



NEWSLETTER

INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF INTELLECTUAL DISABILITIES

President's Report - 2003

The last year has been one of considerable advancement for IASSID.

Buenos Aires

Buenos Aires hosted the first Council meeting of the IASSID to be held on the South American continent and we hope it is not the last. We are indebted to **Professor Maria Malbran** and her group for all of their effort in organizing this Council venue and for what she personally has gone through to receive us so hospitably. It was also a very special occasion, as our meeting preceded the inaugural gathering and conference of our new regional group, "IASSID-SudAmerica." It is certainly our hope that there will be many more such meetings and IASSID Sud-America will become an important partner within IASSID. We also note the generosity and excellent initiative taken by Council member Kurt Sorensen and his Danish association in sponsoring and enabling two colleagues from Los Pipitos in Nicaragua to go to Buenos Aires to be part of the conference.

Regional Groups

The creating and the setting up of regional associations has been an exciting new aspect of our association. There are now three such groups: IASSID/Europe, IASSID/SudAmerica and IASSID/Pacific. The inclusion of these regional groups within IASSID will allow greater participation of our members in areas of the world where IASSID's presence has only begun to be felt. With

the emergence of our regional organizations, the mission of IASSID to distribute new research information and support collegial networks will be even more strengthened as they enable us to hold more local meetings and conferences in between our Congresses and permit more people to attend when economic situations don't permit international travel.

The IASSID-Europe regional group held a very successful meeting in June 2002, the next one being conducted by **Wil Buntix and Henny Lantman** will be held in Maastricht in 2006. **Lisa Wang** is preparing a meeting in Taiwan which will be the first meeting of our new IASSID-Pacific regional group. Its inaugural conference will be held in Taipei, Taiwan on June 12-15, 2005. The location is the Howard International Guest House Conference Hall, an excellent and well-chosen venue. In this same vein, our SIRGs are continuing to hold international meetings on their areas of special interest. Over the past couple of years, the aging, health issue, profound and multiple disabilities, and ethics SIRGs have held roundtables attended both by members of IASSID and others particularly interested in the topics of the roundtables. I am particularly pleased over the diversity of venues used for these roundtables, signalling our growing international focus. These roundtables were held in Japan, Sweden, Scotland, Greece, Australia, and The Netherlands.

Functional Outlook

Our Association has improved its financial status and would seem to be quite healthy. During these four



INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF INTELLECTUAL DISABILITIES
Association Internationale pour l'Étude Scientifique de la Déficience Intellectuelle
Internationale Vereinigung zum wissenschaftlichen Studium von Intelligenzstörungen
Asociacion Internacional para el Estudio Científico del Deficiencia Intelectual
Associação Internacional para o Estudo Científico da Deficiência Intelectual

See Internet at <http://www.iasid.org>

years, we had set ourselves a goal of bringing the Association on a sound financial footing by expanding our membership, developing better fiscal management, and setting the quadrennial Congress organizational and financial control more directly under IASSID. I am pleased to say that in continuing the legacy and vision of our past presidents and in particular my immediate predecessors, Dr. Michael Mulcahy, Terry Dolan, and Trevor Parmenter, I have been able to move the Association into the forefront of the world's disability networks as a formidable organization within the field of intellectual disabilities. We have also expanded our membership bases considerably through the tireless efforts of our officers and the leaders of our various Special Interest Research Groups. Our membership recruitment efforts have been very productive and we have expanded our affiliative organizations to include some 35 research centers from all over the world. We have also more engaged our individual members, in part through our efforts in reminding members to pay their fees, in keeping associations in the loop, and our special efforts to canvass and seek out new members for the research center group.

Journals

Our current affiliated journal, the *Journal of Intellectual Disability Research* (JIDR) has selected Professor Anthony Holland of Cambridge University as the new Editor to replace **Professor Bill Fraser** who has retired from the University of Cardiff and who is also stepping down as the editor of JIDR after many years of excellent service. Professor Fraser is to be thanked for all the work he did for the journal and for IASSID as it was he that promoted the joint venture whereby JIDR became the affiliated journal of our association. I am also pleased to announce that, with Professor Fraser's help, we have successfully organized a new agreement with Blackwell Publishing in Oxford, England to begin a companion journal to the JIDR. Our new journal, stimulated and to be supported during its formative

years by a generous grant-in-aid from the Tosinvest/San Raffaele Foundation in Rome, Italy, will enable us to focus publications in the area of research practice and policy. Titled the *Journal of Policy and Practice in Intellectual Disabilities*, the new journal will be published quarterly and will be IASSID's contribution to the international literature in intellectual disabilities. I want to stress that this new effort would not have been possible without the insight and work of Dr. Giorgio Albertini, our new Council member from Italy, and without the generous support of, the **Tosinvest organization**.

Website

With an ever expanding international focus on electronic information exchange, we have updated and redesigned our IASSID website. This redesign was stimulated by our interest in making our Association more accessible to all of our members and for Council. We have also set up a forum for members and a special forum for councillors and I see this service expanding in use considerably over the next few years. Our website, as we continue to expand and develop it for other uses, will grow in prominence. In the next month we will use the members' only section to post our membership directory and the public pages to list our ever-growing list of affiliated organisations and add a scheduled conferences section. Our website will also take on more importance as a vehicle for announcing and facilitating registration for the 2004 World Congress.

Publications

Over the past two years, we have also seen the successful launching and publication of three texts, as part of the IASSID series on aging and adult development. The three books included texts on women's health, physical health and mental health. We have copies of the most recent text here today - the one by Prof. Philip Davidson of the University of Rochester. I'd like to thank our members, Prof. Patricia Noonan Walsh, Prof. Tamar Heller, Dr. Vee

Prasher, and Prof. Davidson, for their work and contributions to IASSID in serving as the editors for these text. I'd also like to recognize all of the IASSID members who contributed chapters for these three texts and forwent any royalties in favour of IASSID. My thanks also to Prof. Matthew Janicki who developed the series, worked with Blackwell Publishing to see that they were successfully completed, and also served as the series editor for the books. More importantly, I see this series as the forerunner of many more such ventures, with a number of publishers around the globe, positioning IASSID as the premier research and dissemination organization in the area of intellectual disabilities. As a result I have tasked our Publication's Committee to examine other such projects and report back to me on their ideas for additional book projects under the IASSID imprimatur.



Meeting in Rome in respect of new Journal

Site Selection Committee

A special site selection committee has been set up for vetting the venue for the 2008 IASSID World Congress. Core members of this committee are Matthew Janicki, Patricia Noonan Walsh, and Glynis Murphy. They have been tasked to evaluate alternative sites and support proposals and to report back to Council. They will be working with Prof. David Felce and it is our expectation that we will have a recommendation for a site at our next Council meeting in 2004. I anticipate that by using a selection site committee we can lighten the load of the President-Elect who is at this time of the cycle already very busy with the organization of the 2004 World Congress and would find securing a congress site as a diversion from his every expanding duties over the next months.

WHO

I am pleased to say that the work of my predecessor, Professor Trevor Parmenter, in developing a formal relationship with the World Health Organization continues to bear fruit. IASSID, through Trevor's foresight and excellent contacts, is in formal affiliative status with the WHO and is in consultation and maintains a workplan with the WHO. At this time we are following closely the work plan he set out for our relationship with other associations and organizations such as the WHO. Our last significant contribution to the WHO was the background work in intellectual disabilities and aging that was done for the 2002 World Assembly on Aging in Madrid, Spain.

World Congress, Montpellier

Professor David Felce and his Programme Committee in conjunction with Professor Charles Aussilloux and the Montpellier Local Organizing Committee have met their target deadlines. Our next World Congress in Montpellier will be held June 14-19, 2004 and it is gathering momentum and enthusiasm each month. The first IASSID World Congress was held in Montpellier and thus we return for a birthday celebration 37 years later. Some of the organizers of that first congress will be on hand next year.

Conclusion

In closing, I would like to thank my co-officers, Professor Matthew Janicki, our Treasurer, for his tireless efforts at ensuring that our financial status remains viable, and Stephen Kealy, our Secretary, whose counsel and planning for Council and other meetings means my job runs ever so more smoothly. I would also like to thank our Vice-Presidents, Sharon Ramey and Nick Bouras, for their continued support and efforts on behalf of IASSID and of course, Prof. David Felce for his devotion to the 2004 World Congress.

**Dr. Neil Ross, President
December, 2003**

REMINDER

Don't forget -

12th. World Congress of IASSID
June 14 - 19th. 2004

SECRETARY'S REPORT

2003 has seen very significant developments in the membership of IASSID. The increase in all categories of membership, particularly individual membership, has been very encouraging, and due in no small way to the trojan work of Dr. Matthew Janicki. At the time August Council meeting 446 people had signed up as an individual member.

Changing Membership

The participation of the membership in the governance of the IASSID is critical to the its continuation as a well-respected international research organisation, which can bring a global perspective on intellectual disabilities.

The changing membership structure has an impact on the current bylaws, the composition of Council, and of course on the organisation's governing body, the Assembly.

The successful Council meeting in Buenos Aires, South America provided an opportunity to foster new links and strengthen existing ones in South America.

IASSID-Pacific Rim:

Lisa Wang in Taiwan is actively involved in developing a programme for an IASSID Pacific Rim Conference in Taipei in 2005. Lisa is open to offers of support and help for either the programme or with organising the event.

Congress 2008:

The venue for the 2008 World Congress will play an important role in putting down an IASSID root where it has not yet been planted. The President's new site selection committee, under the chairmanship of Dr. Matthew Janicki will look at proposals from the membership in respect of suitable venues.

Montpellier as a Congress venue provides an opportunity to foster support in France for IASSID.

Assembly 2004

The Council has to address the challenge of addressing the change in the membership, the

development of SIRGs and Regional groups against the current Articles and Bylaws and propose changes to the Assembly.

Election & Council:

In June 2004 some people will be retiring from Council. One of the issues which has to be addressed is the participation of Council members in the work of IASSID through their attendance at Council meetings, membership of committees, participation in SIRGs and involvement in regional groups.

The Work plan of IASSID:

The work programme of IASSID in any one term is moved forward by:

- SIRGs
- Committees
- Officers of IASSID
- Regional groups

However, progress is dependent on the voluntary commitment of Council members and the general membership, whether as members of committees or SIRGs.

When organisations or Council members are making nominations for Council active consideration should be given by the nominated individual whether he or she can attend meetings.

Geographical Spread

The Articles and Bylaws identify the need for geographical spread. Regional representation will achieve a better spread and enable more active participation and development of IASSID in those regions.

New Journal

2004 will see the launch of a new IASSID journal on Policy to Practice. The journal will provide an opportunity for researchers to link with practitioners, and vice versa.

Montpellier

The plans for the Congress are well advanced. As to the final call abstracts quickly followed and have been collated. The SIRG structure of IASSID provided opportunities for focusing presentations in key areas.

Awards & Recognition

Dr. Sharon Ramey, Chairperson of the IASSID Committee on Awards & Recognition invites nominations for the following awards:

- Distinguished Achievement Award - Research
- Distinguished Achievement Award - Scientific Literature.
- Distinguished Achievement Award - Service.
- Distinguished Service citation.

The Committee, in exceptional circumstances, and by agreement of Council, may make more than one award in each category. Further information is available on the IASSID website.

The Committee also invites nominations for Fellows of the IASSID.

It is important for all nominations to reach Dr. Ramey by 28.2.'04. The deadline is final and necessary to provide sufficient time to review documentation, seek Council approval, appropriate presentations secured and awardees notified.

IASSID Ethics Guidelines

Members of Council received and approved a draft copy. "Ethics guidelines for international, multi-center research involving people with intellectual disabilities" prepared by Keith McVilly (email: kmcvilly@med.usyd.edu.au) and Art Dalton (email: daltonaj@aol.com)

The Council identified a strategy for the document's dissemination.

**Stephen Kealy,
Secretary IASSID.**

12th World Congress in Montpellier 14th-19th June, 2004

UPDATE

David Felce

Chair, Programme Committee

I am writing this update on the Monday after the closing date for the submission of abstracts. I cannot tell you precisely how many proposals for symposia, papers, posters, roundtable or debates I have received as we are still processing the deluge. I was in Brussels on the final Friday for a European project meeting but when I came into the office yesterday to continue to respond to submissions, I had over 460 emails in my inbox. I have every expectation that the Montpellier congress will emulate the breadth and depth of our recent meetings.

Neil Ross and I were in Montpellier the week before the closing date for a very successful day conference organised by Charles Aussilloux. We took the opportunity to meet the conference co-ordinators at Le Corum. The arrangements are naturally by now well advanced but we are still attending to the fine detail so that we can include as much useful information as possible in the Programme Book which is due at the printers at the end of next month. We were pleased to find that a number of delegates have registered already. Nigel Beail from England has the distinction of being the first to book his place.

The Abstract Book will again be two volumes of the Journal of Intellectual Disability Research, so it will be possible to give a peer-reviewed journal citation to all



Le Corum Congress Centre



Le Corum Staff

papers, posters and other presentations given at the congress.

The exhibition space at Le Corum will be very central. It will be located in the main concourse, between the entrance to the Berlioz Auditorium, the plenary lecture hall, and where coffee and tea will be served. I encourage potential exhibitors to contact me.

In the past, the IASSID congress has attracted a relatively small number of commercial exhibitors. I would be interested in hearing from research centres or academic departments who might like to purchase exhibition space to showcase their research or training programmes. This might be a very good way to attract potential collaborators, or future members of staff, or postgraduate students. Centres and departments may not feel that they want to incur the full costs of taking an exhibition booth for the duration of the congress, so I think there may well be potential for collaboration and sharing costs, or more simply hiring the space for part of the time (e.g., a day). Let me know your interest and I will seek to make arrangements which best suit you.

The deadline for sending the Programme and Abstract Books to the printers is 31st January, 2004. I will contact everyone who has submitted a paper, poster or other presentation to me at about that time to let them know that their submission has been accepted and when it is to be scheduled. The Programme will be posted on the IASSID website (www.iasid.org) as soon as possible afterwards. Once typeset, the Abstract Book will be available on the Blackwell Publishing website, hopefully in a searchable format. A link to it will be provided from the IASSID website. Those who want to prepare well for their time spent in Montpellier will be able to

download the Abstracts well in advance of the Congress.

Those who want to prepare well for their time in Montpellier in other ways might want to look at the Montpellier Office of Tourism website (www.ot-montpellier.fr). You can get information on guided visits, museums, parks and gardens, sports and leisure, cultural events, and all you might need during your stay. For example,

www.ot-montpellier.fr/fr/internet/votresejour/0200/listing.php

gives a listing of 49 restaurants in central Montpellier by type of restaurant (brasserie, traditional, specialist cuisine, gastronomic) and price level.

Of course, the region of which Montpellier is the capital, the Languedoc, is famous for fine wines. Close by are the wine growing areas of Corbières, Minervois, Fitou, Faugères and Limoux (Blanquette de Limoux is like champagne). Sweet muscat wines are also made in the area. You can discover more at www.languedoc-wines.com

Report of the Informal Nursing Special Interest Research Group

For the IASSID Council Meeting August 2003

Officers

Because of the informal nature of the group, Kathy Service, from the US has undertaken a co-ordinative role.

Membership

At last count, 19 people reported belonging to the group. I believe that all members are paid IASSID members. Many IASSID members express an interest in this group, but cannot participate actively at this time.

Activities undertaken during the year

In 14th June of 2002, the first meeting of the INSIRG was held in Dublin in conjunction with first IASSID Europe Conference with 8 members in attendance.

During this past year, this small group has set as its primary objective a statement on the vision, aims, role of the group.

Plans

The group are planning three symposia for the Montpellier meeting: The themes are as follows:

- Evidence-based Practice in Nursing,
- Transitions, and
- Mutual Understanding and Compliance.

Meetings

As of this time, no meetings are scheduled.

Recommendations for Future Activities

To actively contribute to the 12th World Congress through specific nursing symposia and active participation such as paper presentations within symposia organized by our other SIRG's.

To explore with the Editor of the new Journal on Policy and Practice a special issue on nursing care management issues.

It is widely recognized that the provision of supports relating to one's health throughout the lifespan contributes to the well-being and quality of life for all individuals. Nurses have a long and rich tradition of supporting individuals without discrimination including those with intellectual disabilities.

The Nursing SIRG has generated much discussion in IASSID: The aim of this group is to understand how the discipline can contribute and support the IASSID Research, Policy and Practice Agenda.

Aims and Visions

- To network and share ideas re: curriculum, research, policies, clinical practice and be a vehicle for exchanging internationally information about publications with a nursing focus that may not be known cross countries.
- To remain an informal dialogue group for nursing and cross-disciplinary challenges about the nursing care issues for persons with ID.
- To synthesize health-related research into

good practice in partnership with the individual with I.D. and their carers.

Guiding Principles

- To be active members of other Special Interest Research Groups.
- To promote individual membership of the IASSID.
- To collaborate or work issue-specific activities as requested or charged by the Council, other formal SIRG's of the IASSID.
- Apply research to policy and practice to enhance the quality of life of individuals with ID and their families.

**Kathy Service, Co-Ordinator
Nursing Affinity Group**

Publications and Research Committee Report to Council August, 2003

Committee's Charge

The Publications and Research Committee shall have the responsibility for encouraging research and establishing scientific publications that are of interest to the Association and advance its purposes.

Committee Members

Bob Schalock - Chair
Jan Blancher - Families
Roy Brown - Quality of Life
Michael Kerr - Health
James Hogg - Aging
Tony Holland - Mental Health
Michael Kamp - Employment
Hans Reinders - Ethics
Sandy Tymchuk - Parenting

IASSID Publications Committee

Functions and Responsibilities:

- Reviewing documents/publications that contain IASSID name, insignia, or

endorsement. This review would be based on a simple checklist of: (a) SIRG- sponsorship; (b) IASSID sponsorship; (c) documentation of involvement with other organizations (such as WHO); (d) and documentation that the document conforms to acceptable (e.g. APA) publication standards (if applicable). This review would take place before any official publication of the materials outside of the IASSID.

- Communicating to the Executive Committee results of the above within one month following receipt by the Chair of the Publications Committee.
- Assisting in the publication of IASSID-sponsored documents (e.g. position papers).
- Reporting annually to Council a summary of the above three functions/ responsibilities.

SIRG Functions and Responsibilities

vis a vis The Publications Committee:

- Planning, conducting, and publishing SIRG-related research (including books). SIRGs would interface with the Publications Committee only during the publishing function, as outlined above.
- Documenting agreements and/or arrangements with other organizations (e.g. WHO).
- Submitting information (via SIRG chairperson) to Web Master.
- Reporting annually to Council: (a) a list of research projects and their current status; and (b) a list of articles/books/book chapters published.

2003 Activities:

1. Assisted in the finalization and contract with Blackwell regarding the new, official IASSID Journal: The Journal of Policy and Practice in Intellectual Disabilities (JPPID).

2. Discussions have commenced regarding: (a) a mechanism for regional development; and (b) potential book titles/proposals.

Respectively Submitted,
Robert L. Schalock, Ph.D., Chair
Publications and Research Committee
June 17, 2003

SIRG on Families Research Report to Council, August, 2003

Families Research SIRG's Charge:

The SIRG on Families Research was organized to serve three purposes: (1) To respond to the growing interest, world wide, in the pursuit of research pertaining to families of individuals with intellectual disabilities; (2) To bring together IASSID researchers who represent diverse methodological and cultural perspectives; and (3) To promote an active family research agenda and to have a substantive presence within the organization of IASSID.

Committee Members:

To date, we have a roster of about 73 interested members of the Families Research SIRG.

- Chairperson: Jan Blacher
- Secretary: Chris Hatton
- Treasurer: To Be Elected at IASSID Montpellier meeting.

SIRG Activities:

The Families Research SIRG has met three times since its "official" formation at the IASSID meeting in Seattle, Washington. The most recent Families SIRG meeting was held during the Gatlinburg Conference for Research and Theory in Annapolis, Maryland, during March, 2003. We are proud of our accomplishments to date:

- We have produced a Special Issue of JIDR on research on families; in fact, there will be two issues, containing a total of 14

papers. The issue was edited by Chris Hatton, Jan Blacher, and Gwenyth Llewellyn

- SIRG members in attendance at the IASSID meeting in Dublin (June, 2002) created working groups to put together symposia on families research for the 2004 meeting in Montpellier. Topics for these symposia include (with topical group members in parentheses):
Cross-cultural work (C. Hatton, J. Blacher, R. McConkey)
Challenging behaviors as they impact families (P. Minnes, L. L. McIntyre)
Social context of families (E. Emerson, G. Llewellyn)
Methodological and theoretical perspectives (O. Barr, J. Blacher)
Positive impacts on parents (R. Hastings, G. Grant)
Mothers and employment issues (B. Redmond, S. Todd)
- SIRG members also developed an agenda of future activities, including:

Collaborative projects among members, especially cross-cultural work.

Pursuit of publications of some of the papers to be presented at Montpellier.

Interest in creating a website for posting information relevant to our SIRG

We welcome the interest, comments, suggestions and support of the IASSID Council.

Respectfully submitted,
Jan Blacher, Ph.D., Chair IASSID SIRG on
Families Research
June 20, 2003

Aging Special Interest Group

SIRGAID Report to the IASSID Council
August 2, 2003, Buenos Aires, Argentina

I. Officers

Chairperson:

Matthew P. Janicki, Ph.D.

Vice-Chair:

Christine Bigby, Ph.D.

Secretary:

Dawna Torres Mughal, Ph.D., RD

Treasurer:

Phillip W. Davidson, Ph.D.

Council Representative:

Henny Lantman de Valk, M.D., Ph.D.

II. Membership

Total membership:

143 affiliated members of IASSID

(as of June 1 2003)

71 paid members

72 IASSID members indicated aging as a SIRG of interest but who had not paid yet.

III. Activities Undertaken During the Year

Dr. Henny Lantman, as the SIRGAIDs' member on the IASSID Council, attended the IASSID Council Meeting in Glasgow, September 13, 2002. Her report at the SIRGAID's business meeting in Volos, Greece, May 3, 2003, included several issues pertaining to the SIRGAID's agenda. It included information on the locations of future meetings: 2003, Buenos Aires, IASSID Congress in 2004; 2005 Regional Meeting of IASSID Pacific in Taipei, Taiwan; and the 2006 IASSID Europe Regional Conference in Maastricht, the Netherlands.

Over the past year, a number of SIRGAID members were intimately involved in producing two text for Blackwell Publishing, one on the physical health issues of older adults (by Dr. Vee Prasher and Dr. Matthew Janicki) and one on the mental health issues facing people with ID as they grow older (by Drs. Philip

Davidson, Vee Prasher and Matthew Janicki). These were part of the three book series developed by IASSID for Blackwell. The first text, on women's health, also was produced by two of our members (Dr. Patricia Walsh and Dr. Tamar Heller). Numerous SIRGAID members contributed chapters to these texts.

At the 2003 business meeting in Volos, Greece, Dr. Christine Bigby assumed the position of Vice Chair, pending an election to be held prior to the Montpellier Congress. Dr. Janicki, the current Chair announced he would be stepping down as of the Montpellier business meeting and it was agreed to hold a poll of the membership for a list of candidates for the SIRGAID's offices and to hold a general election. Several committee and committee chairs were appointed to deal with matters before the SIRG. The SIRGAID Steering Committee was reaffirmed (it currently has 25 members), with several members dropping off and several joining. Dr. Henny Lantman was congratulated for her service as our representative on Council. Because of other commitments, Dr. Lantman will not be able to travel to Buenos Aires for the Council meeting and Dr. Torres Mughal was designed as her official substitute. The SIRGAID authorized the expenditure of up to US\$500 to cover travel expenses for attendance at Council.

Dr. Philip Davidson, the SIRGAID's Treasurer maintains a discrete checking account at a bank in Rochester, New York. SIRGAID fee payments are transferred to this account on a periodic basis from the IASSID main account. The SIRGAID uses its funds to fund member participation in IASSID business, including providing travel reimbursements for its member on Council (Dr. Lantman), its member on the Publications Committee (Dr. Hogg), and its member on the 2004 Congress Programme Committee (Dr. Davidson). Income is derived from member fees and from the annual Roundtable. The registration costs for the annual roundtable are kept low (approximately \$100 for members) in order to encourage participation.

IV. Proposed Activities

The SIRGAID will not hold a roundtable in 2004 due to the Montpellier Congress, but instead will embed its program within the Congress. The SIRGAID plans to offer several travel stipends for students, new professionals and researchers from undeveloped nations to help them attend the Congress. The SIRGAID also plans to organize an extensive social program at the Montpellier Congress so as to attract new members. Given that our members worked to produce three text books for the IASSID book series, we are waiting until after the Montpellier Congress before beginning any new projects.

The SIRGAID is planning to hold its next roundtable in Dortmund, Germany in 2005.

V. Participation in Montpellier

SIRGAID has formed a Program Committee, chaired by Dr. Philip Davidson, to plan its participation in the Montpellier Congress. The committee has received commitments from its members for a total of 27 organized paper sessions or symposia with aging and intellectual disabilities as a principal theme. Seven of the proposals cut across the focus of several other SIRGs, giving opportunities for collaboration through co-sponsorships of these sessions.

In addition, SIRGAID has formed a committee to review field-initiated proposals and posters in response to the Call for Papers issued by President Felce, identified volunteers to chair paper sessions that may result from these proposals, and selected a chairperson for the SIRGAID poster session.

SIRGAID will hold an awards ceremony at its business meeting to honour its second SIRGAID Research awardee. To encourage student participation in SIRGAID and IASSID activities, SIRGAID established a new award to recognize students who submit outstanding papers for presentation at Montpellier.

SIRGAID's Social Program Committee is planning social events that include lunch, reception, and dinner.

Employment Affinity Group

Activities 2002-2003

All persons who showed an interest in forming an Employment-SIRG were invited to join.

From a list of more than 30 people a few people gave response.

The Committee is now as follows:

Chairperson: Michael Kamp (Netherlands)

Vice Chair: Steve Beyer (UK)

Secretary/Treasurer: Maarit Aalto (Finland)

Committee members: Fabrizio Fea (Italy); Bert Boekhoff (Netherlands), Steve Leach (UK)

Other members: Kirsten Stalker (UK), Ralph Kober (Australia).

Meeting May 20th, 2003

A meeting is organised on May 20th in Helsinki. The agenda of the meeting was:

1. Development of an Employment-SIRG
2. Preparation Montpellier
3. Other planned activities

Development of an Employment-SIRG

To directly contact people about joining and promoting an Employment SIRG. At meetings the Employment SIRG at meeting. An invitation article shall be placed on the website.

An action plan shall be carried out to extend the number of people.

A formal empanelling meeting to be held in Montpellier in June 2004.

Preparation Montpellier

Items for presentations in Montpellier are:

- Employment and support,

- Employment and autism;
- Employment and community participation
- A model for payment of persons with a disability in work projects (distinction between support and the business approach).
- Other presentation ideas shall be asked to members

Other planned activities

Another meeting of the Committee with an open invitation to members is planned for 2004 in the UK (London).

Identify researchers and agree a Research Agenda.

Planning of workshops or thematic conferences. A plan shall be presented at the meeting in Montpellier.

Specific information will be posted on the IASSID website.

Members

Most people who have expressed an interest are Individual members.

All will be contacted again to elicit views as to the future direction for the group. A complete list will be available to IASSID in November 2003.

**Michael Kamp
June 2003**

SIRG-Quality of Life

Report to Council-August, 2003

Mission Statement

To further work that enhances the quality of life for individuals and their families.

Goals

- (a) collaborate for change at the societal level;
- (b) conduct collaborative research; and
- (c) participate in collaborative activities such as conferences and publications.

Officers

Co-chairs: Bob Schalock and Denise Poston

Deputy Co-chairs: Ivan Brown and Roy Brown

Secretary/Treasurer: Ralph Kober

Members at large:

Diego Gonzales Castanon,

James Gardner,

Leena Mattika,

Trevor Parmenter,

Jo Shearer,

Ryo Takahashi,

Ann Turnbull,

Vicki Turbiville,

Miguel Angel Verdugo,

Bob Cummins

Pauline Young

Active Membership: 25

2002-2003 Accomplishments

1. Published the SIRG-QOL Consensus Document in *Mental Retardation* (2002, Volume 40 (6), 457-470).

2. Completed an international social validation study of the 15 core conceptualization, measurement, and application principles published in the Consensus Document. Results will be presented at the 2004 IASSID Conference.

3. Cooperated on an international study of core quality of life domains and indicators (coordinated by Dr. Verdugo). Initial results have been reported at a number of conferences; an article is in preparation; final results will be reported at the 2004 IASSID Conference.

4. Participated in a series of conferences including ISOQOL (November, 2002), AAMR (May, 2003), the V Jornadas Cientificas de Investigacion Sobre Personas con Discapacidad in Salamanca, Spain (March, 2003), and the 4th European Congress on "Mental Health and Mental Retardation: A Lifespan Multidisciplinary Approach (September, 2003).

2003-2004 Work Plan:

1. Plan for the 2004 IASSID Conference (initial suggestions have been collected and distributed

among members). Three QOL Strands are being developed: General, Individual, Family.

2. Prepare four documents for our Listserv/web site (housed at the Beach Center-KU): (a) 1 page description of the SIRG; (b) a tabular listing of QOL researchers and their primary research areas; (c) a chart of QOL assessment tools; and (d) an abstracting of QOL research.

**Submitted by
Denise Poston/Bob Schalock**

Citizenship and Empowerment Affinity Group Annual Report 2003

I. Aims of the Affinity Group

As stated in the annual report for 2002, there is still much discussion about the aims and intentions of this group. Broadly, though, it is about people with learning disabilities (intellectual impairments) doing their own research, getting involved in research generally, and having a voice within matters that concern their lives. It is worth repeating some of the points made in last year's report:

- It is not about professionals speaking for people.
- It is not about traditional ideas of research.
- It is something new and challenging, but changing all the time.
- Self advocates are doing many different types of research it is not all the same.

We are trying to make links between all of us, so we can keep talking and move things on together.

2. Participation in IASSID 2004

Discussion about possible symposia has started within the SIRG. Several people are interested in being involved in putting something together (Annibal Amorim, Chris Keys, Katie McDonald and Michel Desjardins). We have only just started to get specific interest from self-advocates who might like to take part.

These are some of the current ideas for symposia:

- a) A session on community living issues with self-advocates from Brazil, the USA and France.
- b) A symposium about person-centred planning.
- c) Young people and transition to adulthood.
- d) Sharing experiences of self-advocacy, with more established groups/countries and newer initiatives.
- e) Symposium on parenthood (parents who have intellectual disabilities).

We are all looking forward to the IASSID congress in 2004, and will continue to plan and discuss our ideas for symposia.

This report has been compiled by

Val Williams (co-chair) on behalf of members of the Citizenship and Empowerment Special Interest Research Group.

July 2003.

HEALTH SIRG NEWS

Conference report: Health Disparities among individuals with Developmental Disabilities An Agenda For Change.

Sponsored by the Special Interest
Research Group on Health of IASSID
the Westchester Institute for
Human Development (WIHD) and
the Association of University
Centers on Disability (AUCD)

Mike Kerr & David O'Hara

Health disparity, most easily recognised as inequality in health status and health care provision, is the universal experience of people with an intellectual disability. In recognition of this the Health SIRG of IASSID held an international consensus conference at the New York Medical Centre, Valhalla, in August of this year.

With over 90 attendees from 11 countries the meeting was able to reflect the views of the international community on a range of important

areas. José Cordero, Director, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, introduced the meeting with Patricia Morrissey, Commissioner, Administration on Developmental Disabilities, U.S. Department of Health and Human Services. These presentations were followed by keynotes on the following topics: (1) The epidemiology of health disparity, (2) Integration of health indicators for people with intellectual/developmental disabilities into Public Health measurement programs, (3) Health disparities in women with disabilities, (4) The impact of Health and Social Care delivery on health disparities, (5) Health promotion: developing healthy lifestyles and reducing health risk, effective models of intervention, (6) Health and behavioral phenotypes: genotype to health phenotype and (7) International policy initiatives on the health of persons with intellectual and developmental disabilities.

In addition to these presentations and in keeping with the conference theme of "An Agenda for Change" participants focussed on consensus statements produced through workgroups.

These are being developed into a report for publication and also as a book on the theme of health disparity.

It is clear that the conference engendered a great deal of interest in the theme and hopefully this will be reflected in Montpellier 2004 and other outputs.

Annual Report of the Special Interest Research Group on Parents and Parenting with Intellectual Disabilities

**Prepared for the meeting of the IASSID
Council on August 2nd 2003**

This is the second annual report to Council prepared by the SIRG on Parents and Parenting.

The SIRG was formally established by decision of IASSID Council at its meeting in Berlin on September 27, 2001. The SIRG's inaugural meeting took place during the IASSID-Europe Conference in Dublin on June 13, 2002. Since that time communication has been by the parenting listserv set up by the SIRG in 2002.

Membership

The membership position will not become clear until the SIRG has created its own web page on the IASSID website giving information to prospective members, features as a membership option on the online banking form, and an annual cycle of membership renewals has been completed. There are a number of people participating in the listserv who are members of IASSID affiliated organisations.

The Executive Committee has continued into 2003 as follows:

Chair: Tim Booth (UK)

Secretary: Gwynnyth Llewellyn (Australia)

Treasurer: Peter Vietze (USA)

Information/website: Sue McGaw (UK)

General Assembly rep.: Gwynnyth Llewellyn

Res. & Publications Cmtte rep.:

Sandy Tymchuk (USA)

Listserves: Tim Booth

Executive members:

Rannveig Traustadottir (Iceland);

Jytte Faureholm (Denmark)

Achievements to Date

Since the first report of the Parents and Parenting with Intellectual Disabilities SIRG in September 2002, the SIRG has:

1) Attracted 34 members on record at IASSID indicating the Parents and Parenting SIRG as one of their affiliative SIRGs.

2) Managed a listserv (parenting@sheffield.ac.uk) on the topic of parents and parenting with an intellectual

disability with upwards of thirty subscribers around the world. This listserv as per the SIRG's 2002-2003 plan serves as a forum for discussion as well as a forum for exchanging information about new publications and about landmark legal decisions and case judgements from international jurisdictions. The activity on the listserv reflects action in various jurisdictions; publication outcomes and so forth.

3) Contributed to the production of a special issue of JARID on parenting published late 2002 and including five research articles on parenting by parents with intellectual disabilities

4) Designed and implemented a website to be included with IASSID's home website. Website is currently with Neil Ross prior to be added to IASSID website.

5) planning has commenced for significant participation in the IAASID Conference in Montpellier in June 2004 by way of at least two themed symposia initiated by the SIRG (on younger and on older children of parents with intellectual disabilities) and by active encouragement of SIRG members and others to prepare and submit free papers and posters to the conference committee.

6) Considered the possibility of translating abstracts of non-English research publications for distribution and resolved that while a worthwhile aim, this can only be met at this time depending on the availability and goodwill of SIRG executive members able to undertake this task.

7) Supported the proposal for and assisted in the finalization and contract with Blackwell regarding the new, official IASSID Journal: The Journal of Policy and Practice in Intellectual Disabilities (JPPID) which will commence publication in 2004. Sandy Tymchuk will serve as Associate Editor representing the Parenting SIRG.

Proposed activities

1. Continue planning for Montpellier conference including a business meeting, development of

strategies to recruit new members, a colloquium to discuss possibilities of collaborative research across continents and a social gathering. Montpelier will provide the context for the next phase in the development of the group, as it is the first opportunity for everyone to get together since the group's Inaugural meeting at IASSID Europe in Dublin.

2. Continue promoting the listserv as an active force in dissemination of timely material pertaining to parents and parenting with intellectual disabilities and as a forum for discussion of critical issues and assistance to fellow SIRG members.

3. Consideration of request by publications committee regarding potential book titles related to parenting.

Report of Mental Health Special Interest Research Group MH-SIRG June 2003

Membership

The past year has been characterized by stable membership. Correspondingly, the cash holdings of the SIRG have slowly grown and at last check, about 90 days ago, stood at about US\$700.

In the past year traffic on the SIRG's internet listserv has diminished greatly, but it still remains an effective means of contacting many SIRG members, with 77 current subscribers. Current traffic consists primarily of notices that are forwarded from the main IASSID email list, and have included solicitations and other information related to submissions for the 2004 Montpelier Congress. About one-half dozen members have contacted the SIRG chairs to inquire about submissions and have uniformly been requested to use the materials at the main IASSID website in order to submit them.

Achievements

In 2001, the report on "Mental Health and Intellectual Disabilities: Addressing the Mental Health Needs of

People with Intellectual Disabilities", was completed by the SIRG and shortly thereafter submitted by IASSID on behalf of the SIRG to the World Health Organization for its review and consideration. The SIRG is still awaiting closure, in the form of a formal response, from WHO on this report.

The principal achievement of the past year was holding of a collaborative roundtable on physical health and mental health in Glasgow, Scotland for September 11-13, 2002. The MH-SIRG component of this meeting, organized and managed through the leadership of Sally Anne (Anna) Cooper, was the first member and formal educational activity undertaken by the SIRG.

Mental health Keynote Lectures featured:

Dr. Betsey Benson, The Ohio State University, Columbus, OH USA;

Professor Patricia Noonan-Walsh, The Dublin U.A.P., Ireland, and The Penrose Lecture, Professor Tony Holland, University of Cambridge, UK

Mental Health Concerns Papers (in symposia) included, representing international presenters from the UK, USA, Australia, Italy, and elsewhere:

The quality of life of adults with psychosis and intellectual disability - C.A. Melville, S-A. Cooper

A year in the life of a new community based forensic service for people with learning disabilities - S. Dinani, J. Leggett, W. Goodman

Vulnerability to mental illness and the impact of trauma - S. Hollins.

Multi-center Vitamin E trial in aging persons with Down syndrome: progress report - A.J. Dalton, P.S. Aisen, M.C. Sano, H. Andrews, W-Y. Tsai, I.T. Lott

A multidisciplinary assessment pathway for people with learning disability and dementia and development of 'learning disability and dementia: a training guide for staff' - C. Wilson

Autism and mental retardation: correlations and prevalence -

G. Albertini, G. La Malfa, S. Lassi, M. Bertelli

Research in self-injurious behaviour, implications for treatment - R.W. Davis

The developmental behaviour checklist for adults: a new contribution to the assessment of psychopathology in people with an intellectual disability - C. Mohr, S. Einfeld, B. Tonge

Use of Care Planning Approach (CPA) in people with learning disabilities: introduction, application and survey of its use in South Bristol, England - S. Dinani, J. Nash, A.Fafiolu

After the promise of health there's only silence
S. Todd.

From the lunatic asylum to the rehabilitation centre. More than twenty years on a front line - F. Fea

Depression and Down Syndrome. -

G Albertini, R. Rubino, G. Orsini, S. Maccioni, P. Abbondanza, F. Landoni

Mental Health Promotion. A personal record
M.del Carmen Malbran

Goals: - Progress Since 2002

From 2002: We hope to increase the membership of the SIRG during the next year, and ...will also revive a membership drive and undertake solicitations through non-IASSID channels to expand these efforts.

Status 2003: We have not been successful in undertaking this drive as yet.

From 2002: We will assure and increase value and utilization of the listserv through identification of priorities of the current members and responding to them. Also... we will investigate the feasibility of establishing a newsletter, probably electronic in format that highlights MH-SIRG concerns and contemporary research.

Status 2003: We are setting this as our primary goal, concurrent with continued soliciting of submissions to the 2004 Congress. Establishment of a newsletter is the logical next step to build membership and

interest in the SIRG, and this will likely be in the form of an electronic newsletter. We shall recruit a suitable editor for this newsletter, as a means to increase the number of people with an active role in the SIRG.

Respectfully Submitted Tony Holland & John Jacobson

MH-SIRG Co-Chairs, June 19, 2003

IASSID Membership is Growing.

During this past year we have seen a dramatic increase in the membership of IASSID, both among individual members and among research centers. We have also seen several new national membership organizations affiliate with IASSID. IASSID's individual membership is now in the 800s and new members are joining each day. Members come from some 35 countries, with a goodly share from Australia, the United Kingdom, and the United States. However, we now have members from six of the seven continents. Our membership is quite diverse and multidisciplinary, with members from medicine, the social and behavioral sciences, education and child development, architecture, public policy, and a range of other disciplines. Many members belong to one of more our formal special interest research groups (SIRGs) as well as affiliate with the emerging affinity groups. Most are Full members, meaning they are eligible to vote in elections, hold office, and serve as leaders in our network of SIRGs. However, given the diversity of IASSID, we also have a number of student and pensioner members.

The number of affiliated research centers has grown to more than 40 (from just a handful two years ago). The research centers represent employee-based organizations from many countries, including the United States, the United Kingdom, Ireland, the Netherlands, France, Italy, Macedonia, Australia, and Canada.

We also maintain a base of affiliated membership-based organizations from around the globe. Many are the major multi-disciplinary research group of their nation, and others represent of the disciplinary professional organizations. The full list of current members is found our website (www.iassid.org). IASSID is proud to have these organizations as its

constituent membership, for each of these organizations' members represent the pool of scientists and researchers of their nation. Our affiliated membership-based organizations are found all over the globe, including Africa, Asia, Australia, Europe, and North America.

In 2004, our Full individual and organizational members will receive an additional membership benefit a gratis subscription to IASSID's new journal, the Journal of Policy and Practice in Intellectual Disabilities (JPPID). These gratis subscriptions are provided through a generous grant from the Tosinvest Sanita Organization of Italy. Other members are welcome to enter a personal subscription at a reduced price (see our website for more information). In early 2004, we will also provide a member directory benefit as part of the member's only section of our website. Members will be able access contact information about IASSID members for purposes of networking, developing collaborations, and exchanging information.

The membership committee of IASSID has worked hard to maintain membership renewal fees at their current level. The annual fee of US\$90 is a relative bargain, given the cost of belonging to other international organizations. This fee includes a subscription to the Journal of Intellectual Disability Research (JIDR) as well as a gratis subscription to Journal of Policy and Practice in Intellectual Disabilities (JPPID).

M. Janicki, Chair, Membership Committee

Make a diary entry for IASSID Pacific inaugural Conference

IASSID-Pacific is sponsoring its inaugural conference in Taipei, Taiwan on June 12-15, 2005. The location is the Howard International Guest House Conference Hall IASSID-Pacific will be holding an organizational meeting in Singapore in early October 2003 at the 8th World Congress of Down Syndrome International. The date and location will be announced later. For more information about IASSID-Pacific please contact

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NOTICES

Montpellier will see a number of changes to the Council. Council members due to retire are:

Kurt Sorensen (Denmark).
Lelia Cooke (England).
John Hillery (Ireland).
Phil Foreman.
Bengt Hagstrom.
P. N. Walsh (elected from Individual Membership).
Travis Thompson (U.S.)
Yuki Ikeda (Japan).
Kanji Wantanabe (Japan).
Atushi Kanno (Japan).
Helena Hiila (Finland).
Denis de Victor (France).

Members of Council at its meeting in Buenos Aires in August 2003 voted a vote of thanks to Dr. Michael Bach. Dr. Bach has generously supported the work of the IASSID over the years. Dr. Vianne Timmons was co-opted for the remainder of the term 2000 2004 to fill the vacancy created by Dr. Bach's resignation.

Nominations to Council

I hereby give notice pursuant to Article W Section 3, subsection (a) that Member Organisations may propose no less than 2 and no more than 4 candidates for Council membership. Member organisations include Research Centre members.

Nominations of Individual members

Individual members may nominate an individual member for Council Membership. There are three positions on Council for the term 2004 - 2008 on the individual member panel.

Nominations of Officers

Nominations are invited for the positions of:

- President elect
- Vice Presidents
- Secretary.
- the treasurer is eligible for a further term

Council meeting

The last meeting of the IASSID Council 2000 - 2004 will take place on 14.6.2004 at 9.30 a.m. in the

Congress Centre, Montpellier. Room number will be in the Congress programme.

Assembly

The Assembly of Members of IASSID will meet in Montpellier on Wednesday, 16.6.2004 at 12.15 p.m. The Room number will be in the Congress programme.

The Assembly of Members of IASSID consists of:

1. Voting members, who are delegates of member organisations, or delegates of Special Interest Research Groups, and those subscribing individual members designated as a delegate by the Council.
2. Non-voting members, who are the other members of the Association.

Member organisations shall appoint a delegate(s) to the Assembly based upon its certified membership-

- less than 100 members,
one voting delegate;
- 100 - 500 members
2 voting delegates
- more than 500 members
3 voting delegates.

Member organisations at the time of the Assembly must be in good financial standing with the Treasurer of the IASSID.

Delegates should make themselves known to the Secretary of the IASSID at the office of the Programme Committee in the Congress Centre before the Assembly meeting to receive their voting cards.

Australia Honours IASSID Member

Dr. Helen Beange has been publicly recognised by her award of an AM in 2004 in Australia Day Honours. The citation reads "for service to medicine, particularly in relation to the health needs of people with intellectual disabilities, and through clinical practice, advocacy, research and training".

Congratulations Helen.

Assembly Business

President's report.

Proposed

Seconded

Treasurer's report.

Proposed

Seconded

Secretary's report.

Proposed

Seconded

Proposed changes to the articles and bylaws

Proposed on behalf of the council of IASSID by Stephen Kealy, Secretary.

Seconded by Neil Ross, President IASSID

Awards ceremony

Election of Officers and New Members of council

Moving of the President Elect to the position of President of IASSID by the outgoing President Dr. Neil Ross

Address of the New President

Any other business

Close of the Assembly.

Proposed changes to the Articles & Bylaws of IASSID:

The proposed changes are in **bold**.

New articles are in *bold italic*.

Article I Section I -

second sentence currently reads:

"Intellectual Disability" as used in the documents of the Association is intended to include a significant deficit present from birth or from an early age.

To read:

"Intellectual Disability" as used in the documents of the Association, is intended to include a significant intellectual deficit present

from: Birth, an Early Age, or During the Developmental Period.

Article II - Members.

Section I reads:

Classes of members. The membership of the Association consists of:

- a) Member Organisations.
- b) Affiliated Organisations.
- c) Subscribing Individual Members.
- d) Honorary Members.

To read:

- a) **Member Organisations.**
- b) **Research Centres.**
- c) **Affiliated Organisations.**
- d) **Individual Members; and**
- e) **Honorary Members.**

Section 2 Member Organisations.

Reads:

Any scientific organization, research centre, society or association having as a significant concern the scientific study of intellectual disabilities may become a member of this association as specified in these bylaws.

To read:

Any organization, society or association having as a significant concern the scientific study of intellectual disabilities may become a member of this association as specified in these bylaws.

New Article:

Any Research Centre having as a significant concern the scientific study of intellectual disabilities may become a member of this association as specified in these bylaws.

Section 2 Article 6 - currently reads:

Each member organisation is entitled to appoint one or more delegates to the Assembly as specified in these bylaws.

Proposed change:

Each member organisation and research centre is entitled to appoint a delegate to the Assembly as specified by the Council.

Should the Assembly accept the new article that article in sequence will become Section 2b with an effect on others e.g. current B becomes C, current C becomes D.

Article II Section 4 -

subscribing individual members paragraph C currently reads:

The Council may appoint one subscribing individual member for each country to serve as a delegate to the Assembly. This delegate is entitled to speak and vote in the Assembly, be elected to Council and serve as an Officer of the Association.

To read:

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.

Article 2 Section 6 - application for membership - first sentence currently reads:

Any organisation or individual seeking regular, subscribing individual or affiliated membership in the corporation shall file a written application with the Secretary.

To read:

Any organisation, research centre or individual seeking regular, individual or affiliated membership in the corporation shall file a written application with the Chair of the Membership Committee.

Article 2 - Section 7: Last sentence currently reads:

Upon payment of all fees in default, the member organization or subscribing individual member shall be reinstated.

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 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.

Article III.

The Assembly of Members section 2 a -composition of Assembly - article currently reads:

The Assembly shall consist of:

i) Voting members, who are the delegates, of member organisations or delegates of special interest research groups, and those subscribing individual members designated as a delegate by the Council.

To read:

The Assembly shall consist of:

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

Section 2 b. Currently reads:

Each member organisation shall appoint one voting delegate(s) to the Assembly based upon its certified organisation membership.

To read:

Each member organisation and research centre shall appoint voting delegates to the Assembly as specified by Council.

Section 2 C. Currently reads:

The Council may appoint a subscribing individual member to serve as a delegate to the Assembly. There can be no more than one such delegate from each country.

To read:

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.

Article III Section 2 e.

First sentence currently reads:

Regarding the identification of eligible voters at General Assembly meetings, the Secretary will provide as many signed cards to member organisations etc.

To read:

Regarding the identification of eligible voters at General Assembly meetings, the Secretary will provide as many signed cards to member organisations, research centres etc.

Article IV Section 3 b Currently reads:

The Nominations and Election Committee shall select from the recommendations, nominees up to a maximum of 30 in number, and in making the selection due attention will be given to ensuring a wide representation of countries in no case will more than 3 persons be nominated by any one country.

To read:

The Nominations and Election Committee shall select from the recommendations, nominees up to a maximum of 30 in number, and in making the selection due attention will be given to membership panels of the IASSID as set down by the Council.

Article V Section I:

The present Article reads:

Officers -

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

Proposed change:

Officers

the Officers of the Association are the President, the President-elect, four vice Presidents, the Secretary, the Treasurer and the immediate Past President.

Article V Section 2 - Nominations & Elections and Term of Office:

Reads:

a) Officers shall be nominated by the Nominations & Election Committee proposed by the existing Officers and Councillors and from proposals by member organisations. The list of nominated Officers shall be placed before the acting Officers who can suggest amendments on it to the Nominations & Election Committee. Before being presented to the Assembly the final list of nominated Officers must be approved by Council.

Proposed change:

Officers and Honorary Officers presented for election shall be drawn from a list of nominees as set out by the Nominations & Elections Committee, following consultation with the Current Officers, Councillors and Member Organisations, Individual Members and Formal SIRGs, all in good standing with the Association. This list of nominees for Officers and Honorary Officers shall be placed before Council for majority approval prior to presentation to the Assembly. Floor amendments to the list can be made at the General Assembly with the approval of at least half of the voting delegates present.

Article 5 - Officers - Section 3 - last sentence reads

“In the absence or temporary disability or death of the President, succession to the Office shall be in the following order:

1. President elect.
2. Vice President, Chairman of the Nominations & Election Committee.

3. Vice President, Chairman of Awards and Recognition Committee.

Proposed change

In the absence or temporary disability or death of the President, the President-elect will succeed to the office. Should the President-elect be unable to succeed to the Office of President, the Officers, in consultation with members of Council, will ask one of the four vice-Presidents to succeed to the office of President for the current term.

Section 5 - Vice Presidents:

The Vice President shall serve one term or until a successor is appointed. The Council will designate the Vice President as chairperson of the Nominations and Election Committee and the other Vice President as chairperson of the Awards and Recognition Committee. The Vice President shall perform such duties as may be assigned by the Council or the President.

Proposed Change:

Vice Presidents:

A Vice-President shall serve not more than one term. Vice-Presidents, not elected, but 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 Presidents shall perform such duties as may be assigned by the Council or President.

Article V - Section 10

Reads:

“The Council shall appoint an ad hoc committee for the nomination of Honorary Officers. The Committee consists of five members nominated by the Officers. The Chairperson is the Vice President who chairs the Awards and Recognition Committee. At least one other member should be an Officer”.

Proposal: Delete see Article V. Section 2.

Article VI Committees.

Section 2 - Articles & Bylaws Committee:

An additional sentence to read at the end of this Article “The Secretary is an ex-officio member of this committee.

Article VI Section 3 - Programme Committee - currently reads

Programme Committee

the Programme Committee shall consist of the President-elect, as the Chairman, the President, the Secretary, the Treasurer and three members appointed by Council for one term.

Proposed Change:

Programme Committee.

The Programme Committee shall consist of the President-elect as Chairperson, the President, the Secretary, the Treasurer and other members appointed by Council. The composition of the Programme Committee may reflect the different membership panels of the Association.

The President-elect may co-opt one or more Vice Presidents to serve on the committee as needed and desired.

The Programme Committee shall serve for the term leading up to the quadrennial congress.

Section 4 - Membership Committee:

First paragraph addition to the last sentence

“The Secretary will be an ex-officio member of the Committee”.

Article VI Section 7:

Publications & Research Committee:

The present Article reads “The Publications & Research Committee shall consist of five members appointed by Council for one term or until successors are appointed. One member shall be

designated by Council as a Chairperson and will have the responsibility for encouraging research and establishing scientific applications that are in the interest of the Association and advance its purposes. The Chair will be the chief representative of the Association on matters pertaining to the official journal of the Association. The Publications & Research Committee shall submit to Council once every term a written report of its activities”.

Proposal

Delete the word Research from the Article title and to read Publications Committee.

Proposed change to Article:

The Publications Committee consists of five members appointed by Council for one term or until a successor is appointed. The President in consultation with the Officers and Members of Council will appoint a Chairperson and give due attention to geographical spread in appointing committee members. The work of the committee can be conducted electronically or by any other means for business to be transacted quickly and efficiently.

One meeting of the Committee will take place annually in conjunction with the Council meeting or at a time suitable to the members of the Committee.

The Committee at its first meeting, in its first term of office, may elect a Deputy Chairperson. The Deputy Chairperson may assume the duties of the Chair in the absence of the Chairperson.

The Committee shall have the responsibility for encouraging and establishing scientific publications that are in the interests of the Association and advance its purposes. The Chair will be the chief representative of the Association on matters pertaining to the official journals of the Association. The

Committee will make recommendations to Council as to the appointment of editors to the official journal of the Association. The Council will set down criteria for the selection of an Editor for any official publication of the Association.

The Chair of the Committee will liaise with the Treasurer with regard to any matters affecting finances of publications or contracts for publications.

New Sections under Article 6:

Article VI Section 9 SIRG Co-ordination Committee.

“There shall be a committee for the coordination of SIRGs within the Association. The Committee on SIRGs shall consist of a Vice President serving as its Chair, the Treasurer, the Secretary and a representative from each formal SIRG. Affinity Groups may petition the Committee to send a representative to serve as an observer.

SIRGs may appoint a permanent representative to the Committee or may appoint a rotating member to represent the SIRG at each meeting. SIRGs may designate an alternative to the permanent member to represent the SIRG in the absence of the permanent member. The Committee shall meet at least once a year and otherwise carry out its business via telephone or Internet conferencing.

The Committee shall coordinate SIRG activities with the functions and activities of the Association to ensure coordinated scheduling of events and active participation in the Association's research activities, conferences and congresses. The Committee shall report to Council at its annual meeting and carry out activities as directed by the President and / or Council.

SIRGs are asked to allocate sufficient funds from their accounts to support their representative at meetings of the Committee”.

Section 10

The President shall appoint an advisory committee called the Site Selection Committee to review potential site alternatives for the next Congress.

The Committee shall make its recommendations to the President at least one year prior to the last Council meeting of the current Council.

The President shall have full discretion in the appointment of the members and number of members to the committee, however, the mandated members shall include the Treasurer, Secretary and one or more Vice Presidents. All members shall be members in good standing with the Association.

FELLOWSHIP OF IASSID

Fellows of IASSID are Association members who have earned distinction by their scientific or practical contribution to the field of intellectual disabilities or by their dedication to the affairs of the Association.

The title “Fellow of the International Association for the Scientific Study of Intellectual Disabilities” shall be given for the life of the recipient and may be abbreviated as F.IASSID.

A person proposed for Fellowship shall satisfy the Council of IASSID that the Nominee:

- 1. Has worked for at least 10 years in the field of intellectual disability.*
- 2. Possess superior knowledge of his or her discipline as applied to intellectual disability.*
- 3. Have made important contributions to the understanding of intellectual disability.*
- 4. Have made an important contribution to the application of scientific knowledge to aiding people with intellectual disabilities and/or their families.*
- 5. Have made a significant contribution to the IASSID.*

A nominee shall meet at least two of the five criteria.

Nominations for Fellowship may be made to Council, where two Fellows are of the opinion the nominated person fulfils the criteria.

Nomination for Fellowship shall be signed by two Fellows. A list of IASSID Fellows can be viewed on the IASSID website iassid.org. Nomination forms may also be downloaded from the website or obtained directly from the Secretary.

*The completed nomination form should be returned to:
The Secretary, IASSID, Moore Abbey, Monasterevan,
Co. Kildare, Ireland.*

IASSID Awards.

IASSID honours every four years at the Congress, people who have made a significant contribution to the field of intellectual disabilities.

There are four award categories for which the Council invite nominations from:

- Member organisations.
- Research centres.
- Individual members.
- Special interest groups.
- Affinity groups.

Categories of Awards:

Research - for formulations and investigations which have contributed significantly to the sciences related to intellectual disabilities for either a major single contribution or a sustained and important contribution over a life time. To be designated

'Distinguished Achievement Award Research'

Scientific literature - for an outstanding publication, published since the last Congress, which contributes substantially to the literature in the field of intellectual disabilities, to be designated

'Distinguished Achievement Award - Scientific Literature'.

Service - for contributions to the improvement of services to persons with intellectual disability which result in substantive contributions to prevention or amelioration. To be designated **'Distinguished Achievement Award Service'**.

Distinguished Service Citation - an award of the Distinguished Service Citation will be made for outstanding or exemplary service to the Association by a person who has served as an officer, councillor, member of a committee or otherwise, who actively participated in the affairs and activities of the Association.

The IASSID Council, in exceptional circumstances, may make more than one award in each category.

Members of the IASSID who wish to nominate a person for a reward should download the IASSID Awards Nomination Form from www.iassid.org. A Nomination Form may also be had from the Secretary.

The proposer should be

- A member of a Member Organisation.
- A member of a Research Centre.
- An Individual Member.
- A member of a SIRG.
- A member of an Affinity Group.

Completed nomination forms should be returned to the Secretary: *Stephen Kealy, Secretary IASSID, Moore Abbey, Monasterevan, Co. Kildare, Ireland*
Email: scjmclinic@eircom.net

Nominations close on the 10.4.2004

Important Notice to members attending the June Congress in Montpellier.

Full student and retired members are advised to let the le Corum know of their membership status in order to obtain the IASSID member rate for the registration at the montpellier congress. **Associate members are not eligible for the IASSID membership rate as stated in the registration form.** Associate members are asked to upgrade their membership if they intend to register for the Montpellier Congress. Please contact the IASSID member affairs office for details on changing membership status.