



International Association  
for the Scientific Study  
of Intellectual Disabilities

# Council Meeting

August 25, 2008

CTICC- Green Room

Cape Town, South Africa

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**IASSID Council Meeting  
Monday, May 28, 2007  
Paris, France**

Attendees: D. Felce (Chair), G. Murphy, M. Janicki, N. Ross, A. Holland, S. Kealy, P. Noonan Walsh, H. Lantman, V. Timmons (Recorder), G. Albertini, M. Bjorkman, J. Blacher, P. Davidson, R. Davis, I. Duvdevany, F. Fabrizio, T. Heller, S. Hollins, M. Kerr, J. Levy, M. Malbran, H. Ouellette-Kuntz, F. Strutz, M. Verdugo,

Regrets: R. Hastings, G. Jesien, U. Jacobson, K. McVilly, H. Reinders, S. Suemitsu, C. Vlaskamp, L. Wang

1. Approval of Minutes: S. Hollins was present at the last Council. Minutes will be adjusted accordingly. Council approved minutes of August 2005 Council meeting.

Matters Arising from Minutes:

- i. There was a subcommittee to be established to look at sponsorship for the Capetown conference.
  - ii. FAQs are on the website.
  - iii. There is still a need to appoint a liaison person to link with research centres and associations
  - iv. V. Timmons, H. Ouellette-Kuntz and K. McVilly will develop a document for the website for new members
  - v. G. Albertini will explore sponsorship for the Santiago conference
  - vi. G. Albertini spoke to a representative from the Child Neurology Association and they are interested in developing links with IASSID. G. Albertini will set up a formal meeting with D. Felce.
  - vii. European conference was successful and appreciation for a job well done was extended to H. Lantman.
  - viii. M. Janicki, while in Japan, met with S. Suemitsu. He asked that K. Otami be the correspondent for issues related to IASSID and the Japanese Association. The Association also agreed to send a delegation to Capetown and expressed an interest in hosting the 2013 IASSID Asian Pacific conference. D. Felce and G. Murphy followed up with letters.
2. Approval of Agenda: Council approved
  3. President's Report: The President's Report (in package) was presented by D. Felce. S. Kealy moved to accept the President's Report and J. Levy seconded it. Council approved.
    - a) J. Blacher volunteered to approach the Gates Foundation on sponsorship for Capetown. G. Murphy will draft a proposal and forward to J. Blacher.

R. Davis recommended approaching Rotary International for scholarship sponsorship. G. Murphy will followup.

4. Treasurer's Report

- a) Finance Committee Report: M. Janicki presented the report to Council.
- i. D. Felce asked how the distribution of funds to SIRGs was working. P. Davidson indicated no problem with the distribution from the Aging SIRG perspective. R. Davis indicated that there was no problem with the Health SIRG. There are legacy funds held for some SIRGs and Affinity Groups. SIRGs have to request the funds. M. Kerr indicated that SIRGs may not know they have to request transfer of funds. H. Lantman will notify SIRGs that the funds are available if needed for their activities.
  - ii. M. Janicki included a report on IASSID Comparable Financials 2001-2007. There was a discussion around the rising expenses. The Executive has increased to nine members and there is an additional meeting outside Council meetings. M. Kerr suggested that we review the expenses and look at savings.
  - iii. M. Janicki presented seven recommendations.
    - a. D. Felce highlighted the importance of increasing membership. M. Janicki indicated that we should look at increasing membership from North America.
  - iv. D. Felce thanked M. Janicki for his report. N. Ross proposed acceptance of the Treasurer's Report and J. Levy seconded. Council approved.
- b) Membership Committee Report: Received and approved. Council members agreed to focus on certain regions to promote membership.
- i. J. Levy: Caribbean
  - ii. M. Malbran: South America
  - iii. M. Bjorkman: Scandinavia
  - iv. L. Wang: Asia Pacific

5. Secretary's Report:

There was a suggestion to use the website more often. Notification to members of the website updates would be helpful. The newsletter works well and the information on the Council meeting is well organized. V. Timmons asked Council members to respond to E. Cardy's requests for information in a timely manner.

6. Conferences:

a) 2007 IASSID Sudamerica:

P. Noonan Walsh provided an update on the Santiago conference planning, now scheduled for September 5-6, 2007. She distributed a draft flyer. There are negotiations being undertaken with 'First Team', an event planner in Chile. D. Felce complimented the IASSID team on their work facilitating the event.

b) 2008 Congress:

G. Murphy provided an update. Comments on the proposed program are to be forwarded to G. Murphy by June 2007. There was a discussion on additional potential speakers:

- i. T. Heller will e-mail G. Murphy a name of a speaker on HIV and M. Kerr will send a name for a speaker on health.
- ii. J. Blacher has a name for a speaker from the Gates Foundation and the head of the CBC. She will forward the names to G. Murphy.
- iii. J. Howes, the Executive Director at the March of Dimes was also suggested. J. Levy knows her well and will e-mail G. Murphy the contact information.
- iv. J. Levy stressed the need to connect with other international organizations that deal with ID.
- v. S. Hollins recommended Mary Kay Smith who works in Zambia on HIV.

G. Albertini recommended that there be courses attached to the conference. G. Murphy asked for volunteers for the pre post conference workshops and she will connect them to the people organizing the event. Pre /post conference workshops will be at another venue. C. Vlaskamp has drafted a letter to the SIRGs asking for suggestions for the pre/post conference sessions.

SIRGS have been asked to develop and submit symposiums. G. Murphy e-mailed SIRGs over a year ago requesting submissions. G. Murphy will be sending out another e-mail asking SIRGs to propose symposiums.

J. Levy recommended that African universities be contacted. The African Association of Universities will be a great resource.

N. Ross showed the logo for the Capetown conference.

## c) 2009 Asia-Pacific:

M. Janicki and L. Wang met with the local organizing committee from Singapore (along with K. McVilly via SKYE) in February 2007; the planning is proceeding well and there is organization in place to help manage the conference. The event will take place in June 2009. There will be a follow-up planning meeting in Bangkok, November 2007.

## d) 2010 Europe (Rome):

G. Albertini and F. Fea have agreed to organize the IASSID Europe regional conference in Rome in 2008. Tosinvest has a new building and if the conference is in September it may be available and thus reduce the costs. A member from the Executive will be assigned to this local organizing committee.

7. SIRG Coordination:

H. Lantman reported that the SIRG Coordination committee agreed to a reduced number of SIRGs. The committee recommended a sub committee be established to oversee the reduced SIRG formulation and transition. There is interest in synchronizing SIRG elections.

## D. Felce thanked the SIRG representatives on their reports:

T. Holland (Mental Health SIRG). He reported that he feels this SIRG is struggling. He needs to find people with time to commit to the SIRG.

J. Blacher (Family SIRG).

P. Davidson (Aging SIRG). They are meeting on May 31 and June 1 for their 16<sup>th</sup> Roundtable in Oslo, Norway. There are 40 persons from outside of Norway attending as well as a number of persons from Norway.

Parent and Parenting. Sent in report.

Comparative Policy and Practice. Sent in report.

M. Kerr (Health SIRG). They met in Prato, Italy on May 21-22. There were 56 attendees and the meeting went well.

Quality of Life SIRG. A Roundtable is planned for San Diego, California in the USA for December 2007.

8. JPPID Editor's Report:  
M. Janicki reported that the Association's journal is now in its fourth year and that there is a steady rate of new submissions of manuscripts. Jenn Hall, the editorial associate is doing an excellent job of providing support and Blackwell is in the process of applying to a number of abstracting and vetting organizations on behalf of the journal to ensure that its impact factor is considered in the fifth year.
9. Website Report:  
N. Ross distributed a report on the website. A consultant was secured to assist IASSID with reskinning the website. The reskinning and maintenance for the year, will cost 10 000 Euros. The report has 9 recommendations that Council supported. We have increased from 400 to 9000 hits per month.
10. Publications Committee:  
T. Holland reported on publications. There was a discussion on how to generate more interest in books among editors and authors. There are guidelines for authors and editors on the website. The committee recommended actively encouraging SIRGs to look at IASSID endorsement of books.
11. Paper on IASSID Development  
D. Felce summarized the key points of the paper he wrote on Development of IASSID as a Member Organization. There was a discussion on the composition and representation of the Council.
- D. Felce recommended a working group be established consisting of V. Timmons, H. Ouellette-Kuntz, S. Hollins, and K. McVilly to deal with benefits package, and a proposal to increase membership. Council accepted. H. Ouellette-Kuntz will lead this working group.
- D. Felce recommended a working group of representation of the 9 SIRGs and H. Lantman lead the group to consider the recommendation pertaining to SIRGs in D. Felce's working paper. M. Janiki will serve as a resource to the group. A report should be presented to Council by 2010.
- Questions to consider:  
Which SIRGs should continue to exist or which new ones are needed?  
What representation should SIRGs have on Council?

What is their relationship to regional conferences and Congresses?  
 Should there be consistency in by laws among SIRGs?  
 How to facilitate cross SIRG collaboration?

The next Council 2008-2012 will be formed based on the current bylaws and procedures. The Council recommends that the editors of JPPID and JIDR, and the webmaster be represented on Council. IASSID by laws will to be revised to reflect this.

The above actions were moved by B. Davis and seconded by N. Ross. Council agreed.

12. Constitutional Issues

- a) Awards: A call will go out in September 2007 with a submission date in March, 2008 and decision in April 2008. There can only be one awardee per award. The process will be typed up and distributed. There was a discussion around paying expenses for awardees. In the future the award selection could be conducted a year before the Congress and therefore the awardee could be a plenary speaker. For 2008 IASSID will cover up to 12 000 Euros for awardee travel costs. 11 voted in favour, 7 disagreed. Motion passed.
- b) General Assembly: There is some organizational preparation necessary for the General Assembly meeting at Capetown. S. Kealy will take responsibility for this.

13. Policy of Para Olympics:

J. Mulder wrote a report on Para Olympics and the 2008 Beijing Para Olympic Game which was attached to the Council report. N. Ross, on behalf of IASSID, will write a letter in support of the inclusion of people with intellectual disabilities in Para Olympic games and the letter will indicate that a process that ensures people who wish to compete have an intellectual disability can be established.

14. The Academy:

A report was attached for Council's information. The Academy is under development and the Academy will be a group that will vet course content and bring forward recommendations to Council. All training should be based on evidence based practice. R. Brown, Academic chair, to be informed that F. Strutz and J. Levy will be added to the Academic Board to represent Council.

15. Other Business:

An agreement has been developed with Alzheimer's Disease International (ADI) and IASSID. T. Holland moved and P. Davidson seconded that Council approve the agreement. Motion passed.

F Fea recommended the establishment of a working relationship between the European Association of Service Providers and IASSID. D. Felce recommended that F. Fea work with N. Ross and M. Janicki to develop a draft of a similar agreement to ADI.

G. Albertini recommended that we consider changing the name of IASSID to include development disabilities. Tabled.

**Next Council Meeting August 25<sup>th</sup>, 9:00 am to 14:00** Capetown, South Africa.

Meeting adjourned by D. Felce at 16:35 pm.

**Agenda**  
**IASSID COUNCIL MEETING**  
**Monday, August 25, 2008**  
**9:00 – 15:00 hrs.**  
**CTICC – Green Room, Cape Town**

1. Commencement and Roll Call
2. Previous Minutes and Matters Arising
3. President's Report
4. Treasurer's Report
5. Secretary's Report
6. Officers for the 2008-2012 Term
7. Bids for the 2012 World Congress
8. Awards and General Assembly
8. SIRG Reports
9. Conference reports
  - 2008 Congress
  - 2009 Asia – Pacific
  - 2010 Europe
10. Other Business

**Council Dinner** - Wednesday, August 27 19:30 – 22:00 hrs.

Nyonis Kraal, 98 Long Street in Cape Town City Centre.  
Telephone (021) 422 0529 / 0525

See [www.nyoniskraal.co.za](http://www.nyoniskraal.co.za)

They are doing a buffet (click on buffet to see menus).

**Report of (*Executive Officer Title*)**  
**IASSID Council Meeting**  
August, 2008

**Summary of Past Year Activities**

*Preparation for the Cape Town World Congress.*

This involved an enormous amount of work: I had over 4,000 emails about the conference, over 3,000 of these being about the abstracts themselves. Basically I have spent two or three days a week on it every week from December 07 til now (mid-August), and quite often have had to spend weekends on it too. I have had two helpers: Nell Ellison who is a psychology graduate and Trish Barton who is a secretary in the Tizard centre. Neither was available full-time but they probably also spent an average of two days per week for 4 or 5 months on it each.

We learnt a great deal about what to do and what not to do and I will put this in writing for the next World Congress team.

In brief: we found **what worked well** was:

- Writing our own simple instructions for abstracts (which went on our IASSID web site)
- Receiving the abstracts directly to us over the email as an attached word document
- Rating them as acceptable/not (by the executive meeting in Cambridge in January)
- Pasting them into the abstract book in word and then formatting them
- People who submitted no more than 1 – 4 abstracts each
- People who organized pre-prepared symposia ie. gathered 3 authors/abstracts together
- SIRG chairs who prepared their theme's mini abstract book once I sent them all the abstracts (with varying amounts of structure)
- Having CMC complete the registration etc for us (but the price for this was high!)
- Having pre-conference workshops (but we need to discuss this at more length later)

What **did not work well** was:

- People ignoring instructions for submitting abstracts (possibly due to CMC's contradictory instructions), so they had to be returned to them – eg. no sub-headings, no title, no author email address, no stated theme, etc, etc
- People having email addresses like [snowleopard@hotmail.com](mailto:snowleopard@hotmail.com) that bore no relation whatsoever to their name
- Having the Conference Management Centre write an inflexible form for the abstracts that could not be easily pasted into word document for the abstract book
- Having the CMC submit these to me electronically on their system (only about 1/3 arrived, though they claimed they could find no fault)

- People submitting e.g. 8 abstracts (very easy for us to get muddled and very hard to stop them clashing in the programme)
- Saving abstracts into separate themes – this sometimes meant they were saved more than once in more than one theme (eg where the author wasn't sure of the theme), so that we later had to prune abstracts out that were repeated
- People changing their minds about what they had submitted (even in August!)
- People withdrawing after their abstract had been accepted
- People telling us they could only be here for one or two days – meaning we had to schedule their paper on a particular day
- The separately bookable Saturday plenaries (less than 10 extra people booked in)

Overall we had nearly 900 abstracts submitted. We have about 800 delegates coming to the conference. This is far fewer than in Montpellier (1500 approx) and we are not sure why (Effect of electronic advertising? Credit crunch? Weak dollar? Long distance? Nervous delegates?).

Budget-wise we feel we have been charged a very high price for the venue and for the audio-visual requirements. We have learnt our lesson from this as you will see when we discuss the venue for the next World Congress.

### **Plans for Upcoming Year**

To have a quiet period for at least a month!

### **Issues or Acting Items**

Budget still to be completed of course but likely we will make no profit at all

### **Discussion Points for Council**

We need to discuss:

- What we want to do differently next time in advertising; abstract submission, etc ?
- Do we want a dedicated conference team ourselves (in IASSID)? – now we are doing a conference every year
- Do we want pre-conference workshops?



# International Association for the Scientific Study of Intellectual Disabilities

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## Report on Membership - 2008

### 1. Individual Memberships

As of the end of July 2008, there are 564 active individual members, an increase of 135 over 2007. In 2007 we had 429 paid or otherwise recognized active individual members in good standing with IASSID, a decrease of 79 members from 2006. In 2006 we had 464 members, in 2005 we had 517 members, and in 2004 we had 763 members. In 2003, we had 487 members (an increase of 64% over the number in 2002). In 2002 we had 370 members

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

The statistics for individual members are shown below.

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

### 2001-2008 Member Stats

In 2001 we had 356 members	
In 2002 we had 370 members	(14 additional members)
In 2003 we had 487 members	(117 additional members)
In 2004 we had 763 members	(276 additional members)
In 2005 we had 517 members	(246 loss of members)
In 2006 we had 464 members	(53 loss of members)
In 2007 we had 429 members	(35 loss of members)
In 2008 we have 564 members	(135 additional members)

## 2003-2008 Member Category Stats<sup>1,2</sup>

Year	FU1	FU2	AS	ST/SJ	AM	RC	Other
2003	383		34	17	9	-	-
2004	481		26	25	13	-	-
2005	154	275	3	9	10	-	-
2006	95	285	-	3	11	-	5
2007	75	243	-	17	4	39	7
2008	190	262	-	44	9	32	22

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

<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 (approximations)

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>2008</b>	478 - 88.4%	63 - 11.6%	0	0
<b>2007</b>	318 - 87.0%	44 - 12.0%	0	4 - 1.0%
<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 - 2007

	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
<b>2008</b>	57.6% <sup>a</sup>				18.5%	4.1%	6.8%	8.6%	4.3%
<b>2007</b>	5.0%	18.8%	46.3%	25.9%	10.6%	1.6%	10.9%	2.5%	.01%
<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. In 2006-07, we endeavored to stimulate membership payments early in the last quarter of 2006 and this resulted in a bump-up in November and December. In January we sent out a mailing to all members who had not renewed resulting a slight bump in March 2007.

☞ Wiley-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 Wiley-Blackwell and increase our workload. We begin sending out electronic reminder notices to pay dues in September and continue sending them to those members who have not renewed (only a small number of non-renewing members reply that they will not be renewing). We only send paper notices to those members without email or whose email addresses have proved faulty.

<sup>a</sup> All memberships from September to December were processed in December

### Payment Forward

11 are paid to end of 2009

### JIDR Subscribers

287 had paid for the JIDR for 2002  
 350 had paid for the JIDR for 2003  
 516 had paid for the JIDR for 2004  
 319 had paid for the JIDR for 2005  
 306 had paid for the JIDR for 2006  
 246 had paid for the JIDR for 2007  
 268 have paid for the JIDR for 2007

### JPPID Subscribers

7 had paid for JPPID for 2004  
 616 were given gratis subscriptions for 2004<sup>6</sup>  
 478 had JPPID included in their membership fee for 2005  
 443 had JPPID included in their membership fee for 2006  
 361 had JPPID included in their membership fee for 2007  
 501 have JPPID included in their membership fee for 2008

## **2. Association Memberships**

Currently, we have **15** paid up Association members and **22** which have not paid. In 2007, we had **5** national associations as paid-up members and **30** which have not paid. In 2006, we had **17** national associations as paid-up members and **16** which had not paid for 2006. In 2005 we had **20** national associations with paid-up status, and **14** national associations which had not paid their assessment. In 2004, we had **25** national associations maintain affiliative status with IASSID, representing 19 nations (with three associations' dues payments pending - representing 2 additional nations). In 2003, we had **21** national associations maintain affiliative status with IASSID, representing 15 nations.

Payment of association membership dues has improved in 2008, with only 22 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**

Currently, we have **44** paid up Research Centers, and **35** which have not yet renewed. In 2007, we had **44** paid-up Research Centers, and **35** which had not renewed. In 2006, we had **49** paid-up Research Centers, and **12** which had not renewed. In 2005 we had **36** paid-up Research Centers and **20** which did not renew. In 2005, of paid-up Centers, 19 were in Europe, 12 in North America, and 5 in Asia/Pacific. In 2004, we had **45** (29 were in Europe, 5 in Asia-Pacific, and 12 are in North America). In 2003, we had **32** institutes, university departments, foundations, and other staff-based organizations classified as IASSID research center members.

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

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

Submitted 25 August 2008  
M.P. Janicki  
Membership Committee Chair

☺

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

**Name of Organization**

A.P.A.E.  
American Association on Intellectual & Developmental Disabilities  
Association of University Centers on Disabilities  
BILD - British Institute of Learning Disabilities  
Canadian Association for Research & Education in Intellectual Disabilities  
Deutsche Interdisziplinäre Gesellschaft zur Förderung der Forschung für Menschen mit geistiger Behinderung e.V.  
Down Syndrome Association (Singapore)  
Down Syndrome Association of Nigeria  
G. Allen Roeher Institute  
Inclusion Ireland  
Polish Association for Persons with Mental Handicap  
SIRM - Italian Society for the Study of Mental Retardation  
South African Association for the Scientific Study of Mental Handicap  
Special Education Association of Taiwan  
Svenska Lakarforeningen för Omsorgs - och Handikappmedicin

**Appendix B****Paid-up Staff-Based Research Centers and Organizations****Name of Center**

Academic Department of Psychiatry of Disability  
Aging & Health Centre for Research, Education & Service Development for Aging People w/ID  
Akademia Pedagogiki Specjalnej im. Marii Grzegorzewskiej  
Australian Family & Disability Studies Research Collaboration  
Beach Center on Disability  
Beit Issie Shapiro Research Center  
Center for Social Development and Education  
Centre for Disability Studies  
Centre for Developmental Disabilities Studies  
Centre for Developmental Disability Health Victoria  
Department of Psychiatry and Mental Health  
Department of Disability & Human Development  
Department of Experimental Psychology  
Disability Study Unit  
Division of Disability Studies  
Donald Beasley Institute  
Down Syndrome Educational Trust  
Down Syndrome Research Foundation  
Fundacion ITINERIS  
Institute of Special Education & Rehabilitation  
Institute on Community Integration  
Istituto APAE  
Lebenshilfe Visakhapatnam  
Matheny Institute for Research in Developmental Disabilities  
Mental Health Foundation  
MINDS  
National Institute of Education  
National Institute of Child Health and Human Development  
Norah Fry Research Centre  
Open Doors for Special Learners  
Physiotherapy Department  
Research Department COPE Foundation  
San Raffaele Pisana Clinic  
School of Medicine, Health Policy & Practice  
School of Health and Rehabilitation Sciences  
Specialist Physician Training in Intellectual Disabilities  
Strong Center on Developmental Disabilities

The Glasgow U.A.P.  
Tizard Centre  
UH-Manoa Center on Disability Studies  
Uliazpi Fundazioa  
University of Queensland  
Waisman Center  
Young Adult Institute, Inc.

## Appendix C

### Staff-Based Research Centers and Organizations (From Website)

[AFRICA](#)  
[EUROPE](#)  
[NORTH AMERICA](#)  
[SOUTH AMERICA](#)  
[ASIA-PACIFIC](#)  
[MIDDLE-EAST](#)

#### AFRICA

RC-070  
Department of Psychiatry and Mental Health  
Western Cape Forum for Intellectual Disability  
University of Cape Town  
Groote Schuur Hospital  
Observatory, 7925 Western Cape Province  
South Africa  
Contact: Dr. Christopher D. Molteno ([molteno@curie.uct.ac.za](mailto:molteno@curie.uct.ac.za))

RC-072  
School of Health and Rehabilitation Sciences  
Division of Occupational Therapy  
University of Cape Town  
F45 Old Main Building  
Groote Schuur Hospital  
Observatory, 7925, Western Cape Province  
South Africa  
Contact: Ms. Amshuda Sayed([amshuda.sayed@uct.ac.za](mailto:amshuda.sayed@uct.ac.za))

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

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

#### EUROPE

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

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

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

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

RC-010  
Centre for Disability Studies  
National University of Ireland Dublin  
Room D004B, JHN Building  
Belfield Dublin Ireland 4  
Contact: Prof. Patricia Noonan Walsh ([patricia.walsh@ucd.ie](mailto:patricia.walsh@ucd.ie))  
<http://www.ucd.ie/uip/directory/csdd.html>

RC-011  
Institute on Community Integration  
Faculty of Psychology  
University of Salamanca  
Avda. De la Merced, 109-131  
Salamanca SPAIN 37005  
Contact: Dr. Miguel Angel Verdugo Alonso ([inico@usal.es](mailto:inico@usal.es))

[www.usal.es/inico/inico/html](http://www.usal.es/inico/inico/html)

Research/focal topics: quality of life, supported employment, self determination, aging, school inclusion

RC-014

Governor Kremers Centrum  
c/o BEOZ  
University of Maastricht  
PO Box 616  
NL-6200 Maastricht, The Netherlands  
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R-016

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Contact: Mandy Twyman ([m.s.twyman@ukc.ac.uk](mailto:m.s.twyman@ukc.ac.uk))  
[www.ukc.ac.uk/tizard](http://www.ukc.ac.uk/tizard)

RC-017

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St. George's Hospital Medical School  
University of London  
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London England SW17 0RE  
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[www.intellectualdisability.info](http://www.intellectualdisability.info)

RC-018

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Callan Road  
Kilkeny, Ireland  
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[www.jwolfeassociates.com](http://www.jwolfeassociates.com)

RC-020

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

RC-021

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Tosinvest Sanità  
235, Via della Pisana  
Rome, Italy 11063  
Contact: Giorgio Albertini ([giorgio.albertini.giorgio@sanraffaele.it](mailto:giorgio.albertini.giorgio@sanraffaele.it)) or  
Carla Albertini ([carla.albertini@sanraffaele.it](mailto:carla.albertini@sanraffaele.it))  
[www.sanraffaele.it](http://www.sanraffaele.it)

RC-022

Research Department  
COPE Foundation  
Bonnington

Montenotte Cork Ireland  
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RC-023  
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University of Glamorgan  
School of Care Sciences  
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Pontypnnd Wales CF37 4BS  
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<http://udid.weblog.glam.ac.uk>

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

RC-027  
The Glasgow U.A.P.  
Section of Psychological Medicine  
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Academic Centre  
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1055 Great Western Road  
Glasgow Scotland G12 0XH  
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[www.gla.ac.uk/departments/psychologicalmedicine/index.html](http://www.gla.ac.uk/departments/psychologicalmedicine/index.html)

RC-029  
School of Medicine, Health Policy & Practice  
Institute of Health  
University of East Anglia  
School of Medicine  
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RC-030  
Institute of Special Education & Rehabilitation  
Faculty of Philosophy in Skopje  
University "St. Cyril and Methodius"  
Bull. Krste Misirkov b.b.  
Skopje, Macedonia 1000  
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<http://www.fzf.ukim.edu.mk/en/defektologija/index.htm>

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<http://www.lancs.ac.uk/fass/ihr/>

RC-033

Foundation for People with Learning Disabilities  
Sea Containers House  
20 Upper Ground  
London, England SE1 9QB  
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[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

RC-034

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Bangor, Gwynedd, Wales LL57 2AS  
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RC-036

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Stewarts Hospital Services, Ltd.  
Palmerstown  
Dublin 20 Ireland  
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RC-037

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3 Priory Road  
Bristol, England BS8 1TX  
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RC-039

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Portuetxe 53B  
Local 112  
Donostia San Sebastián Gipuzkoa Spain 20018  
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RC-041

Specialist Physician Training in Intellectual Disabilities  
Erasmus MC Department for General Practice  
Room FF 326  
P.O. Box 1738  
3000DR Rotterdam The Netherlands  
Contact: Fran Ewals ([avgopleiding@erasmusmc.nl](mailto:avgopleiding@erasmusmc.nl))  
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RC-042

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

RC-043  
White Top Research Unit  
University of Dundee  
White Top Research Unit  
Springfield House  
15/16 Springfield  
Dundee, Scotland DD1 4JE  
Contact: Prof. James Hogg ([j.h.hogg@dundee.ac.uk](mailto:j.h.hogg@dundee.ac.uk))

RC-046  
Special Education Department  
St. Patrick's College  
Drumcondra  
Dublin 4 Ireland  
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RC-047  
Development and Intellectual Disability Team  
University of Edinburgh  
School of Education  
Holyrood Road  
Edinburgh, Scotland EH8 8AQ  
Contact: Dr. Katie Williams ([katie.williams@ed.ac.uk](mailto:katie.williams@ed.ac.uk))  
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RC-048  
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2 Hay's Lane  
London England SE1 2HB  
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[www.scie.org.uk](http://www.scie.org.uk)

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

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

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

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

RC-066  
Scottish Consortium for Learning Disability  
The Adelphi Centre, Room 16  
12 Commercial Road  
Glasgow, Lanarkshire Scotland G5 0PQ  
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<http://www.sclld.org.uk>

RC-067  
Praxis Care Group  
Queens University of Belfast  
25-31 Lisburn Road  
Belfast, Northern Ireland BT9 7AA  
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[www.praxiscaregroup.org.uk](http://www.praxiscaregroup.org.uk)  
Research/focal topics: intellectual disability, mental health, elderly, leaving care, vulnerable individuals

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RC-003  
Department of Disability & Human Development  
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Chicago IL 60608-6904 USA  
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RC-004  
Centre on Intellectual Disabilities  
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RC-006  
Laboratoire de Recherche Interdepartementale en Deficiance Intellectuelle  
LARIDI  
University of Quebec at Trois-Rivieres  
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C.P. 500  
Trois Rivieres QC Canada G9A 5A7  
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RC-012  
Schieffelbusch Institute for Life Span Studies  
University of Kansas  
100 Sunnyside Avenue  
1052 Dole  
Lawrence KS 66045-7555 USA  
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<http://www.lsi.ku.edu/lsi/>

RC-015  
National Institute for People with Disabilities  
Young Adult Institute, Inc.  
460 West 34th Street  
New York NY 10001-2382 USA  
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[www.yai.org](http://www.yai.org)

RC-019  
Waisman Center  
University of Wisconsin-Madison  
1500 Highland Avenue  
Madison WI 53705 USA  
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[www.waisman.wisc.edu](http://www.waisman.wisc.edu)

RC-025  
Beach Center on Disability  
University of Kansas  
Schieffelbusch Institute for Life Span Studies  
1200 Sunnyside Avenue, Room 3111  
Lawrence KS 66045-7534 USA  
Contact: Dr. Ann Turnbull ([turnbull@ku.edu](mailto:turnbull@ku.edu))  
[www.beachcenter.org](http://www.beachcenter.org)

RC-028  
Strong Center on Developmental Disabilities  
University of Rochester  
School of Medicine and Dentistry  
PO Box 671  
601 Elmwood Avenue  
Rochester NY 14642 USA  
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RC-038  
Neurodevelopmental Psychiatry Services  
University of Nebraska College of Medicine  
985578 Nebraska Medical Center  
Omaha NE 68198-5578 USA  
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<http://www.unmc.edu/index2.htm>

RC-040  
Services de Réadaptation L'Intégrale  
Institut Universitaire en Santé Mentale  
Hôpital Louis-H. Lafontaine  
75, de Port-Royal Est

Bureau 10  
Montreal QC Canada H3L 3T1  
Contact: Jean-Pierre Aumont ([jpaumont@ssss.gouv.qc.ca](mailto:jpaumont@ssss.gouv.qc.ca))  
<http://www.integrale.org>

RC-044  
Stímulo Centro de Estimulación y Desarrollo Neurocognitivo A.C.  
Av. Chalman Sur 113  
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Cuernavaca  
Morelos, Mexico 62180  
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RC-053  
Down Syndrome Research Foundation  
1409 Sperling Avenue  
Burnaby BC Canada V5B 4J8  
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[www.dsrf.org](http://www.dsrf.org)  
Research/focal topics: Down syndrome, motor development, cognitive development, language development, speech language therapy

RC-057  
Centre de réadaptation Lisette-Dupras  
Centre de documentation  
Direction des technologies de l'information et de la recherche  
8000, rue Norte-Dame Ouest  
Lachine QC Canada H8R 1H2  
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RC-060  
Matheny Institute for Research in Developmental Disabilities  
Matheny Medical and Educational Center  
PO Box 339  
Peapack NJ 07977 USA  
Contact: Kenneth L. Robey ([research@matheny.org](mailto:research@matheny.org))  
[www.matheny.org](http://www.matheny.org)  
Research/focal topics: medical education regarding disability, Lesch-Nyhan disease, disability identity

RC-064  
John Langdon Down Foundation  
Selva 4  
Insurgentes Cuicuilco  
Coyoacan, Mexico DF Mexico 14350  
Contact: Sylvia Escamilla ([noralazcano@fjldown.org.mx](mailto:noralazcano@fjldown.org.mx))  
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RC-065  
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RC-082

Center for Social Development and Education  
University of Massachusetts-Boston  
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## **SOUTH AMERICA**

RC-068  
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rua Loefgreen, 2109  
04040-033 São Paulo sp, Brasil  
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[www.apaesp.org.br](http://www.apaesp.org.br)  
Research/focal topics: comorbidities, cardiovascular disease, community inclusion

RC-069  
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Research/focal areas: neurophysiology

## **ASIA-PACIFIC**

RC-026  
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580 George Street  
Sydney NSW 2135 Australia  
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RC-032  
Centre for Developmental Disabilities Studies  
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Ryde NSW Australia 1680  
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RC-035  
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RC-045  
Guam Center for Excellence in Developmental Disabilities Education, Research & Service  
CEDDERS  
University of Guam  
Office of Academic Affairs  
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RC-056  
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RC-058  
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Tokyo, Japan 162-0846  
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RC-062  
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RC-059  
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RC-075  
Lebenshilfe Visakhapatnam  
Association for the Mentally Handicapped  
26 Lawsons Bay  
Visakhapatnam  
530017 A.P. India  
Contact: Saraswathi Devi Tallapragada ([tsarahdevi@yahoo.com](mailto:tsarahdevi@yahoo.com))  
<http://lebenshilfeindia.org>

RC-077

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44 Dundas Street

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RC-078

National Institute of Education

Early Childhood and Special Needs Education

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1 Nanyang Walk

Singapore 637616

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RC-079

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RC-81

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## MIDDLE-EAST

RC-061

National Institute of Child Health and Human development

Office of the Medical Director

Division for Mental Retardation

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P.O. Box 1260

IL-91012 Jerusalem, ISRAEL

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RC-80

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## **Report of VP for Liaison with WHO and other organizations**

### **IASSID Council Meeting**

August, 2008

#### **Summary of Past Year Activities**

Although David Felce and I met Shekhar Saxena at WHO headquarters in Geneva in 2005 and agreed on a work plan to fit the revised policy of WHO on liaison with NGOs, our aspirations have not been fulfilled and it is not easy to say why this is so. However, IASSID subsequently consulted with the team in Montreal charged with preparing the WHO *Atlas* (2007). In addition, the co-editors of the recent special issue of JPPID (Emerson, Felce, McConkey & Walsh) invited some of the Montreal team to contribute an article and this has now been published.

Since the 2<sup>nd</sup> Regional Conference in Santiago de Chile in September 2007, our contact with PAHO has been negligible. Members of Council may recall that the Santiago event attracted 300 participants, and was co-hosted by IASSID, the Faculty of Law at Diego Portales University and by PAHO – which is the WHO body in North and South America. While the cooperation from Javier Vasquez, human rights expert at PAHO in Washington DC, was most helpful, we have not established a longstanding relationship with PAHO.

In May 2008, I wrote to Shekhar Saxena (WHO, Geneva) about various matters, and include here the section of his reply of particular interest to IASSID:

*As you are aware, we at WHO are very keen to take the large agenda for ID forward, but find our resources quite insufficient to do this. The Atlas-ID has been our small step in this area and we do want to build upon its success.*

*I will be very interested in further exploring the plans for collaboration with IASSID, with you and Professor Murphy, when convenient to you. We really need to make some concrete plans and then implement them; otherwise the risk of discontinuation of the official relationship is high.*

*I also wish you a great conference at Cape Town.*

#### **Plans for Upcoming Year**

I recommend that IASSID make all appropriate efforts to continue its present relationship as recognized NGO with WHO. Although challenging and perhaps awkward, it is nonetheless important – in my view – for IASSID to have recognition as the only scientific and international body in our field.

### **Issues or Acting Items**

It is likely that Council should now consider a decision on whether IASSID should build on its existing links in the South America region, for example, by promoting a research event in collaboration with some of the agents who helped in Santiago, as well as with PAHO.

### **Discussion Points for Council**

It is for the incoming Executive and Council to decide whether to build strong links with WHO and/or PAHO. If the decision is positive, I suggest that 1-2 members of Council might be delegated to strengthen these relationships through further, quite focused collaboration and regular exchanges of information.

---

Patricia Noonan Walsh  
Vice-President, IASSID (2004-2008)

Dublin  
August 2008



# International Association for the Scientific Study of Intellectual Disabilities

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

## 2009 Budget

Budget Period - 1 January 2009 to 31 December 2009

### A. IASSID Executive

IASSID Executive Meetings & Expenses	\$ 15,000	<u>\$ 15,000</u>
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### B. 2009 Council Meeting

Lodging	\$ 7,500.00	
Catering	\$ 500.00	
Council Travel	\$ 4,500.00	
Council Dinner	\$ 900.00	<u>\$ 13,400</u>

### C. JPPID

Support Expenses	\$ 4,000	<u>\$ 4,000</u>
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### D. IASSID Academy

Support Expenses	\$ 6,000	<u>\$ 6,000</u>
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### E. Admin Expenses - Officers

Treasurer	\$ 7,500.00	
Secretary	\$ 3,000.00	
President	\$ 5,000.00	
President-Elect	\$ 2,000.00	
Vice-Presidents	\$ 4,000.00	
Past-President	\$ 1,500.00	<u>\$ 18,500</u>

### F. Regional Congress Preliminary Expenses

2009 IASSID Asia-Pacific Congress	\$ 7,500	
2010 IASSID Europe Congress	\$ 5,000	<u>\$ 12,000</u>

### G. Journal subscriptions

JIDR <sup>2</sup> Estimated subscription costs	\$ 11,180	
JPPID <sup>3</sup> Estimated subscription costs	\$ 19,604	<u>\$ 30,784</u>

### H. Website Expenses

	\$ 1,000	<u>\$ 1,000</u>
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### Total Budget for 2009

\$100,684

<sup>1</sup> Includes estimated expenditures for equipment and start-up expenses

<sup>2</sup> Estimate includes 20% drop off in memberships that take JIDR (unit cost: \$52 x 215 subscriptions)

<sup>3</sup> Estimate includes 25% drop off in membership (unit cost: \$52 x 377 subscriptions)



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## **2007 Income and Expense Statement** Budget Period - 1 January 2007 to 31 December 2007\*

### **Revenue**

#### *Primary Revenue*

Interest (Bank of America)	26,301	
Income - Memberships	73,638	
Registrations	<u>18,233</u>	\$ 118,172

#### *Secondary Revenue*

Wiley-Blackwell (for JPPID)	6,000	
Royalty Income	<u>455</u>	\$ 6,455

#### *Grants Revenue (Donations)*

Toinvest Support Grant	35,643	
Santiago 2007 Congress Grants	1,734	
Africa Research Fund	<u>11,625</u>	\$ 49,002

**Total Revenue** \$ 173,629

### **Expenses**

#### *Operating Expenses*

General Administrative Expenses	2,839
Credit Card Fees - Amex and VISA/MC	3,163
Bank charges, Fees & Adjustments	2,756
Internet Access	196
Website Expenses	1,199

Postage	752	
Journal Subscriptions	<u>37,033</u>	\$ 47,938

***IASSID Executive and Council Expenses***

IASSID Council Expenses	7,853	
Secretary - Expenses	2,865	
IASSID Executive	42,068	
JPPID Editorial Support	<u>5,600</u>	\$ 58,386

***Charitable Function Expenses***

Santiago 2007 Congress Expenses	42,370	
2008 World Congress Expenses	30,586	
Singapore 2009 Congress Expenses	11,668	
IASSID Academy	<u>223</u>	\$ 79,847

***Transfers of Funds to Sub-Units***

Transfer of registration funds to Aging SIRG	18,233	
Transfer of funds to QoL SIRG	<u>1,500</u>	\$ 19,733

<b>Total Expenses</b>		<b><u>\$205,904</u></b>
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Revenue/Expenses		<b><u>\$- 32,275</u></b>
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\* prepared for submission of 2007 Tax Return - July 16, 2008



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## Internal Control Audit

Date Performed: August 25, 2008

### IASSID Council Members - Members of the Finance Committee

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

### Comments and Recommendations

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1.

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2.

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3.

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4.



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## 2007-08 Obligated Funds

Budget Period - 1 January 2007 to 10 August 2008

### SIRG and AG Funds

#### 1. Legacy SIRG assessments collected and held & 07/08 allocation residuals

	2003	2004/5	2006	2007	2008	Total
Aging	0	0	0	909.10	1139.50	\$ 2049.10
Comp Policy/Practice	<sup>a</sup>	<sup>a</sup>	<sup>a</sup>	648.15	1040.60	\$ 1688.75
Families	0	685	60	709.55	1006.20	\$ 2460.75
Health Issues	0	0	0	826.21	1152.40	\$ 1978.61
Mental Health	1420	1550	540	961.29	1247.00	\$ 5718.29
Parenting	160	280	220	724.90	812.70	\$ 2197.60
Prof/Multiple Dis	0	0	0	0 <sup>b</sup>	933.10	\$ 933.10
Quality of Life	0	0	0	0 <sup>b</sup>	1268.50	\$ 1268.50

<sup>a</sup> new SIRG    <sup>b</sup> 2007 funds already paid to SIRG

Legacy & other funds held for SIRGs from 2003-2008

\$ 18,110.00

#### 2. Legacy funds held for Affinity Groups\*

	2003	2004/5	2006	2007	Total
Nursing	120	60	0	**	\$ 180.00
Ethics	100	60	20	**	\$ 180.00
Employment	20	0	0	**	\$ 20.00
Social Integration	60	0	0	**	\$ 60.00
Women's Issues	20	0	0	**	\$ 20.00
Forensics	120	0	0	**	\$ 120.00

\* Funds in 2003-06 were earmarked by members and paid separately

\*\* no AG funds were collected or allocated beginning in 2007 due to the new SIRG funding system

Legacy funds held for AGs from 2003-2006

\$ 580.00

Total funds held for SIRGs & AGs

\$ 18,690.00

### 3. SIRG funds available for disbursement for 2008

## 2007-08 Obligated Funds

Budget Period - 1 January 2007 to 10 August 2008

Page 2

<i>Disbursement for Funds - May 2008</i> Name of SIRG	N	% of Total	% Funds	Fixed Funds	Total Allocation
Aging	85	14.0	\$602.00	\$537.50	\$1,139.50
Comparative Practice & Policies	71	11.7	\$503.10	\$537.50	\$1,040.60
Families	66	10.9	\$468.70	\$537.50	\$1,006.20
Health Issues	87	14.3	\$614.90	\$537.50	\$1,152.40
Mental Health	100	16.5	\$709.50	\$537.50	\$1,247.00
Parenting	39	6.4	\$275.20	\$537.50	\$ 812.70
Profound/Multiple Disabilities	56	9.2	\$395.60	\$537.50	\$ 933.10
Quality of Life	103	17.0	\$731.00	\$537.50	\$1,268.50
$\Sigma$	607	100.0%	\$4,300.00	\$4,300.00	\$8,600.00

NOTE: In 2008, **430** members paid \$20 each toward the SIRG fund, totaling US\$8,600; 50% (or \$4,300) of these funds were distributed evenly across the 8 SIRGs or \$537.50 each. The balance, \$4,300, was distributed proportionally according to the percentages noted above. Each SIRG's total allocation for 2008 is shown above as well. The factor number (used to derive percentages) used was <607>, representing multiples of the 430 paid members declaring a SIRG of interest. Members are entitled to declare up to five SIRGs of interest.



# International Association for the Scientific Study of Intellectual Disabilities

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## Statement of Reserves

August 10, 2008

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

Funds carried in Savings Account	\$ 34,843.62
Funds carried in Checking Account	<u>\$ 110,616.29</u>
 Liquid Funds - USA\$	 <u>\$ 145,459.91</u>
 Fixed Term CD #0404	 \$ 112,963.01
Fixed Term CD #7975	\$ 115,465.18
Fixed Term CD #0417	\$ 89,105.67
Fixed Term CD #9911	<u>\$ 90,489.18</u>
 Total investment funds	 <u>\$ 408,023.04</u>
 Total US dollar funds	 <u>\$ 553,482.95</u>

### *Funds held at Banque Populaire (Paris, France)*

Funds in Checking Account	€ 10,609.86
Funds in Savings #1	€ 25,000.00
Funds in Savings #2	€ <u>64,056.00</u>
 Total Euro funds	 <u>€ 99,662.86</u>

(equivalent US\$ funds = \$149,534)  
(US\$1.50 = €1.00)

***Total IASSID funds*** \$ 703,016.95

# IASSID Comparable Financials - 2001-2008

	2001	2002	2003	2004	2005	2006	2007	2008
<b>Income</b>	\$41,076 <sup>1</sup>	\$106,146 <sup>1,2</sup>	\$41,477	\$88,748	\$112,127 <sup>6</sup>	\$130,978 <sup>6</sup>	173,629 <sup>6</sup>	-
<b>Expenses</b>	\$42,002 <sup>1</sup>	\$45,813 <sup>1</sup>	\$57,165	\$73,182	\$106,444 <sup>6</sup>	\$121,917 <sup>6</sup>	205,904 <sup>6</sup>	-
<b>Reserve<sup>3</sup></b>	\$137,236	\$170,985	<sup>5</sup>	\$244,048	\$588,218 <sup>4</sup>	\$ 662,221	\$665,611	\$703,016

<sup>1</sup> Approximate figures as approximate midyear-to-midyear was used for Council reports

<sup>2</sup> Includes funds from Dublin IASSID-Europe Conference

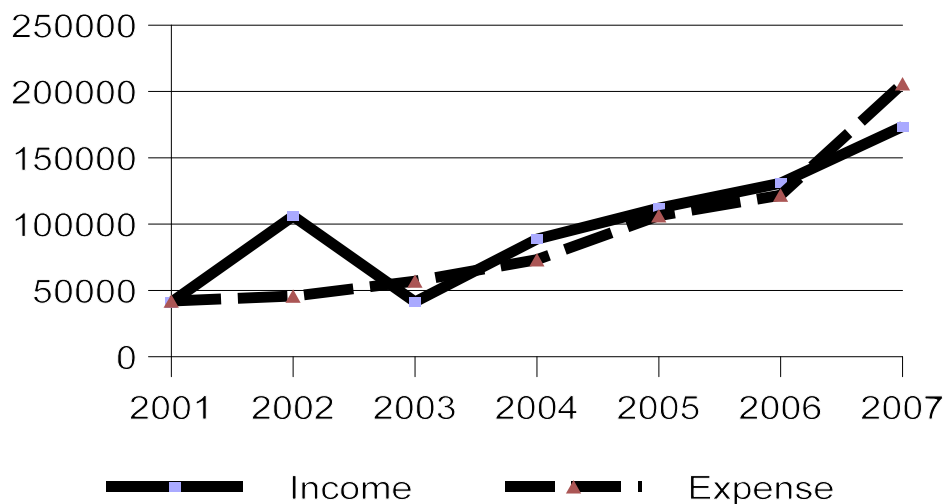
<sup>3</sup> Funds held by IASSID at time of annual Council meeting

<sup>4</sup> US Dollar and Euro conversions (Euro estimated at par with US Dollar)

<sup>5</sup> Unavailable

<sup>6</sup> End of year figures (December 31)

## Income-Expense 2001-07



Income	41076	106146	41477	88748	112127	130978	173629
Expense	42002	45813	57165	73182	106444	121917	205904



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## **Treasurer's Report**

### **1. Statement of Finances**

- a. 2006 Income and Expense Statement (Attachment)
- b. Statement of Reserves (Attachment)
- c. Obligated Funds for 2008 (Attachment)

### **2. Administrative Functions**

- a. Treasurer filed the 2007 Income Tax Submission with the US Internal Revenue Service
- b. Treasure filed the corporate status report with the Secretary of Institutions of the State of Wisconsin
- c. Negotiated the continuation agreement with Wiley-Blackwell for 2008 and 2009.

### **3. Arrangements with Blackwell Publishing**

- a. Our agreement with Wiley-Blackwell keeps the per member cost of JIDR at \$52 for 2009 and keeps the per member cost of JPPID at \$54 for 2009

### **4. Commentary**

- a. Treasure's Closing Commentary and Recommendations (attached)

## **Treasurer's Closing Commentary**

It has been my pleasure to serve the Association as its Treasurer for the past eight years. When I was first elected in 2000, I inherited a bank account with some \$30,000 and no inherent structure to process and manage our membership and expanding activities. I leave the office with some \$700,000 in our bank accounts, and a complex production structure that permits for on-line payments, credit card processing and a relatively sophisticated banking operation. While I certainly do not take credit for the dramatic increase in revenue, I do feel comfortable with what I was able to accomplish in terms of the financial supports now in place within the Association. I expect the next Treasurer will have an easier time with the transition than I did, and will have the opportunity to see the Association's resources and practice become even more sophisticated and rewarding.

As I leave the office, I would like to report that the state of IASSID finances is relatively healthy, but more needs to be done to insure a stable and enhanced income stream. Things to consider regarding our finances:

### **A. Royalties:**

1. Royalties from Blackwell have diminished and are no longer a reliable source of income. No new products are in the pipeline at this time.
2. Royalties from Radcliffe, while modest, will most likely diminish next year. No new products are in the pipeline at this time.
3. No new revenue is expected from our agreement with MENCAP regarding JIDR, but MENCAP has agreed to contribute funds for special causes associated with the quadrennial Congress.
4. JPPID is currently in its fifth year and not yet generating any revenue for the Association (we don't expect any until year eight). Most subscriptions are from the Association at this time. Expectations are that as JPPID becomes mainstream and institutional subscriptions pick up, revenue will be forthcoming - but this may not be for another three to four years. This year, with the Tosinvest Sanità grant, JPPID is currently cost-neutral for the Association, but this will end in 2008, the fifth year and end point of the grant.

### **B. Toinvest Sanità:**

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

### **C. Memberships:**

Membership fees for Full Memberships (\$120 and \$170) have been sufficient to cover the fixed costs associated with journal invoicing by Wiley-Blackwell, when the JPPID was subsidized by Tosinvest, but may be insufficient to cover costs of Association business in the long run. Some 12% of each \$170 and 17% of each \$120 membership is devoted to the SIRG disbursements, as well as 62%, and 43%, respectively, cover the cost of JIDR/JPPID and JPPID of each membership fee. Thus, 60% of each \$120 and 74% of each \$170 membership fee are spoken for. This means that only \$60 of each \$120 membership and \$45 of each \$170 membership can be used for paying expenses and invested toward reserves. In one sense, this also means that we are giving our members who take both JPPID and JIDR a nice deal, but to our detriment.

### **D. Conferences**

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

The 2004 Montpellier World Congress was exceptionally profitable for the Association, generating some \$300,000 in revenue. What the 2008 Capetown Congress will bring is unknown. If at minimum, the Congress is cost-neutral or makes a small profit then that will aid the bottom line, but if it runs a deficit this will have to be absorbed by the Association and will draw against our reserves.

The new Academy is only beginning its work with some workshop planned at the Cape Town Congress and work toward doing the same in conjunction with the Singapore Congress. However, it appears that most of the planning is for sessions in mostly in low economic regions -- which may not bode well for generating income. It would be good to have these sessions at least cover costs. Once more fully established it is possible (and expected) that the Academy will be a profit center that will contribute modestly to the annual revenue of the Association.

## **RECOMMENDATIONS:**

1. We need to be more aggressive in soliciting texts from our member that can be brokered for publication with revenues ensuing to IASSID. It is recommended that at minimum some 3-4 works be in the pipeline each year. This should generate from \$4,000 to \$7,500 in royalties annually.
2. Ensure that the Asia-Pacific IASSID Conferences have a built-in revenue generator with a goal of providing IASSID with from \$10,000 to \$20,000 in revenue, through aggressive marketing for registrations in North America, Australia-New Zealand, and Europe – which tend to generate full pay registrants.
3. Organize more conferences in North America. With the problems experienced by our American affiliated member associations, it may be timely for IASSID to have more of a presence in North America. Areas for consideration should also include the Middle-East, the Carribean Region, and the Indian subcontinent when conditions are auspicious.
4. Actively solicit additional membership from staff-based organization at universities and related facilities to build up the Research Center membership and create a more active benefits program for Research Center members.
5. Enhance the activities of the Academy so it can offer more fee-based courses and workshop throughout the world, with the goal of generating at minimum \$15,000 in revenue annually.
6. Expand IASSID's involvement in international affairs in order to generate grants and development funds for special projects and activities that will off-set administrative costs and provide a revenue stream.
7. Site the 2012 World Congress in a city that will attract the most delegates and maximize revenue by securing favorable contractual conditions with conference venue vendors. Current thinking of holding the Congress in Eastern Canada will help us access the critical mass of academics and service providers resident in this most populous area of Canada and the US.

---

Matthew P. Janicki, Ph.D.  
Treasurer 2000-2008



# 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  
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USA

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## Report to Council (August 2008)

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

● **Background.** JPPID, established in 2003, is the official journal of the IASSID, and has been underwritten through a grant received from the Toinvest Sanità Organization in Rome, Italy. It is co-owned with Wiley-Blackwell Publishing, which provides editorial support. JPPID is now into its fifth year of publication and is doing well with respect to subscriptions, submissions, and maintaining publication schedules. The work of JPPID is managed by Matthew Janicki, the Editor-in-Chief, and Jenn Hall, JPPID's Editorial Coordinator; who are both located in Maine (USA).

● **Manuscript Central.** In 2006, we switched over to electronic manuscript submission with Manuscript Central (MC) from Scholar One and this has worked out quite well, as both Jenn and I have become more familiar with MC. MC enables authors to submit their article electronically and then track its progress during the review process. MC permits us to assign reviewers and track the progress and submission of the reviews, make editorial decisions, and forward correspondence to the authors. The automated process has some peculiarities, but overall has been very useful as a time-saving tool and mechanism for tracking and submitting for production the manuscripts received and accepted.

● **Wiley-Blackwell.** Ms. Angela Richardson of Wiley-Blackwell (W-B) is our key contact person at Wiley-Blackwell's Boston office; Angela works closely with me and is aided by Gerald Koh, the production editor for JPPID in W-B's Singapore office. Angela is working with me to organize an on-line editorial board meeting for later this year. With respect to other abstracts and indexing, JPPID is part of several abstracting services, and is listed in PsycINFO and Social Care online. In 2006, Wiley-Blackwell organized our acceptance by PsycINFO, the American Psychological Association's indexing service. Applications by W-B have been filed with Cinahl, CIRRIE and

Medline. Additionally an application has gone into Scopus, another such service. We anticipate that JPPID will be accepted within these services by the end of its sixth volume in 2009. Also, W-B will include JPPID into the 'BIG DEAL' [a massive journal subscription package for institutional subscribers] starting in 2010 for on-line access. The BIG DEAL is a marketing tool that W-B uses to promote its journals for institutional buyers. Also, JPPID is part of the offering in Hinari, which provides gratis on-line access for 467 institutions in Europe and 2128 in the rest of the world. Such access is provided to institutions in low income or developing nations.

- **Impact Factor.** With respect to JPPID being listed among those journals with measured impact factors, W-B is resubmitting an application to Thompson ISI this September. If accepted, JPPID will be tracked in ISI from 2009. This means that JPPID would have an Impact Factor in 2011, as the previous two years' articles need to be tracked (2009 and 2010). Also, the 2011 impact factor will come out in June 2012, as ISI spends 6 months collecting all of the citation data. We are optimistic that given our current track record (on-time publication, relevance, and manuscript gravitas) we will be accepted this time around.

- **Status of Articles.** In 2006, we published 31 main manuscript articles. However, since in 2006, we ran 285 pages, 45 pages over the page budget of 240, in 2007 we consequently instituted a closer control over the manuscripts (partly attributed to a new production editor who was more communicative on these matters) and kept fairly well within the 240 pages/per year limit. In 2007, we accepted and published 30 discrete main articles, including those encompassed within a special issue (guest edited by Prof. James Hogg on profound and multiple disabilities). In 2008, we have regularized our production work even more and now maintain a production schedule with Wiley-Blackwell that involves issue manuscript submission on March 10th, June 10th, September 10th, and December 10<sup>th</sup>. We have also instituted a tighter review procedure for manuscripts that are submitted from other-than-English speaking authors or who are inexperienced with journal-quality writing. In the past we tried to aid authors by providing editorial suggestions – particularly when the authors' first language was not English -- however, with a backlog of manuscripts we will no longer provide this assistance to a large degree. An extenuating circumstance is when the topic or work submitted is of such overriding interest, we will invest time in helping with editorial work. In 2008, we included a special issue on comparative social policies, guest edited by Prof. Eric Emerson, to coincide in distribution with the 2008 Cape Town World Congress. To date we have published 30 articles in issues 5-1, 5-2, and 5-3 and eight more are scheduled for issue 5-4. This increase in pages is the result of W-B upping the page allocation for JPPID in 2008 so that we now have 96 pages per volume. At this time, there is no plan to increase the frequency of publication (currently at four issues per year). In 2009, we will also have 96 journal pages and have two special issues potentially coming out, one guest-edited by Profs. Roy Brown, Ivan Brown, and Robert Schalock on applied practices in quality of life, and one guest-edited by Profs. Meindert Haveman and Christine Bigby on recent research in aging. We continue to publish Association news, such as the annual Council minutes and listings of upcoming meetings, as well as book reviews, brief research reports and policy briefs. Our back cover is dedicated to advertising upcoming IASSID conferences.

- **Comments.** The contract between IASSID and W-B relative to JPPID was automatically renewed for a further five year term at the end of 2007. This means that in 2013, the contract will be rolled

over for another 5 year term unless either party gives notice in writing at least twelve months prior (i.e. not later than the end of 2012). The Tosinvest grant for JPPID support ends at the end of 2008 and we are not aware of the status of any further support. The editorial leadership of the journal is running well and is aided in large part by an excellent editorial coordinator (Ms. Jenn Hall) and the editor's proximity to the US offices of Wiley-Blackwell in Malden, Massachusetts. The adoption of Manuscript Central has helped us manage the submission work load. As with many journals, a common challenge is identifying reviewers and obtaining reviews in a timely manner. Manuscript submission is at a reasonable rate and our acceptance/ rejection ratio is being tightened. Articles of lesser quality are being rejected or returned for significant revisions at a greater rate than before (when the number of manuscripts per volume was low), although in reality most articles submitted are of sufficient quality and interest that they generally are assigned a 'revision' recommendation. A goal in 2009 will be to broaden the editorial board with one or two subordinate editors who can help manage the work flow and reviews. I expect also that we may gain some new members for the editorial board. The key objective for the next year will be to broaden our acceptance within abstracting and indexing services and to be recognized by the organization that measures the impact factor.

Submitted  
M. Janicki  
Editor-in-Chief  
18 August 2008 (rev.)

# Report of the Special Interest Research Group on Aging and Intellectual Disability (SIRGAID) IASSID Council Meeting August 25, 2008

## ***Summary of Past Year's Activities***

**Roundtables.** The SIRGAID 16<sup>th</sup> Roundtable was held in Oslo, Norway on May 30-June 1, 2007. It was sponsored by the Development Program on Ageing in People with Intellectual Disabilities (UAU) at The Norwegian Centre for Dementia Research. Approximately 60 SIRGAID members attended the two-day meetings. A parallel local congress took place on May 29-May 30, 2007. Over 200 local service providers, policy makers and academics registered for this event.

**Elections.** The SIRGAID elected its 2008-2012 leadership in May 2008. The membership elected Christine Bigby (Australia) Heather Wilkinson (UK) as co-Chairs, Philip McCallion (USA) as Treasurer, and Sonny Kalsy as Secretary. Matthew P. Janicki (USA) will continue as a member of the leadership as Past Chair. He will be joined by Philip W. Davidson (USA), immediate past chair. The membership also elected four At-Large members: Maria van Laake (The Netherlands), Jennifer Torr (Australia), Lisa Wang (Taiwan) and Frode Larsen (Norway). Dawna Torres Mughal (USA) leaves the Executive Committee after many years of service to the SIRGAID. Dr. Mughal most recently served with distinction as SIRGAID Newsletter Editor. We are all grateful for her fine contributions.

**Membership.** The IASSID Treasurer reports that we currently have 88 IASSID members who have elected membership in the SIRGAID.

**Budget.** At its Business Meeting at Oslo, Dr. Davidson, on behalf of Dr. McCallion, reported total unobligated assets of \$ 4,881.28, anticipated additional revenues of \$911.00, anticipated expenses of \$2,200.00, and an anticipated end-of-year balance of \$3,592.28. The budget was approved.

## ***Plans for Upcoming Year***

The SIRGAID program on Aging and Intellectual Disabilities to be presented at the International Congress in South Africa in 2008 includes 19 symposia covering a broad range of issues pertinent to aging with an intellectual disability. As has been the normal practice, the SIRGAID will hold no Roundtable during the International Congress year. The 17<sup>th</sup> Roundtable will be held in Edinburgh, Scotland on September 23-25, 2009, hosted by the University of Edinburgh. Guidelines for the organization of roundtables have now been drawn up and endorsed by the Executive Committee.

The SIRGAID plans a number of initiatives to boost participation of existing members in upcoming IASSID events and to increase the SIRGAID membership.

In March 2007, The SIRGAID's first Newsletter was disseminated to all members via e-mail. Dr. Mughal has prepared five additional issues since then.

The Executive Committee will continue its practice of holding frequent Skype meetings.

Submitted – PW Davidson and Christine Bigby, Co-Chairs/Aging SIRG  
15 July 2008

**Report of (*Mental Health SIRG*)  
IASSID Council Meeting  
August 25, 2008**

**Summary of Past Year Activities**

There have been no formal meetings of the MH-SIRG this past year. During this time there has been an e-mail consultation exercise about the future of the MH SIRG and specifically whether it should be changed to include challenging behaviour. The responses to the consultation were overwhelmingly in favour of this course of action.

**Plans for Upcoming Year**

At the Cape Town meeting we propose to change the name of the MH-SIRG to the Mental Health and Challenging Behaviour SIRG. A notice has been circulated to this effect. A new committee will be elected and it will be their task to develop the future programme for this SIRG.

**Issues or Acting Items**

None

**Discussion Points for Council**

This has been previously discussed at Council, however, as co-chair would like the formal agreement of Council for this course of action given the more recent discussions that have been taking place about SIRGs.

Tony Holland  
Co-Chair of the MH SIRG

**Report of Parents and Parenting with Intellectual Disabilities**  
**IASSID Council Meeting**  
August 25, 2008

**Summary of Past Year Activities**

Over the past year the SIRG has successfully prepared a Special Issue of the *Journal of Applied Research in Intellectual Disabilities*, published as Vol 21, no. 4, July 2008. This issue contains 8 papers representing five countries which highlight the important and informative research occurring on this topic around the world.

In addition the Special Issue contains the position paper of the SIRG on parents and parenting by people with intellectual disabilities. This paper has been endorsed by IASSID Council and is another significant achievement for this SIRG. The paper is titled: **Parents labeled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities**, *IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, JARID, 21(4), 296-307.*

Professors Llewellyn, Traustadottir, McConnell and Sigurjónsdóttir have secured a contract with Wiley for a book provisionally titled **Parents with intellectual disabilities and their children: Living and learning in the community**, to be published in mid 2009. The 14 contributors to this publication come from seven countries; all are members of IASSID. This is an exciting endeavor which will further raise awareness of this important topic of parenting by people with intellectual disabilities.

**Plans for Upcoming Year**

1. To conduct the SIRG's first Roundtable in Cape Town on August 23<sup>rd</sup> just prior to the IASSID Congress in Cape Town.
2. To plan a series of international collaborative research efforts as an outcome of the Roundtable
3. To offer a Parenting Stream at IASSID Congress in Cape Town (19 papers accepted) and to similarly offer a well subscribed Parenting Stream at IASSID 2<sup>nd</sup> Asia Pacific Regional Conference in Singapore in June 2009.
4. To develop a series of Awards and possibly scholarship activities for early career researchers contributing to the knowledge base about parents and parenting with intellectual disability.
5. To consider ways in which we can engage more directly with parents with intellectual disability and support their inclusion in research which most affects their lives and their inclusion in dissemination of research through publication and conference presentation.

### **Issues or Acting Items**

At our General Meeting at IASSID Congress in Cape Town we need to reconsider the Executive membership given that Gwynnyth Llewellyn has served now as Chair since 2004.

### **Discussion Points for Council**

No current items. The SIRG thanks Council for its timely consideration of the Position Paper and in particular Professors David Felce and Glynis Murphy and Pat Clelland for their support and encouragement in the preparation of the Special Issue of JARID.

**Report of the Families SIRG  
IASSID Council Meeting  
August 25, 2008**

**Summary of Past Year Activities**

The Families SIRG was represented at the Council meeting in Paris in May, 2007. Our SIRG has remained quite active since the 2006 meeting in Maastricht. While we have accomplished cross-fertilization with the parenting SIRG (no pun intended), we continue to strive for a presence at both regional and major IASSID meetings. Tasks that we need to set as priorities include the development of a research agenda to be endorsed by the Families SIRG; a managerial plan that will extend from the Cape Town meeting and about two years beyond that; more communication among Executive Committee members; and more aggressive planning for co-presenting or cross-listing of conference papers with other SIRG's.

To date, there have been two Special Issues of JIDR focused on families research (both bumper issues), and we have others planned (see below.) Thus, there has been enthusiasm and action from our members in terms of research publications. Approximately once a year members of the SIRG meet at a national (e.g., the Gatlinburg Conference in the U.S.) or regional conference (e.g., IASSID in Maastricht), though admittedly communication among SIRG members could be improved.

**Plans for Upcoming Year**

Now that the Families SIRG has a solid membership and circle of regular participants, the group may want to consider appointing a small (approximately 6 or 8) steering committee representative of various continents and regions. The steering committee could assist the Families SIRG executive committee (Chair, past-Chair, Secretary, Treasurer) in governing and planning activities. These decisions will be discussed at the meeting in Cape Town, though final execution will be up to the new Chair, Eric Emerson.

New publication activities are also underway for the upcoming year. Another Special Issue of JIDR, on family resilience, is underway, with Eric Emerson, Jan Blacher and Malin Broberg Olsson as co-editors. Plans for a Special Issue of JARID are underway, with Laraine Glidden, Jan Blacher and Richard Hastings as co-editors. The JARID issue will likely focus on family-related themes, with the goal of publication in early 2010. Any empirically-based family research is welcome, but particular interest is in contributions that focus on the family as a whole, on more than one member of the family, or on issues of family diversity.

### **Issues or Acting Items**

Current issues or action items of interest to the Families SIRG include the following:

- (1) Turning over the executive leadership of the Families SIRG to a new executive group, led by Eric Emerson;
- (2) Increasing our membership, in light of competing organizations and their meeting schedules;
- (3) Increasing involvement by colleagues outside of the U.S., the U.K. and Australia, in order to develop a truly international perspective and knowledge base on families and intellectual disability. Along with this comes the challenge of having a strong program of families SIRG presentations at the major and regional IASSID conferences.
- (4) Developing a pre-conference roundtable on families research that would dovetail a major IASSID meeting; this may be difficult, given that our SIRG membership resides across a wide geographic area.

### **Discussion Points for Council**

There appears to be widespread interest in families who have children, adolescents and young adults/adults with ID across the globe. The Families SIRG would like to emphasize the relevance of families research for researchers and policy makers alike, and to highlight this topic at the next major IASSID meeting, perhaps with joint presentations by a researcher and a local politician addressing similar family issues.

Members of the Families SIRG appreciate the support of the Council. We would welcome a joint roundtable with another, related SIRG to facilitate our first effort at such a venue.

Respectfully submitted,

Jan Blacher, Ph.D., Past-Chair, Families SIRG  
Professor and Founding Director  
SEARCH family autism resource center  
University of California, Riverside

**Report of Health SIRG  
IASSID Council Meeting  
August 25, 2008**

**Summary of Past Year Activities**

The SIRG has focused on the following areas over the last year:

- a. Attendance and representation at IASSID Council
- b. SIRG Conference on the management of chronic health conditions held in Prato Italy in 2007. This was a very successful conference focusing on models of health care delivery for people with a learning disability
- c. SIRG Newsletter
- d. SIRG executive teleconference
- e. Planning submissions to Cape Town 2008
- f. Organising the health care symposia in Cape Town 2007
- g. Considerable research and service development from SIRG members
- h. On going production of renewed epilepsy guidelines
- i. Continued membership growth, last count 87 members

**Plans for Upcoming Year**

Our key focus will be the following:

1. Cape Town IASSID Conference. SIRG members will present and facilitate
2. AGM Cape Town
3. SIRG Meeting Kingston Ontario September 2009
4. To continue membership growth

**Issues or Acting Items**

Nil

**Discussion Points for Council**

The SIRG will have a new chair after Cape Town  
Allocation of membership funds from central IASSID account would be valued

To: All Council Members –

Dear Colleagues,

Set out below are the people who will be leaving Council in Capetown, August 2008.

At Montpellier we agreed a panel system of representation. The panel were

- o Regional – Europe / South America / Asia Pacific
- o SIRGs – Families / Ageing / Health / Mental Health.
- o Individual members.
- o Organisational members.
- o Research centre members.

SIRGs are currently represented by –

Families – Jan Blacher.

Ageing – Phil Davidson.

Health – Bob Davis.

Mental Health – Tony Holland.

Severe and profound – Hans Reinders.

SIRGs not represented – Comparative Policy and Practice.

Parenting.

Quality of life.

SIRGs can be represented by their Chairperson or in that person's place, another nominee. Should the respective SIRGs re-nominate their current representative they are eligible for another term.

SIRGs have their own chair, secretary, treasurer which may change and for that reason representation is for one term.

**Retiring members:** Sheila Hollins.  
Fabrizio Fea.  
Monica Bjorkman.  
Carla Vlaskamp.  
Lisa Wang.  
Henny Lantman.  
Angel de Verdugo  
Maria Malbran.  
Neil Ross.  
Matthew Janicki.  
Stephen Kealy.  
Patricia N. Walsh.  
Ilana Duvdevany

For the Council meeting of the term 2004 – 2008 a list of nominees will be circulated to Council for their approval to present to the Assembly. The list of names will reflect the panel representation as agreed in Montpellier giving attention to geographical spread, individual membership, SIRGs, research centres, and national organisations.

Yours sincerely,

Vianne Timmons,  
Secretary IASSID.

To: All Council Members of IASSID.

Re: **Nominations to IASSID Council.**

Dear Colleagues,

I refer to the nominations to the Council of IASSID for the term 2008 – 2012. attached are:

**The people currently on Council**

**The number of Council Members by Region**

**The people serving a further term**

**The nominees for the Research Centre and Organisational Membership Panels**

**The elected individual members for the term  
2008 – 2012**

**Routes to Council:**

In the past people were elected to Council by one route only – National Associations.

Changes to the Bylaws brought in two new membership categories –

- Individual members.
- Research centres.

The size of the Council is limited to 30.

**Individual members:**

David Felce and Patricia N. Walsh were the first two individual members elected to Council. The Council agreed the level of representation as, one individual member for 100 paid up members.

As of July 31<sup>st</sup>. 2008 there are 561 paid up members Individual members are polled separately.

**Research Centres:**

No ratio formula for the representation of Research Centres has been agreed by Council. There are currently 42 paid up research centres as of the 31.7.2008.

**National Organisations:**

No ratio formula for the representation of National Organisations has been agreed by Council. There are currently 14 paid up national organisations as of the 31.7.2008.

**Defining the membership for elections:**

This year, the cut off point was extended to the 31.7.2008. The incoming Council may wish to have a fixed date in place going forward, for example –

Invoices to go out in December with a 3 month deadline, with reminders after 2 months. This does not mean not accepting members throughout the year but rather before any election to have an agreed cut off date to allow for a reasonable run in time and to take the paid up membership as of an agreed date.

This is important in any year in which an election takes place or in the event of an extraordinary general meeting of the Assembly.

### **Geographical spread:**

The Articles and Bylaws place a requirement on Council to seek a geographical spread. Originally this was achieved by looking at the country of origin of national organisations and later research centres but in the overall context of what the then Council considered as to what representation was in the best interests of IASSID.

### **SIRGs:**

Prior to Montpellier, at Assembly meetings SIRGs were not formally represented on the Council. The Assembly meeting agreed to a change in the Bylaws to panel representation as set down by Council (Article IV, section 3 b). There are 8 recognised SIRGs. David, in his discussion paper, identified the importance of SIRG representation on Council. SIRGs have the potential to act as significant drivers for the research agenda. SIRGs will be represented on Council by their Chairperson or another nominee of the SIRG. SIRG representative serve **for one term** unless re-appointed at the SIRG AGM to serve for a second term.

### **Individual membership requirement to be a member of Council:**

If the rule changes are agreed at the Assembly meeting all members of **Council must be paid up individual members.**

### **Assembly:**

Research centres and organisational members appoint delegates to the Assembly. The number of delegates depends on the size of the organisation / research centre. Currently the formula is –

- 1 voting delegate for an organisation / research centre with less than one hundred (100) members.
- 2 voting delegates for an organisation with one hundred to five hundred (100 – 500) members.
- 3 voting delegates for an organisation with over five hundred (500) members.

The Secretary has written to named people in both categories of membership asking that their named delegate contact her office in Cape Town prior to the Assembly.

The Council at its meeting appoints Individual Members as delegates to the Assembly.

Currently Council members cannot act as a delegate to the Assembly (Article III Section d).

### **Changes in this procedure:**

One of the proposed changes in the Bylaws is to remove the delegate requirement to the Assembly and give the franchise to:

- All Individual members.
- Named nominees of –  
                                    Research Centres                                      National Organisations

and remove the restriction on members of Council. The number of named representatives from research centres and national organisations will be -

- One named voting member for a member organisation with less than three hundred (300) members.
- Two named voting members for a member organisation with three hundred or more (300 +) members.

### **Research centres:**

Some research centres, listed as research centres may have a number of members in single digits. The incoming Council may wish to re-define what is a research centre in the context of numbers etc.

### **Automatic representation:**

Under the existing rules, the only automatic right of representation rests with:

- Individual members on the basis of the formula of representation outlined above.
  
- The SIRG Panel as determined by Council:

After the Montpellier meeting, people were assigned to represent SIRGs.

From Cape Town Chairs of SIRGs or another agreed nominee of a SIRG will be represented on Council but only for **one term** to take account of a change in the SIRG officers and membership.

As outlined above, 8 SIRGs will be represented on Council for the period 2008 – 2012. At the time of writing, some of the nominees are known but others will not be known until after their respective meetings.

**Transition:**

The above transition in Council representation has taken place over two Assembly meetings. The Assembly meeting in Cape Town allows for further changes.

**Deciding the slate of nominees for the Assembly meeting:**

At the Council meeting on August 25<sup>th</sup>, members of Council will decide on the slate of nominees for the General Assembly.

Once the SIRG positions have been assigned, and as the Individual Member positions are now filled there are seven free places on Council. There are however, 10 people nominated from Research Centres and National Organisations for these 7 positions.

I hope the foregoing clarifies the position for the Council meeting.

Kind regards,

Stephen Kealy.

## NOMINATIONS FOR COUNCIL 2008 – 2012

### Nominations for Council 2008 – 2012.

#### Officers:

- President: Professor Glynis Murphy.
- President-elect:\* Dr. Vianne Timmons / Dr. Giorgio Albertini.

\* For voting on by secret ballot at Council meeting, August 25<sup>th</sup>. 2008.

- Secretary: Dr. Helene Oulette Kuntz. **Unopposed.**
- Treasurer: Dr. Phil Davidson. **Unopposed.**

Council members not in a position to attend at Cape Town have been asked to send a proxy vote to Stephen Kealy.

#### Nominations – SIRG Panel:

SIRGs	Currently	2008 - 2012
Families	Jan Blacher	Awaiting nomination.
Quality of Life		Ivan Brown
Ageing	Phil Davidson	Christine Bigby
Health	Bob Davis	Bob Davis
Comparative policy and practice		Jim Mansell
Mental health	Tony Holland	Awaiting nomination.
Profound and multiple disabilities	Carla Vlaskamp	Bea Maes
Parenting		Awaiting nomination.

**Nominations - Research Centres Panel:**

<b>Research Centre Name</b>	<b>Candidate</b>
Welsh Centre for Disabilities Studies	Mike Kerr
UCD Centre for Disabilities Studies	Philip Dodd
Down's Syndrome Research Foundation – (Vancouver, Canada)	Naznin Virji Babul
Disability Study Unite – National Chung Cheng University in Min-hSiung, Taiwan.	Jin Dig Ling.

**NOMINATIONS FOR COUNCIL  
2008 – 2012****Nominees - National Associations:**

South African Association for the Scientific Study of Mental Handicap	Prof. Coleen Adnams
AAIDD	Professor Tamar Heller
Inclusion Ireland	Dr. Kathy O'Grady
Royal College of Psychiatrists	Dr. Tom Berney
German Society of Mental Handicap (DGSGB)	Dr. Michael Siedel
African Ass. of Psychiatrists & Allied Professions	Dr. Frank Njenga Gitau Njenga

**Council members serving a second term or a further term by virtue of their position as an Officer.**

Glynis Murphy	President-elect.
Vianne Timmons	Possible President-elect.
Hans Reinders.	
Giorgio Albertini.	Possible President-elect.
Helene Oulette Kuntz.	Secretary.
Phil Davidson.	Treasurer.
David Felce (ex-officio)	
Bob Davis.	
Richard Hastings.	
Joel Levy.	
Ulla Jacobsen.	
Keith McVilly.	
Franck Sturtz.	
Shigeru Suemitsu.	

**Individual members:**

3 positions to be filled from individual membership.

National Associations nominees listed below.

Research Centres nominees listed below.

## Appendix 4

Individual members	Retiring	Second term	Original point of entry.
Patricia N. Walsh	√		Individual member
Maria Malbran	√		Individual member
Joel Levy		√	Individual member.
Richard Hastings		√	Individual member.
Helene Oulette Kuntz		√	Individual member.
Hans Reinders		√	Individual member
Miguel del Verdugo	√		
David Felce		Ex-officio member of Council	Individual member.

Vacant slots for Individual Members - 3.

Why?

**Hans Reinders** was assigned in 2004 following the Montpellier meeting to the Ethics Affinity Group

**Helene Oulette Kuntz** nominated as Secretary. As the only nomination, will be elected as Secretary.

**David Felce** – as President, vacated an individual member slot in 2004.

<b>National Associations</b>	<b>Retiring</b>	<b>Second term</b>	<b>Original point of entry.</b>
Oulette Jacobsen		√	Danish Association
Matt Janicki	√		AAMR
Stephen Kealy	√		Inclusion Ireland
Sheila Hollins	√		Royal College of Psychiatrists
Shigeru Suemitsu		√	Japanese Association
Keith McVilly		√	ASSID
Neil Ross	√		Villepinte
Tamar Heller		For re-election	AAIDD
Iliana Duvdevany	√		Israel Association
Carla Vlaskamp	√		Dutch Association
Monica Bjorkman	√		Swedish Association
Fabrizio Fea	√		MAMH
George Jessien	√		Association of University Affiliated Programmes.

## Appendix 5

Research Centres	Retiring	Second term	Original point of entry.
Franck Sturtz		√	Jerome le Jeune Fondation
Glynis Murphy		President	Tizard Centre
Giorgio Albertini		√	Casa di Cura
Vianne Timmons		√	Research Department, University PI.
Lisa Wang	√		National Chung Cheng University
Tony Holland	√		Research Dept. Cambridge Univ. (Assigned to Mental Health).
Henny Lantman	√		

### Result of Individual Polling:

NAME	COUNTRY
Liliana Mayo	Peru
Gwynneth Llewelyn	Australia
Germain Weber	Austria

<b>SIRG</b>	<b>REPRESENTATIVE</b>	<b>RETIRING</b>	<b>2008 - 2012</b>	<b>ORIGINAL POINT OF ENTRY</b>
Families	Jan Blacher	√	May be re-appointed	Families
Health	Bob Davis	√	Has been re-appointed	Health
Mental Health	Tony Holland	√	Nominee to be appointed.	Research centre assigned to Mental Health SIRG
Ageing	Phil Davidson	√	Christine Bigby	Originally assigned Ageing SIRG (P. Davidson)

## Current distribution by Country:

United Kingdom	Glynis Murphy Sheila Hollins David Felce Richard Hastings Tony Holland Mike Kerr (Observer)	5 + 1 observer
Japan	Shigeru Suemitsu	1
France	Neil Ross Franck Sturtz	2
Netherlands	Hans Reinders Henny Lantman Carla Vlaskamp	3
Italy	Fabrizio Fea Giorgio Albertini	2
Taiwan	Lisa Wang	1
Australia	Keith McVilly Bob Davis	2
Canada	Vianne Timmons Helene Oulette Kuntz	2
Argentina	Maria Malbran	1
Spain	Miguel de Verdugo	1
Israel	Iliana Duvdevany	1
Ireland	P.N. Walsh. Stephen Kealy	2
USA	Tamar Heller Matt Janicki Phil Davidson Jan Blacher Joel Levy George Jessien	6
Denmark	Ulla Jacobsen	1
Sweden	Monica Bjorkman	1

**Regions:****Number**

Europe including Israel	17 + 1 observer + 1 Ex-officio
North America (USA / Canada)	8
South America	1
Africa	0
Asia / Australia	4

**STEVEN'S SHAPIRO FELLOWSHIPS**

NAME	COUNTRY	AMOUNT	WAIVED REGISTRATION
Katie McDonald	USA	€1,400	√
Shaun Cleaver	Canada	€1,400	√
Ine Hostyn	Belgium	€1,400	√
Grace Kelly	Ireland	€1,400	√
Total		€6,600	€1,800
Combined total		<b>€8,400</b>	

**MENCAP FELLOWSHIPS**

<b>Name</b>	<b>Country</b>	<b>Amount</b>	<b>Waived Registration</b>
Ereny Gobrial	Egypt	€1,400	√
Evariste Karangwa	Rwanda	€1,400	√
Paul M. Ajuwon	Nigeria	€1,400	√
Kelvin Mwaba	South Africa		√
Ancent Muli Muraba	South Africa		√
Nomonde Ngada	South Africa		√
El Marie Janse van Rensberg	South Africa		√
Amud Sayed	South Africa	€250	√
Marinda Roelofse	South Africa		√
Amanda Roux	South Africa		√
Maletsatsi Annah Ttshabangu	South Africa	€110	√
Karen Spenser	United Kingdom	€1,000	√
Craig Hart	United Kingdom	€1,000	√
Total:		€6,860	€3,235
<b>Combined total</b>		<b>€10,095</b>	

**STEVENS SHAPIRO FELLOWSHIPS**

<b>NAME</b>	<b>COUNTRY</b>	<b>AMOUNT</b>	<b>WAIVED REGISTRATION</b>
Kate McDonald	USA	€1,400	√
Shaun Cleaver	Canada	€1,400	√
Ine Hostyn	Belgium	€1,400	√
Grace Kelly	Ireland	€1,400	√
Total		€6,600	
Combined total		<b>€8,400</b>	

## **POLICY FOR COUNCIL MEMBERS TRAVEL**

In the past, costs incurred for attending Council meetings have been borne by each Council member or his or her organization. Over the past few years, IASSID has helped defray costs by paying for the lodging in the city where Council has met -- and these decisions were made on a year-to-year basis.

To help standardize this policy and to encourage attendance, it has been decided to provide a standard stipend to assist with Council attendance. In 2007, for the May 27-28, 2007 Council meeting in Paris, France, the following policy was established. The amount of the stipends was contingent on the city and distance traveled. Council members were eligible to claim reimbursement of expenses as follows: (1) Travel from within Europe (\$400); (2) Travel from North America/ Middle East (\$600); (3) Travel from South America/Asia/ Australia (\$800). In 2008, as the Council meeting will precede the 13th World Congress, travel will not be reimbursed, but a reimbursement of up to US\$300 has been authorized to defray the additional hotel nights associated with attending the Council meetings. Reimbursement will be provided up to this amount upon documentation of expenses (e.g., hotel invoice).

All reimbursement claims must be submitted via the IASSID Expense Reimbursement Form and be received by the IASSID office by October 15, 2008. As many hotels will be used for the Cape Town Congress, hotel charges for the meeting will not be direct billed and all reservations and miscellaneous charges are the responsibility of each Council member. IASSID will provide meals at the Council meeting and cover the cost of the Council Dinner.

This policy for 2008 applies to Council members attending the old Council meeting on August 25<sup>th</sup> and the new Council meeting on August 30<sup>th</sup>. Payment is limited to a total of US\$300 irrespective of whether the Council member attends both meetings.

The policy for 2009 has not yet been established.

The special stipend for individual member representatives is no longer in effect.

# Bylaws of the International Association for the Scientific Study of Intellectual Disabilities.

## Proposed changes to the Articles and Bylaws.

### Article I

#### Section 2.

Paragraph b. **Reads:** Organise international and regional congresses, conferences and seminars.

**To read:** Organise international and regional congresses, conferences, seminars and meetings of Special Interest Research Groups.

Paragraph f. **Reads:** Encourage and assist in the creation of international organisations concerned with scientific study of intellectual disabilities.

**To read:** Encourage and assist in the creation of national organisations, and research centres concerned with the scientific study of intellectual disabilities.

### Article 11

#### Section 2. Member organisations.

Paragraph c **Reads:** Each member organisation and research centre is entitled to appoint a delegate to the Assembly as specified by the Council.

**To read:** Each member organisation and research centre is entitled to appoint a voting representative to the Assembly as prescribed in these Bylaws.

Paragraph d **Reads:** Each member organisation is privileged to attend and speak at the meeting of the Assembly though not entitled to vote unless serving as a delegate.

**To read:** Each individual member of a member organisation is privileged to attend but not entitled to vote at the meeting of the Assembly unless as the named voting

**representative of the member organisation or as otherwise prescribed in these Bylaws.**

Paragraph e New article.

**To read:** Each Special Interest Group, in good standing with the association, is entitled to appoint a voting representative to the Assembly or as otherwise prescribed in these Bylaws.

#### **Section 4.**

Paragraph b **Reads:**

A subscribing individual member is privileged to attend and speak at the meetings of the Assembly though not entitled to vote unless as a delegate.

**To read:** A subscribing individual member is privileged to attend, speak and vote at the meetings of the Assembly as prescribed in these Bylaws.

**Paragraph c. Reads –**

The Council may appoint individual members to serve as a delegate to the Assembly. This delegate is entitled to speak and vote in the Assembly.

Proposal - **Delete.**

Paragraph d. **Reads -**

The privileges ascribed to subscribing individual members should be those assigned by Council, including, but not limited to, complimentary subscription to the Association's official journal and newsletter and member directory. Individual subscribing members shall be eligible for reduced registration at the IASSID World Congresses and other meetings as deemed by Council or Meeting Program committees.

**To read:** The privileges ascribed to a subscribing individual member shall be those assigned by the Council, including but not limited to the Association's official journal and membership directory. Individual subscribing members shall also be eligible for reduced registration at the IASSID World Congresses and other meetings as deemed by the Council or Meeting Program Committees.

## Section 5.

### Paragraph b **Reads:**

Honorary members are considered as individual members of the Association with the privileges of subscribing individual members excluding complimentary provision of the official journal and reduced registration fees of World Congresses. They are privileged to attend and speak at the meeting of the Assembly though not entitled to vote unless serving as a delegate.

### **To read:**

**Honorary members are considered as individual members of the Association with the privileges of subscribing individual members and a reduced registration fee at world Congresses as determined by Council. They are privileged to attend and speak at the meetings of the Assembly though not entitled to vote unless as an individual subscribing member or as named representative by a member organisation or research centre.**

## Section 7

Paragraph b. **Reads:** Member organisations and subscribing members in default of payment of annual fee shall be given an additional year in which to pay. If the annual fee is not paid at the end of one year extension, the Council may elect to place the member organisation or subscribing members in probationary status. During the probationary status, the individual member of the member organisation and subscribing member shall be ineligible to vote, to hold office or be a member of any committee of the Association. A member organisation or individual member is in good standing with the Association if its / his / her fees or dues are paid within the year of membership. Membership normally lapses at the end of each calendar year and a member is only in good standing with the payment of fees prior to the beginning of or during the next calendar year.

**To read: A member organisation or individual member is in good standing with the Association if its / his / her fees or dues are paid up within the year of membership. Membership lapses at the end of each calendar year and a member is only in good standing with payment of fees prior to the beginning of or during the next calendar year.**

Section 8 Termination of membership.

Paragraph b. **Reads** A member may be terminated from membership for conduct which tends to injure the Association, contrary to or destructive of its

purpose. Charges of such conduct shall not be entertained unless submitted to the Council, in writing, and signed by two members of the Association. Upon receipt of charges, the Council shall determine whether the charges shall be dropped. If the charges are not dropped, the member concerned shall be given an opportunity, either to resign, or be heard in defence. If said member chooses a hearing, he / she shall not be terminated from membership except by 3/4<sup>th</sup> vote of the Council members present and 3/4<sup>th</sup> of the delegates present at an Assembly of the Association.

**To read:** **The IASSID may terminate from membership a member for conduct which is contrary to the purpose and means of the Association as set out in Article 1, sections 1 and 2 of the Association. Council shall entertain a proposal of termination of membership when submitted in writing and signed by two members of the Association. Membership will be terminated by three-fourths (3/4) vote of the Council members present and three-fourths (3/4) vote of those members entitled to vote in vivo or by proxy at an Assembly of the Association.**

**Article III** The Assembly of Members.

Section II Composition of Assembly.

Paragraph a. **Reads:** The Assembly shall consist of:

- i) Voting members who are delegates of member organisations, research centres, regional groups, special interest research groups and individual members designated as a delegate by the Council.
- ii) Non-voting members who are the other members of the Association.

**To read:** **The Assembly shall consist of:  
Designated voting members of –**

**Member organisations.  
Research centres.  
Special interest research groups.  
and  
Individual members.**

- iii) Non-voting members, who are the other members of the Association.

Paragraph b.

**Reads:** Each member organisation or research shall appoint voting delegates to the Assembly as specified by Council.

- one voting delegate for an organisation with less than 100 members,
- two voting delegates for an organisation with 100 to 500 members.
- Three voting delegates for an organisation with over 500 members.

**To read:**

**Each member organisation and research centre shall appoint a designated representative to vote on their behalf at the Assembly as prescribed in these Bylaws.**

- a. **One named voting member for an organisation with less than 300 members.**
- b. **Two named voting members for an organisation with 300 or more members.**

Paragraph c. **Reads:**

The Council may appoint individual members to serve as delegates to the Assembly. Such delegates will be those from each country represented in the membership.

Proposal: **Delete.**

Paragraph d.

**Reads:** Council and Officers cannot be appointed as delegates to the Assembly.

Proposal: **Delete.**

Paragraph e.

**Reads:** Regarding the identification of eligible voters at a General Assembly meeting, the Secretary will provide as many signed cards to member organisations, research centres and special interest research groups as they are entitled to have voting delegates as well as to the delegates appointed by Council. Delegates should make themselves known to the Secretary before the meeting in order to be entitled to vote in the General Assembly.

**To read:**

**A designated voting member(s) of member organisations, research centres, special interest groups, will identify themselves to the Secretary prior to the General**

**Assembly. The Secretary will provide signed cards to designated voting members of member organisations, research centres, special interest research groups, and individual members.**

**All designated voting representatives and individual members must be in good standing with the Association two months prior to the General Assembly.**

Paragraph f **Reads:**

The period between Assembly – meetings of one world congress to the next is considered the term of office for a voting delegate.

**To read:**

**Designated voting representatives may vote by proxy. A proxy vote must reach the Secretary of IASSID at least two weeks before a General Assembly or extraordinary general meeting of the association. Proxy votes may be delivered via post, electronic mail or by fax in a format prescribed by Council.**

Paragraph g **Reads:** One third (1/3) of the member organisations, subscribing individual members, who are appointed as delegates shall constitute a quorum for the transaction of business.

**To read:**

**One third (1/3) of those members entitled to vote shall constitute a quorum for the transaction of business.**

#### **Article IV**

The Council of the Association – section 2 – composition of Council.

**Reads:**

The Council of the Association shall consist of the Officers and the Council of the Association, each of whom shall be elected by the Assembly as described in these Bylaws.

**To read:**

**The Council of the Association shall consist of the elected officers and councillors of the Association, each of whom shall be an individual member in good standing with the Association elected by the Assembly or as otherwise prescribed in these Bylaws.**

#### **Article V.**

Section 1. Officers

**Reads:**

The Officers of the Association are the President, the President-elect, Four Vice-Presidents, The Secretary, The Treasurer and the immediate past-President.

**To read:** The elected Officers of the Association are the President, the President-elect, the Secretary and the Treasurer. The President can appoint from the members of Council not more than 4 Vice Presidents as prescribed in these Bylaws. A Vice President may serve successive terms, at the discretion of the President and Council, if the Vice Presidents responsibilities to Council remain the same.

## Section 2 – Nomination, Election and Term of Office.

Paragraph a **Reads:** Officers and Honorary Officers presented for election shall be drawn from a list of nominees as set out by the Nomination and Elections committee following consultation with the current officers, councillors and member organisations, individual members and formal SIRGs, all in good standing with the Association.

**To read:** Officers and Honorary Officers presented for election shall be drawn from a list of nominees as set out by the Nominations and Elections Committee following consultation with the current officers, councillors and member organisations, individual members and SIRGs, all in good standing with the Association or as otherwise prescribed in these Bylaws.

## Section 4 President-elect.

**Reads:** The President-elect shall serve for one term or until a successor is elected and shall succeed to the office of President upon completion of his / her term of office. He / she shall perform such other duties as may be assigned by the Council or the President. In the absence or temporary disability of the President-elect, necessary duties shall be undertaken by:

- (i) Vice-President (Chairperson of Nominations & Elections Committee).
- (ii) Vice-President (Chairperson of Awards & Recognitions Committee).

**To read:** The President-elect shall serve for one term or until a successor is elected, and shall succeed to the office of President upon completion of his / her term of office. He /she shall perform such other duties as may be assigned by the Council or the President. In the absence or temporary disability of the President-elect, necessary duties shall be undertaken by an officer or member of Council as recommended by the Officers of the Association and agreed by the Council.

Section 5. Vice-Presidents.

**Reads:** A Vice-President shall serve not more than one term. Vice-Presidents, appointed to complete the term of a vacated Vice-Presidency may stand for election for another term. A Vice-President may serve more than one term provided the additional term is not in succession. The Vice-President shall perform such duties as may be assigned by the Council or President.

A Vice-President shall perform such duties as may be assigned by the President or Council.

**To read:** **A Vice-President may be appointed for successive terms by the President, with the approval of Council. A Vice-President shall perform such duties as may be assigned by the President or Council.**

Section 7 Treasurer

Paragraph b. new article

**To read:** **The outgoing Treasurer may serve in an advisory capacity, at the request of the President, and the agreement of the Council, one further year to assist the incoming Treasurer.**

Section 8 Immediate past President

**Reads:** The Immediate Past President shall serve for one term, beginning immediately at the termination of his / her presidency. He / she shall be a full member of the Council, and shall perform such duties as may be assigned by the Council or the President.

**To read:** **The immediate past President, as an ex-officio member of Council, shall serve one term beginning immediately at the termination of his / her Presidency. He / she will be a full member of the Council and perform such duties as may be assigned by the Council or the President.**

Section 9 Miscellaneous provision –

Paragraph a.

**Reads:** In the event of a Vice-President, the Secretary, or the Treasurer are unable to perform the duties of their respective offices, they may ask the President to be relieved of their responsibilities. The Officers can appoint a deputy-officer in his / her place. For this a postal

election can be held. A majority of the votes from the Officers is required. Upon the decision of the Council, one Officer may be vested with more than one office.

**To read:** In the event of a Vice President, the Secretary, Treasurer, are unable to perform the duties of their respective office, they may ask the President to be relieved of their responsibilities. The Officers can appoint a deputy officer in his / her place. An electronic election can be held. A majority votes can be sufficient to determine the outcome.

Section 9 New article

Paragraph e.

**To read:** The editors of JPPID, JIDR (as long as it remains affiliated with IASSID) and the Association's website are ex-officio non voting members of Council.

**Article VI** Section 8 Finance Committee.

**Reads:** The Finance Committee shall consist of the Treasurer as its chairperson and three members appointed by Council for one term or until successors are appointed. It shall be concerned with the financial affairs of the Association.

**To read -** The Finance Committee shall consist of the Treasurer as the chairperson, the outgoing Treasurer and three members appointed by Council for one term or until successors are appointed. They shall be concerned with the financial affairs of the Association.

**Article X** Amendments & Dissolution:

Section 1. Amendments to the Articles of Incorporation.

**Reads:** Amendments to the Articles of Incorporation may be instituted on recommendation of the Council or by a postal petition of one-third (1/3) of the member organisations and subscribing individual members who are appointed as Delegates to the Assembly. Notice of proposed amendments shall be mailed to the member organisations and subscribing individual members entitled to vote by the Secretary at least three months prior to a meeting of the Assembly. An amendment, cancellation or addition of which due notice has been given, will be carried to the Articles when accepted

at a meeting of the Assembly by a two-thirds (2/3) vote of the Delegates in attendance.

**To read:**

**Amendments to the Articles of Incorporation may be instituted on recommendation of the Council or by a petition, postal or electronic, of one-third (1/3) of the member organisations, research centres, SIRGs designated as voting members, and individual members, all in good standing with the organisation. Notice of proposed amendments shall be communicated to member organisations, research centres, subscribing individual members and SIRGs entitled to vote by the Secretary at least two months prior to a meeting of the Assembly. An amendment, cancellation or addition of which due notice has been given, will be carried to the Articles when accepted at a meeting of the Assembly by a two-thirds (2/3) vote of those members entitled to vote at an Assembly of the Association and in attendance.**

Section 2. Amendments to the Bylaws.

**Reads:** Amendments to the Bylaws may be instituted on recommendation of the Council or by motion of five Delegates to the Assembly at a regular meeting. A simple majority of the votes given by the Delegates entitled to vote shall be necessary to carry on an amendments, cancellation, suspension or addition to the Bylaws.

**To read -** **Amendments to the Bylaws may be instituted on recommendation of the Council or by motion of five members entitled to vote, as prescribed in these Bylaws, at an Assembly at a regular meeting. A simple majority of the votes given by those members entitled to vote shall be necessary to carry on an amendments, cancellation, suspension or addition to the Bylaws.**

Section 3. Dissolution.

**Reads:** The Association shall be dissolved only by consent of two-thirds (2/3) of the member organisations at a meeting of the Assembly. There shall have been notification to the member organisations and the subscribing individual members of the proposal to consider dissolution at least six months prior to the meeting. This proposal is made by the Council and sent to the Secretary. Should there be no possibility to hold an Assembly meeting within one year after the proposal is made, or should there be representation of less than two-thirds of the members entitled to vote at the Assembly meeting at which dissolution is considered, a postal referendum shall be effected and consent of two-thirds of the member organisations and

subscribing individual members entitled to vote shall be required for dissolution.

**To read -** **The Association shall be dissolved only by consent of 2/3rds of the member organisations as per article 3 Section 2(a), 1, b, c, d, e, g. There shall have been sufficient notification to the membership of the proposal to consider dissolution at least 6 months prior to the meeting. This proposal is made by the council and sent to the Secretary. Should there be no possibility to hold an Assembly meeting within one year after the proposal is made or should there be a representation of less than of two-thirds (2/3) of the membership entitled to vote at the Assembly meeting at which dissolution is considered, an electronic referendum shall be affected and consent of two-thirds (2/3) of the membership entitled to vote shall be required for dissolution.**



## International Association for the Scientific Study of Intellectual Disabilities

August 19, 2009

To: All Individual IASSID Members  
Chairs of SIRGs  
Chairs of Affinity Groups  
National Organisations  
Research Centres  
Council Members

RE: **Africa Service Network Meeting - Building a network of support in Africa post the IASSID Cape Town Congress.**

Dear Colleagues,

In Capetown, on Tuesday, August 26<sup>th</sup> 2008, at 18.00 – 19.15 hours in the CTICC in room 1.44 there will be an Africa Service Network meeting to explore building networks of support with colleagues in Africa over the next four years.

The essential purpose of the meeting is to identify colleagues in African countries with whom IASSID can form a working relationship over the next four years. One of the primary objectives is to raise an understanding of the needs of people with an intellectual disability. Achieving a higher profile for people with an intellectual disability may be difficult to accomplish against a backdrop of competing demands for resources both financial and human. However, IASSID would like to explore how their current structure of –

- Specialist Interest Groups
- Individual Members
- Research Centre Members
- Organisational Members

could participate in the development of networks of support but rooted in the context of what is culturally appropriate.

/...2

The meeting is exploratory and will endeavour to identify a number of small steps as a start in building a strong network of support for the future.

The meeting will be chaired by Mr. Brian O'Donnell of the Federation of Voluntary Bodies in Ireland.

Venue: CTICC  
Room: 1.44  
Date: Tuesday, August 26<sup>th</sup>. 2008.  
Time: 18.00 – 19.15 hours.

If you are attending the Congress and interested in giving of your time and expertise to this proposal please set aside time on the 26<sup>th</sup>. to attend the meeting.

Yours sincerely,

Stephen Kealy,  
Vice-President,  
IASSID.