

# NEWSLETTER

INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF INTELLECTUAL DISABILITIES

## PRESIDENT'S NOTE:

The IASSID held its annual Council meeting in Berlin, Germany in conjunction with the Fourth Congress of the European Association for Mental Health in Mental Retardation. Attendance of Council members was excellent with about 60% of Council present at the meeting. As President, I would like to thank all for their continued support.

Some of the important points to note for the upcoming year 2002 will include the inaugural meeting of IASSID-Europe (I-E) to be held in Dublin, Ireland from June 12-15, 2002. It is hoped that many of you will make arrangements to attend this meeting. The purpose of the IASSID-Europe is to promote regional groups which can meet in the intervening years between the quadrennial IASSID World Congresses. This action will enlarge the scope of IASSID and the number of member countries. For example we have only a few members from South America and it is our hope that we can encourage more to join IASSID and even to form an IASSID-South America. The regional groups would allow IASSID to be active in other areas, reduce travel costs for people who want to participate in international meetings but find the trips and expenses to Europe or North America too costly. To encourage more development in areas where IASSID is not yet strong, we are considering having Council meetings to help stimulate interest. For example, we are looking into holding a future Council meeting in South America in order to promote this development. We realized that to be effective in these types of international exchanges, we must deal with the language problems (perhaps through simultaneous translation and expression languages other than English). This task, while solvable, will not be easy.

Another notable achievement by Council is the approval of a contract with Blackwell Science, a major

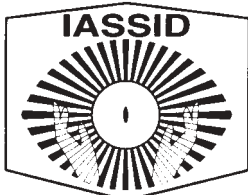
publisher in the United Kingdom, to publish three new books on behalf of the IASSID. The Aging SIRG responsible for this successful arrangement and several of its key members are involved with the writing and editing of these texts. The first, on women's health and intellectual disabilities, will be launched at the upcoming IASSID-Europe meeting. Drs. Patricia Noonan Walsh and Tamar Heller are the senior editors of this first text.

Council also approved, at the Berlin meeting, the newly developed Edinburgh Principles, which speak to promoting high quality care and in community services for adults with intellectual disabilities affected by Alzheimer's disease and related dementias. The Principles are posted on our website and will shortly appear in the Journal of Intellectual Disability Research (JIDR).

Dr. Kyo-yu Wang, our Councilor from the Republic of China has taken the lead for developing a regional group in Asia and the Pacific Rim and will be reporting back to us on her advancement during the next months. It is our hope that she and her colleagues may have created this regional group by the time of our next Council meeting. We know that she will be joined by our Past-President, Dr. Trevor Parmenter, who has also expressed a strong interest in creating an IASSID-Asia.

You will note that the IASSID web site has developed a marketplace page and in conjunction with our bank we can now offer secured on-line banking for fee payment for individual members. The web site has become an important communication tool of our association as shown by the statistics noting that the number of visits has increased from 300 per month to more than 1,200 visits last month.

We take pride in now having four members in the research center category of membership, and they are:



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 Intellectual  
Associação Internacional para o Estudo Científico da Deficiência Intellectual

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

Developmental Psychiatry Section, Department of Psychiatry University of Cambridge Douglas House,  
Contact: Dr. A.J. Holland, E-mail: ajh1008@hermes.cam.ac.uk

Reena Foundation,  
Toby & Henry Battle Developmental Centre, 927 Clark Avenue West Thornhill, ON L4J 8G6, Canada,  
Contact: Sandy Keshan, E-mail: skeshan@reena.org.  
Website: www.reena.org.

Department of Disability & Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Road, Room 436, Chicago, IL 60608-6904, USA  
.Contact: Dr. Tamar Heller. E-mail: theller@uic.edu

Centre on Intellectual Disabilities, School of Social Welfare, University at Albany, Richardson 208 135 Western Avenue, Albany, NY 12222, USA. Contact: Dr.Philip McCallion. E-mail: mccallion@albany.edu.

Our immediate Past-President has been keeping up his untiring efforts for IASSID on the international level. He has helped us to obtain NGO status with the World Health Organization. NGO status implies that the organizations have observer status at WHO meetings and NGOs can raise matters for WHO to consider. In relationship to IASSID the history is pertinent. Before 1996 IASSID and Inclusion International (II) had a Joint Commission status with the WHO. Under that arrangement the three groups worked on various matters. Dr. Michael Mulcahy, another Past-President, was very active, as was Peter Mittler from II. To obtain this status IASSID had to produce a work plan acceptable to the WHO for a 3-to-4 year period. It was this arrangement that led WHO to support the Ageing Papers and subsequently the other three position papers it now has on mental health, health issues and quality of life.

Professor Parmenter is also working on an update of the IASSID history which will be a follow up to the signal article written by Alan Clark in conjunction with the 9th World congress in Australia in 1982. We look forward to this document.

I would encourage you to contact our secretary, Mr. Stephen Kealy via email, if there are any meetings that you would like to draw our attention to or an article that you might like to see appear in the IASSID Newsletter or on our web site. We are particularly looking for articles about activities within your

organizations or notable achievements by our individual members. We will use our website and email notices to help spread information quickly among the IASSID family. Your contributions to this information sharing will be greatly appreciated.

**Neil Ross**

## SECRETARY'S NOTE

IASSID continues as a vibrant international organisation. The surge of new individual membership is indicative of the continuing interest researchers have in the organisation. The Special Interest Groups have been augmented by two recently approved SIRGs at the Council meeting in Berlin.

Family Research SIRG –

Contact: Jan Blacher - jan.blacher@ucr.edu

Research Group on Parents & Parenting with Intellectual Disabilities:

Contact: Tim Booth – t.booth@sheffield.ac.uk

Bob Schalock, in his position as Chair of the Publications Committee, will be linking with the new SIRGs asking for a nomination to the Publications Committee. The IASSID, at its Council meeting, agreed to have all SIRGs represented on the Publications Committee to ensure co-ordination of the Publications agenda of the Organisation.

SIRGs in Forensic and Nursing Research are endeavouring to meet the criteria for formal recognition.

### IASSID Governance:

The changing membership of IASSID means the Articles and Bylaws of the Organisation have to change to reflect the future direction. Dr. Coen de Jong at E.mail:coendejong@compuserve.com would like to hear from any member who wishes to influence the future governance direction of the IASSID.

Congratulations to Dr. Maria del Carmen Malbran, Argentina who was elected by the Individual Membership to fill the vacancy of Prof. David Felce.

To meet the IASSID's objective of involving a greater number of individual members in the governance of the Organisation, Dr. Miguel Angel Verdugo Alonso of the

University of Salamanca, Spain, was co-opted onto the Council at its meeting in Berlin.

There are now three Council positions for which the Individual membership will vote on for future Councils. Elections will take place before the meeting in Montpellier, with the results available at the Assembly.

The IASSID has forged a strong working relationship with the European Association of Service Providers. This Organisation has NGO status within the European Union. The IASSID collaborated with the EASPD at its successful conference in Verona in October 2001.

The IASSID continues to grow from strength to strength and now possibly has the largest international network of researchers linked by their shared interest in intellectual disabilities.

- *Continue your interest*
- *Be involved*
- *Answer the call*
- *Have others join IASSID*

**Stephen Kealy,  
Secretary**

## Good News for Members

### Journal of Applied Research in Intellectual Disabilities

As an IASSID, Individual Member you now have the opportunity to take out a specially discounted subscription to the Journal of Applied Research in Intellectual Disabilities (JARID). JARID is one of a number of journals published by Blackwell Publishing covering research in our field. It has subscribers to the paper version in 22 countries across the world.

In addition, it has an expanding online subscriber base and JARID is part of a complete package of online journals from Blackwell Publishing being purchased by more than 1,000 consortium sites so far this year. This means that the potential readership of the journal continues to expand. Blackwell Publishing have also recently concluded special arrangements to supply the Journal to six sub-Saharan African countries and in a separate arrangement to 300 institutions in the Russian federation.

Now approaching its 15th. volume, JARID aims to publish findings from original applied research in

intellectual disabilities in its four issues per year. It seeks to report research from all professional disciplines to an international, multidisciplinary readership. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear.

Topics in papers in the last two volumes have included:

Quality of life.	Ageing.
Challenging behaviour.	Supported employment.
Risk assessment.	Social networks.
Communication	Staff stress.
Sexuality	Staff training.
Medication	Family issues.

Both quantitative and qualitative methodologies are welcomed. JARID has also published special issues in recent years on Biobehavioural Factors, Ageing, Sexuality and Challenging Behaviour, and in 2002 will be publishing two further special issues

- Parenting by people with intellectual disabilities.
- Forensic issues in intellectual disabilities, including papers presented at IASSID World Congress in Seattle 2000.

The current volume also includes publication of the five IASSID/WHO Healthy Ageing with Intellectual Disability Papers prepared by the IASSID Special Interest Research Group on Ageing expert panels.

The editors, Professors Glynnis Murphy and David Felce encourage those involved in IASSID activities through its Membership, Special Interest Research Groups or Congresses to submit original articles for publication – please contact us at:

Welsh Centre for Learning Disabilities  
Meridian Court,  
North Road,  
Cardiff CF14 3BG,  
Wales  
United Kingdom.

JARID has a rising impact factor – currently 0.642 in the Educational Psychology and Rehabilitation sections of the Social Science Citations Index and JARID articles have been cited in 22 other journals. **This increasingly highly regarded journal is an essential outlet for our research.**

**David Felce.**

cead mile failte go h-eireann.  
baile atha cliath

**1st. IASSID Europe Regional  
Conference Dublin.**

IASSID Europe is the first regional grouping within IASSID and will host its inaugural conference at the National University of Ireland, Dublin, Ireland from 12 – 15 June 2002. Growing European integration provides the backdrop to this initiative to create a forum for dialogue between scientists interested in intellectually disability across the continent. Europe has a strong but diverse research tradition in this area. It is the aim of IASSID Europe to establish a quadrennial meeting for sharing current research between IASSID World Congresses.

Keynote speakers are:

Jan Blacher (USA)	Roy McConkey (N.I.)
Glynnis Murphy (U.K.)	Gerard Quinn (Irl).
Robert Schalock (USA)	Rannveig Traustadottir (Iceland).

Symposia topics range from Ageing to Family Quality of Life to User Views and Participation.

To register for the IASSID Europe Conference, please contact:

Marie O'Connor,  
Centre for the Study of Developmental  
Disabilities  
Room G06,  
Arts Annexe,  
University College Dublin,  
Belfield, Dublin 4,  
Ireland.

To submit an Abstract, please send 3 paper copies and an electronic copy to:

David Felce  
Welsh Centre for Learning Disabilities  
Meridian Court, North Road,  
Cardiff CF14 3BG,  
Wales, United Kingdom.  
felce@cf.ac.uk

All speakers must register for the conference and pay the registration fee. For further information consult the IASSID website.

Patricia Noonan Walsh PhD  
University College Dublin  
Belfield,  
Dublin 4,  
Ireland.  
patricia.walsh@ucd.ie

## Montpellier 2004 – Update

The Scientific Programme Committee for the 2004 World Congress has been formed and its first meeting held alongside the IASSID Council meeting at the end of September. The Committee has a core membership of the four executive officers (Neil Ross, Stephen Kealy, Matt Janicki and myself) together with Professors Glynnis Murphy and Charles Aussilloux. Glynnis is a respected friend and colleagues of mine at the Tizard Centre at the University of Kent at Canterbury, England. She has research interests in biobehavioural factors, challenging behaviour, the criminal justice system and psychological intervention. Charles is an eminent French professor of child psychiatry working in Montpellier with research interests in autism. He is heading the Local Organising Committee, and brings the support of his academic colleagues in Montpellier to making our next Congress a success. I met this great group of people in glorious sunshine in Montpellier this Summer.

The Programme Committee will work with a Scientific Programme Advisory Board to develop the programme under a number of organising themes currently being discussed. The Advisory Board will include representatives of the IASSID Special Interest Research Groups and other researchers around the World who have made a strong contribution to IASSID activities. The aim is to be as inclusive of as many points of view as possible and to arrange a Congress in line with people's interests and academic aspirations. It will not be possible for so many people always to meet

together but individuals are welcome to attend the Programme Committee meeting if they can. Bob Davis and Helen Beange from the Physical Health SIRG, Tony Holland from the Mental Health SIRG and Phil Davidson from the Ageing SIRG had input into the September meeting and others made electronic contributions.

I am now in the process of finalising the themes under which the programme will be organised. Then I will establish the panel of experts for each theme who will collectively constitute the Advisory Board. At this stage, the themes are:

**Theme** *to include*

**Biological Understanding**

*Genetics  
Syndromes  
Biobehavioural processes  
Brain Research/Neurotransmitters  
Risk Factors for ID*

**Behavioural Development and Mental Health**

*Adaptive Behaviour Development  
Challenging Behaviour  
Mental Health  
Diagnosis/Assessment and Classification Systems  
Psychopharmacology  
Behavioural Phenotypes  
Psychological Intervention  
Therapies*

**Cognition and Communication**

*Autism  
Communication and Language  
Cognitive Development*



*Montpellier*

**Physical Health and Profound Multiple Disabilities**

*Physical Health  
Medical Intervention/Medication  
Profound Intellectual Disability  
Sensory and Physical Disabilities  
Epilepsy*

**Families**

*Genetic Screening  
Early Counselling and Adjustment  
Family Experience  
Family Supports  
Family Lifecycle  
Siblings  
Ageing Carers  
Parents with ID*

**Education and Work**

*Early Intervention/Pre-school Development  
Schooling  
Employment  
Day Occupation Supports*

**Community Living**

*Residential Support  
Integration  
Leisure  
Personal Relationships and Sexuality*

**Lifespan and Ageing**

*Ageing and Health Status  
Functional Decline  
Lifespan Transitions  
Death and Dying*

**Quality of Life**

*Values and Ethics  
Quality of Life Assessment  
Quality of Life Supports/Determinants  
Self-determination  
Person-centred Planning  
Vulnerability, Abuse, Protection  
Spirituality*

**Individual in Society**

*Law and Civil Rights  
Advocacy and Self-advocacy  
User Views/Participation/Empowerment  
International Perspectives  
Cross-cultural Studies/Developing World  
Gender  
Culture and ethnicity  
Criminal Justice System/Forensic Issues  
Welfare Benefits and Income*

## Populations and Service Systems

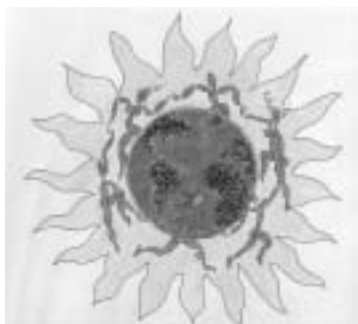
Classification  
Epidemiology  
Displaced Populations and Disability  
Policy and Service Patterns  
Achievement of Strategic Change  
Services to Minority Communities  
Health Economics  
Cost-effectiveness  
Service Management and Quality Assurance  
Staff Training and Professional Development

## Environment

Risk Factors for ID  
Developmental and  
Behavioural Neurotoxicology

## Science and Research Methodology

Science and Ethics  
Ethics of Research  
Research Paradigms  
Measurement and  
Methodological Development



Finally, the 12th World Congress has an overall theme and a logo. In English, the theme is *Towards mutual understanding: person, environment, community, in French La personne, l'entourage, la société: Vers une compréhension mutuelle*. Towards understanding conveys a sense of not only our association's remit to further scientific knowledge but also the vitally important attitude required between people to build healthy diverse communities - the communities in which we live and our communities of knowledge. Mutual conveys a sense of shared responsibility for reaching understanding of other people's:

- situations – in different societies, cultures and economic circumstances around the world,
- experience - of different opportunities and status within societies, and
- perspectives – in general but in particular on the

role and conduct of scientific inquiry. Person, environment and community represent three levels for understanding the impact of intellectual disability on people's quality of life and what might be done to benefit individuals.

The logo was designed by a French artist friend of Neil Ross. It has an overall image of the sun and of sunflowers representing the French Midi. The continental grapes or seeds of the earth represent our international remit and the Matisse-like ring of dancing figures our world community in happy association.

**David Felce**  
President-elect

## **NEWS ON MEMBERS**

It is my pleasure to outline the distinguished career of **Dr. Heleen Evenhuis** as a clinical practitioner and researcher in the field of intellectual disability. Heleen spearheaded one of the IASSID's first special interest research groups as chairperson of the SIRG on physical health issues. Dr. Evenhuis recently asked to be relieved of these duties because of the ever increasing demands made on her time in the Netherlands, her native country.

Heleen has been an outstanding and untiring worker in the field of intellectual disability. She has also been an active participant in our association for more than 25 years.

She started her career in 1973 as part-time institute Physician in Hooge Burch, Zwammerdam, the Netherlands and after having two children in 1972 and 1974 she started a new family in 1985, including three step-children born in 1968, 1970 and 1972.

She wrote her 1990 PhD thesis on Alzheimer's dementia and hearing loss in Down Syndrome and commenced work on the development of evidence-based multidisciplinary consensus guidelines on identification and diagnosis of hearing and visual impairment.

From 1995 – 1999 much of her clinical work was

carried out in Hooge Burch Centre as well as undertaking work for the National Government on a Development Grant, the focus of which was the identification of the criteria for medical and scientific research in the special interest field of physical health and intellectual disability.

In 1996 Dr. Evenhuis founded the IASSID SIRG on Physical Health after the IASSID World Congress in Helsinki, Finland. She ceased her clinical work at the Hooge Burch Centre to start part-time clinical work as a Consultant in several children's day-care centres.

In 1998 she initiated two large epidemiological studies on visual and hearing impairment with the Department of Ophthalmology at the Utrecht University and the Department of Audiology at the Erasmus University in Rotterdam. At the same time she carried out the second study on dementia in Down Syndrome with the Department of Epidemiology at the Erasmus University Rotterdam.

Having successfully completed this seminal work she commenced in 2000 a study on audiological intervention with the Department of Audiology and the Department of Child Psychiatry and Quality in Health Care Erasmus University, Rotterdam.

In April 2000, Heleen was appointed Professor in Intellectual Disability Medicine for the Department of General Practice at the Erasmus University in Rotterdam whilst beginning two studies on intervention in visual impairment with the Department of Visuology at the Groningen University and the Department of Child Psychiatry and Quality in Health Care at the Erasmus University, Rotterdam. The second study was on feeding and pulmonary problems in children with severe generalised cerebral palsy.

We are indebted to Dr. Evenhuis and the tremendous work she completed for IASSID, and the physical health SIRG. We can only hope, that even from afar, she will somehow find the time to continue to help us. As Heleen herself would say "there is a lot more to tell".

**Neil J. Ross**

## **News on Members**

The new address for Stephen Roy Brown is,  
Stephen Roy Brown, Ph.D.

411 Sheringham Point Road, Sooke, BC Canada.  
Tel | 250 646 2532 email irwin54@attglobal.net

Emeritus Professor University of Calgary, Canada  
Flinders University, Australia

*Current positions:* Adjunct Professor, School of Child and Youth care University of Victoria, Canada. Consult Down Syndrome Research Foundation, Adjunct Professor Simon Fraser University Vancouver, Canada.

## **NEWS FROM DOWN UNDER ASSID'S NEW COMMITTEE**

ASSID is the official IASSID member representing Australia. The Executive Office Bearers are:

President: Ms. Sue Peden  
pedens@dsc.wa.gov.au

Vice President: Mr. Steve Bristows.  
bristow@endeavour.com.au

Treasurer: Mr. Bill Taylor  
milparinka@ozemail.com.au

Registrar: Mr. Daniel Leighton  
Seadog@alphalink.com.au

Secretary: Mr. Keith McVilly  
Kmcvilly@med.usyd.edu.au

The ex-officio Office Bearers are:

Journal editor: Prof. Phil Foreman  
Phil.Foreman@newcastle.edu.au

Magazine editor: Ms. Ann Penhallurick  
Penhall@bigpond.net.au

ASSID is eager to co-operate with IASSID. ASSID matters are regularly discussed at our council meetings and actively promote involvement of our members with IASSID SIRGs. We would be pleased to discuss with you ways in which ASSID could work collaboratively to support research and best practice in the interests of people with intellectual disability both in Australia and around the world.

**Keith R. McVilly - ASSID National Secretary.**

## The relationship between IASSID and the World Health Organization (WHO)

In the late 1960s a Joint Commission was established as a partnership between IASSMD, the International League of Societies for the Mentally Handicapped (Inclusion International) and WHO, the purpose of which was to produce materials of benefit to the field, be a link between the two international disability organizations, and to be afforded Non-government Organization status with WHO.

By the mid 1990s the activities of the Joint Commission had become sporadic and the parties agreed to its suspension in 1996. It was resolved that IASSID and Inclusion International would independently seek NGO status with WHO.

The privileges of a NGO relationship include the opportunity to have observer status at meetings of WHO in Geneva, meetings of its Regional Committees and to make written submissions to WHO. A requirement of the relationship is the submission and adoption of an agreed work plan between the NGO and WHO.

A 3 year work plan between IASSID and WHO was adopted in 1997. A major component of the Plan was the preparation by IASSID of position papers on Ageing, Physical Health, Mental Health and Quality of Life for endorsement by WHO. At the Seattle Congress in 2000 the comprehensive documents on Ageing were jointly launched by WHO and IASSID. The remaining position papers are currently being reviewed by WHO.

In accordance with the Principles governing relationships between WHO and NGOs, the WHO Executive Board will review the collaboration between the organizations at its 109th session to take place in January 2002.

In anticipation of a continuing relationship a Work Plan for a further three years has been submitted to WHO for its consideration. Components include an international survey of provisions for people with intellectual disabilities with an emphasis upon developing countries; the development of a position statement on Ethics in the field of intellectual disability and an examination of the application of the ICF and ICD-10 to persons with an intellectual disability.

It is anticipated that the execution of these tasks will again be assisted by the Association's Special Interest Research Groups (SIRGs) with reports being presented at the Montpellier Congress in 2004.

The new relationship with WHO has been beneficial in that it has afforded an opportunity for the SIRGs to become more productively involved in the Association's activities. It has also raised the profile of our Association's activities, and the field of intellectual disabilities in particular, within WHO. Given the role WHO plays in addressing the health needs of people in disadvantaged parts of the world, our Association's relationship with, and activities in developing countries, are being challenged. This was the basis of a petition presented to our President, Dr Neil Ross, at the conclusion of the Seattle Congress. The WHO Work Plans of the Association are one mechanism by which it can respond to the needs of people with intellectual disabilities in less affluent areas of our world.

**TREVOR R. PARMENTER, Immediate Past President**

### CHANGES IN IASSID MEMBERSHIP FEE STRUCTURE (2002)

#### National Associations:

1 – 49 members	\$125
50 – 99 members	\$350
100 + members	\$800

**Non-industrialised /special conditions:** \$ 25

#### 2002 Research Center Membership Fee

##### Structure:

Research Centers	\$125
Foundations	\$125
Service Organisations	\$125

#### 2002 Individual memberships Fee Structure

<b>Full IASSID Member/Journal (FU)</b>	
if paid by 31.12.'01	\$80
if paid on or after 1.1.'02.	\$85
<b>Full IASSID Member/non-Journal (FN)</b>	
if paid by 31.12.'01	\$50
if paid on or after 1.1.'02	\$55
<b>Associate IASSID Member (AS)</b>	<b>\$25</b>

<b>Student/Special/Pensioner IASSID Member/Journal (AJ) – same benefits as Full IASSID Member/Journal, except cannot vote:</b>	
if paid by 31.12.'01	\$60
if paid on or after 1.1.'02	\$65

<b>Student/Special/Pensioner IASSID Member/non-Journal (ST) same benefits as full IASSID Member/nonjournal, except cannot vote:</b>	
	<b>\$25</b>

<b>Dues Exempt (Emeritus)</b>	<b>\$0</b>
Members who have contributed to IASSID or be associated with IASSID are eligible for this membership category upon retirement – voting rights and eligible to serve on Council; includes past officers.	

<b>Dues Exempt (Special conditions)</b>	<b>\$0</b>
Persons under special conditions (from countries with non-industrialised economies or similar financial conditions); vetted by Secretary and approved by President annually – no voting rights and ineligible to serve on Council unless representing association designated to serve on Council.	