerzeel,

Belgium

Bea Maes

SIRG is not holding any funds

IASSID is holding SIRG funds

IASSID is holding 360 US\$ on June 1, 2006

5. If the person responsible for managing the funds will change during 2006-07, please provide name of the new person responsible for funds.

6. Please list sources of income for the SIRG

SIRG dues collected by IASSID and SIRG

Revenue from Roundtable and/or other meetings

Donations

Grants, awards, etc. – Fund by the Flemisch Fund for Scientific Research for the organisation of the 2<sup>nd</sup> Roundtable of the SIRG in Bruges.

	Aging	Families	Health Issues	Mental Health	Parenting	Profound & Multiple	Quality of Life
<b>Contact person</b>	Dawna Torres Mughal	Richard Hastings	Vee Prasher	Tom Cheetham	Peter Vietze	Bea Maes	Ralph Kober
<b>Contact information</b>	a. Postal address: 1731 Skyline Drive, Erie, PA 16509 USA b. Telephone & Fax: Phone (Day): 814-871-5452 Fax: 814-871-5662 c. Email: Dawnaphdrd@aol.com or mughal@gannon.edu	a. Postal address - School of Psychology, University of Wales Bangor, Bangor, Gwynedd, LL57 2AS, UK b. Telephone & Fax - +44 1248 388214; +44 1248 382599 (Fax) c. Email - r.hastings@bangor.ac.uk	a. Postal address Greenfields, Monyhull, Kings Norton, Birmingham Uk b30 3QQ b. Telephone & Fax 0044 121 449 2293 c. Email vprasher@compuserve.com	a. Postal address: Queen University Department of Family Medicine Rideau Regional Centre, PO Box 2000, 3312 County Road # 43 East Smiths Falls, Ontario, Canada K7A4T7 b. Telephone: 613-284-0123 ext 2377 Fax: 613-284-0669 c. Email: cheetham@post.queensu.ca	Vietcoat@verizon.net	a. Postal address: University of Leuven, Vesaliusstraat 2, 3000 Leuven, Belgium b. Tel. 00-32-16326224 Fax 00-32-16325933 c. Bea.Maes@ped.kuleuven.be	a. Postal address: Department of Accounting and Finance, The University of Auckland Business School, Private Bag 92019, Auckland New Zealand b. Telephone & Fax: Telephone: +64 9 373 7599 ext. 87174 Fax: +64 9 373 7406 c. Email: r.kober@auckland.ac.nz
<b>Amount of funds held by SIRG as June 1, 2006</b>	\$ 5,551.37 (Current balance less \$6,081.82 paid to the Univ of Toronto for the Roundtable Expenses, May 30, 2006)		\$3621.00			SIRG is holding 212,55 on June 1, 2006	
<b>Name and address of bank or institution holding funds</b>	JP Morgan Chase Bank PO Box 5206 New Hyde Park, NY 11042		NatWest Bank Kings Heath Birmingham, UK			KBC Bank Steenokkerzeel, Van Frachenlaan 9, 1820 Steenokkerzeel, Belgium	

# IASSID SIRG Financial Statement

Submitted: July 10, 2006

1. Name of SIRG: **SIRGAID**

2. Name of person completing report: **Dawna Torres Mughal**

3. Contact information of person completing report

a. Postal address: 1731 Skyline Drive, Erie, PA 16509 USA

b. Telephone & Fax: Phone (Day): 814-871-5452 Fax: 814-871-5662

c. Email: [Dawnaphdrd@aol.com](mailto:Dawnaphdrd@aol.com) or [mughal@gannon.edu](mailto:mughal@gannon.edu)

4. Statement of Holdings

***Check as appropriate:***

**(X ) SIRG is holding funds**

a. Amount of funds held by SIRG as June 1, 2006

\$ 5,551.37 ( Current balance less \$6,081.82 paid to the Univ of Toronto for the Roundtable Expenses, May 30, 2006)

b. Name and address of bank or institution holding funds

JP Morgan Chase Bank

PO Box 5206

New Hyde Park, NY 11042

c. Name of person responsible for maintenance and disbursement of funds

Dawna Torres Mughal and Philip Davidson

d. Name of person(s) responsible for auditing disbursement and receipt of funds

Dawna Torres Mughal, Philip Davidson, Chris Bigby

e. Date of last audit of funds (i.e., review of bank statement by responsible SIRG officer)

April 29, 2006

(X ) SIRG is not holding any funds (As of June 1, 2006)

( ) IASSID is holding SIRG funds

a. Amount of SIRG funds held by IASSID as of June 1, 2006

5. If the person responsible for managing the funds will change during 2006-07, please provide name of the new person responsible for funds  
Information is not available at this time.

**IASSID SIRG Financial Statement, Page 2/2**  
SIRGAID Report

6. Please list sources of income for the SIRG

SIRG dues collected by IASSID and SIRG

2005 Dues (Received from IASSID in 2006): \$ 810

2006 Dues: \$ 640

Revenue from Roundtable and/or other meetings

15th Roundtable, Toronto: \$ 5,881.45

(Details of funds)

\$450

\$ 5223.45

\$ 208.00

Donations

Grants, awards, etc.

(SIRG Financial Statement SIRGAID Report 7-10-06)

## IASSID SIRG Financial Statement

Please provide the following information by July 10, 2006

1. Name of SIRG - Families
2. Name of person completing report - Richard Hastings
3. Contact information of person completing report
  - a. Postal address - School of Psychology, University of Wales Bangor, Bangor, Gwynedd, LL57 2AS, UK
  - b. Telephone & Fax - +44 1248 388214; +44 1248 382599 (Fax)
  - c. Email - r.hastings@bangor.ac.uk
4. Statement of Holdings  
*Check as appropriate:*
  - ( ) SIRG is holding funds
    - a. Amount of funds held by SIRG as June 1, 2006
    - b. Name and address of bank or institution holding funds
    - c. Name of person responsible for maintenance and disbursement of funds
    - d. Name of person(s) responsible for auditing disbursement and receipt of funds
    - e. Date of last audit of funds (i.e., review of bank statement by responsible SIRG officer)
  - ( ) SIRG is not holding any funds
  - (X) IASSID is holding SIRG funds
    - a. Amount of SIRG funds held by IASSID as of June 1, 2006  
  
\$1085.00, as reported by Dr Janicki
5. If the person responsible for managing the funds will change during 2006-07, please provide name of the new person responsible for funds
6. Please list sources of income for the SIRG
  - (X) SIRG dues collected by IASSID and SIRG
  - ( ) Revenue from Roundtable and/or other meetings
  - ( ) Donations
  - ( ) Grants, awards, etc.

**Please submit via email (in email or as attached file) or via fax (+1 207 236 8070) by July 10, 2006**

6/10/06+

## IASSID SIRG Financial Statement

Please provide the following information by July 10, 2006

1. Name of SIRG **Health**

2. Name of person completing report

**Vee Prasher**

3. Contact information of person completing report

- a. Postal address **Greenfields, Monyhull, Kings Norton, Birmingham Uk b30 3QQ**
- b. Telephone & Fax **0044 121 449 2293**
- c. Email **vprasher@compuserve.com**

4. Statement of Holdings

*Check as appropriate:*

SIRG is holding funds

- a. Amount of funds held by SIRG as June 1, 2006 \$3621.00
- b. Name and address of bank or institution holding funds NatWest Bank Kings Heath Birm
- c. Name of person responsible for maintenance and disbursement of funds vprasher
- d. Name of person(s) responsible for auditing disbursement and receipt of funds vprasher/mike kerr
- e. Date of last audit of funds (i.e., review of bank statement by responsible SIRG officer)

jan 2006

SIRG is not holding any funds

IASSID is holding SIRG funds

- a. Amount of SIRG funds held by IASSID as of June 1, 2006

5. If the person responsible for managing the funds will change during 2006-07, please provide name of the new person responsible for funds

6. Please list sources of income for the SIRG

- SIRG dues collected by IASSID and SIRG
- Revenue from Roundtable and/or other meetings
- Donations
- Grants, awards, etc.

**Please submit via email (in email or as attached file) or via fax (+1 207 236 8070) by July 10, 2006**

## IASSID SIRG Financial Statement

Please provide the following information by July 10, 2006

1. Name of SIRG  
Mental Health
2. Name of person completing report  
Tom Cheetham
3. Contact information of person completing report
  - a. Postal address Queen's University Department of Family Medicine  
Rideau Regional Centre  
PO Box 2000  
3312 County Road # 43 East  
Smiths Falls, Ontario, Canada K7A4T7
  - b. Telephone 613-284-0123 ext 2377  
Fax 613-284-0669
  - c. Email cheetham@post.queensu.ca
4. Statement of Holdings  
*Check as appropriate:*
  - ( ) SIRG is holding funds
    - a. Amount of funds held by SIRG as June 1, 2006
    - b. Name and address of bank or institution holding funds
    - c. Name of person responsible for maintenance and disbursement of funds
    - d. Name of person(s) responsible for auditing disbursement and receipt of funds
    - e. Date of last audit of funds (i.e., review of bank statement by responsible SIRG officer)
  - ( ) SIRG is not holding any funds
  - (X) IASSID is holding SIRG funds
    - a. Amount of SIRG funds held by IASSID as of June 1, 2006 US \$ 2090
5. If the person responsible for managing the funds will change during 2006-07, please provide name of the new person responsible for funds  
N/A
6. Please list sources of income for the SIRG
  - (X) SIRG dues collected by IASSID and SIRG
  - ( ) Revenue from Roundtable and/or other meetings
  - ( ) Donations
  - ( ) Grants, awards, etc.

**Please submit via email (in email or as attached file) or via fax (+1 207 236 8070) by July 10, 2006**

## **Report on the SIRG *Profound Intellectual and Multiple Disabilities (PMD) 2005-2006***

### **Board**

The SIRG PMD board is constituted as follows:

Chair : Loretto Lambe (UK) and Carla Vlaskamp (NL)  
Chair elect and secretary : Bea Maes (Bel)  
Treasurer : vacancy , (seat temporarily taken over by Bea Maes)  
Past chair : Han Nakken (NL)

Members:

- Mary Arnold (USA)
- Anne Brown (UK)
- Care Fabila (Mex)
- Barbara Fornefeld (Ger)
- Mats Granlund (Swe)
- Paul Pagliano (Aus)
- Knut Slåtta (No)
- Jenny Whinnet (UK)
- Sui Sone (Japan)

### **Activities June 2005 –June 2006.**

#### ***Terminology***

Although in the 12<sup>th</sup> World Congress of 2004 there was an impressive number of presentations on planning, executing, and organizing education, health care, and support for individuals with ‘PMD’, it was not absolutely clear, if the speakers were talking about the same ‘group’ of persons. As a number of different terms were used to describe the target group, it may very well be that different (sub)groups were being referred to. This brings us to the urgency for an international agreement on a general accepted classification, which will facilitate communication and prevent misunderstanding. As the term Profound Intellectual and Multiple Disabilities is the term most widely used and accepted, we decided to favor this term over the term Profound Multiple Disabilities.

#### ***Round Table***

A Round Table invitational conference was held in Brugge, Belgium, in October 13-15 th. Two broad topics were chosen as key topics for the conference:

- (1) quality of service provision and support in community services and families, with special attention to staff attitudes, skills, working methods and training
- (2) procedures and evaluation of educational and developmental programs and activities and of (pseudo)treatment programs and methods

As part of the Invitational conference, which was attended by members from the UK, Scotland, Sweden, Ireland, Japan, Germany, Belgium and the Netherlands, the

contribution of our SIRG to the 2nd European IASSID-conference at Maastricht (the Netherlands) was discussed. As the program committee had already decided that there will be 4 symposia under the theme 'PMD', topics and our contribution was discussed. Convenors were designated for each symposium. In each symposium there will be 4 presentations.

### ***Newsletter***

In the beginning of 2006, our sixth Newsletter was sent to all our members. The newsletter also included the request to fill in a so-called 'membership card'. The members were also brought up to date on the development of a website.

### ***Web-site / E-mail***

The SIRG information can be found on the web-site of the IASSID under [IASSIDoffice@aol.com](mailto:IASSIDoffice@aol.com), SIRG, Profound Multiple Disabilities. The information on this web-site has recently been revised.

Next to the information on the IASSID website, another website is up and running, on <http://www.sirgpmdb.be>. On this website, our 'mission statement' can be found. An important part of this website is the 'membership card'. With these cards, vital information on members is gathered and can be used to facilitate contact between members. In the sections 'announcements' and 'reports', information on e.g. recent research projects is stated. This website needs further development but will hopefully grow to an interactive site that can run next to the regular IASSID website.

### ***International Masters***

Members from the Netherlands, Belgium, Germany and Scotland have started an initiative on the development of an International Masters. After initial contact by e-mail, a meeting was organized in Cologne, Germany, in March 2006. It was decided upon that we would start with the development of preliminary modules. The group will meet again in August 2006.

### ***Colloquium for young researchers***

At the round table conference, a suggestion came forward to organize a colloquium for young researchers. This idea has been worked out steadily but surely by Colin Griffiths in close cooperation with some board members. Arrangements have now been made, and the colloquium will be held in August 1<sup>st</sup>-2<sup>nd</sup> at Maastricht.

### **Financial Statement**

The report on the financial statement was completed by Bea Maes. This report is attached.

Groningen, 3<sup>rd</sup> July  
Carla Vlaskamp, chair.  
Bea Maes, secretary and treasurer.

**Attachment: Financial Statement**

Name of SIRG: Profound Intellectual and Multiple Disabilities (PMD)

Name of person completing report: Bea Maes

Contact information of person completing report:

University of Leuven, Vesaliusstraat 2, 3000 Leuven, Belgium

Tel. 00-32-16326224 Fax 00-32-16325933

[Bea.Maes@ped.kuleuven.be](mailto:Bea.Maes@ped.kuleuven.be)

Statement of Holdings

SIRG is holding funds

SIRG is holding 212,55 € on June 1, 2006

KBC Bank Steenokkerzeel, Van Frachenlaan 9, 1820 Steenokkerzeel,

Belgium

Bea Maes

SIRG is not holding any funds

IASSID is holding SIRG funds

IASSID is holding 360 US\$ on June 1, 2006

5. If the person responsible for managing the funds will change during 2006-07, please provide name of the new person responsible for funds.

6. Please list sources of income for the SIRG

SIRG dues collected by IASSID and SIRG

Revenue from Roundtable and/or other meetings

Donations

Grants, awards, etc. – Fund by the Flemisch Fund for Scientific Research for the organisation of the 2<sup>nd</sup> Roundtable of the SIRG in Bruges.

**Parenting SIRG  
Treasurer's Report  
July, 2006**

<i>Date</i>	<b>Income Source</b>	<i>Amount</i>	<i>Date</i>	<b>Expenditures Purpose</b>	<i>Amount</i>	<b>Balance</b>	<b>Balance Forward</b>
2003	Dues	\$160	None	NA	0	\$160	\$160
2004-2005	Dues	\$280	None	NA	0	\$440	\$440
2006	Dues	\$220	None	NA	0	\$660	\$660

## **IASSID Financial Report for Quality of Life SIRG**

1. Name of SIRG:

Quality of Life

2. Name of person completing report:

Ralph Kober

3. Contact information of person completing report

a. Postal address:

Department of Accounting and Finance  
The University of Auckland Business School  
Private Bag 92019  
Auckland  
New Zealand

b. Telephone & Fax:

Telephone: +64 9 373 7599 ext. 87174  
Fax: +64 9 373 7406

c. Email:

r.kober@auckland.ac.nz

4. Statement of Holdings

Check as appropriate:

() SIRG is holding funds

a. Amount of funds held by SIRG as June 1, 2006:

US \$1,060

b. Name and address of bank or institution holding funds:

IASSID managing funds on behalf of SIRG as I am based in New Zealand

c. Name of person responsible for maintenance and disbursement of funds:

Ralph Kober in liaison with Mat Janicki

d. Name of person(s) responsible for auditing disbursement and receipt of funds:

No disbursements to date.

e. Date of last audit of funds (i.e., review of bank statement by responsible SIRG officer):

No audit to date of SIRG funds

5. If the person responsible for managing the funds will change during 2006-07, please provide name of the new person responsible for funds:

Treasurer for SIRG will not change during 2006-07.

6. Please list sources of income for the SIRG

- SIRG dues collected by IASSID and SIRG
- Revenue from Roundtable and/or other meetings
- Donations
- Grants, awards, etc.

Please submit via email (in email or as attached file) or via fax (+1 207 236 8070) by  
July 10, 2006



# Journal of Policy and Practice in Intellectual Disabilities

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

## Editor-in-Chief

Matthew P. Janicki, Ph.D.  
P.O. Box 870  
Rockport, ME 04856  
USA

Report to Council

Matthew P. Janicki, Ph.D.

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● 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 third year and doing well with respect to subscriptions, submissions and maintaining publication schedules.

● During 2006 . . .

- we switched over to electronic manuscript submission with Manuscript Central (Scholar One).
- we have prepared three issues, two of which are in print, and one in proof stage. The final issue will be a special issue of family services practices currently being collated by Dr. Roy Brown of the University of Victoria.
- received listing in PsycINFO, the American Psychological Association's indexing service.
- we continued our Editorial Board and all members have indicated a desire to continue.
- we obtained the editorial assistance services of Jenny Emma Hall, who works with JPPID as an independent contractor
- we meet with Blackwell Publishing staff in Malden several times to coordinate JPPID publication and marketing activities and meet new staff. In March, Amanda Martinez, a new editor, was assigned to JPPID

- During 2007 . . .
  - Blackwell intends to apply to the major indexing services for listing JPPID (Medline, etc) – a journal has to be in regular publication for three years before it it can be referred for indexing.
  - Several special issues have been organized and will appear as the publication schedule permits (e.g., on multiple and profound intellectual disabilities, social policy).