

## Development of IASSID as a Member Organisation

*Paper for Discussion*

*Second Draft, April 2007*

### **Introduction**

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

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

### **Background: Membership, Governance, Structures and Representation**

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

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

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

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

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

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

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

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

### **Background: Development of SIRGs**

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

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

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

As an interim development, it was thought that the additional fee for members to join SIRGs was a disincentive to their participation, particularly if individuals wanted to become involved in more than one. The 2006 Council meeting decided to raise the general Individual Membership fee by \$20 to provide funding for all SIRGs but to remove all supplementary fees for SIRG membership<sup>1</sup>. Members are encouraged to join as many SIRGs as befits their work interests.

### **Background: Finances**

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

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

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

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

### **Governance and management structure**

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

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

Recommendations:

1. The panel representation model is retained as the basis for forming the 2008-2012 Council as it fulfils a function of broadening international representation. The model should be extended to include Africa.
2. The current size of Council should be maintained at 30 members.  
  
(Note: a rule change to reduce its size might be considered in order to make the move to covering the full costs of Council members attending the meetings more affordable. However, a lower number would reduce the scope to maximise international representation and the representation of constituent membership communities. Ideally, the financial concerns would be met by increasing all forms of membership, thereby increasing fee income.)
3. The Council would include an Executive which would comprise the four Officers (President, President-elect, Secretary and Treasurer) and a number of Vice Presidents with specific roles to be determined by the President, but selected from among Council members. The Immediate Past president should continue as an ex-officio member of Council and Executive.
4. The Council discuss the roles which Vice Presidents might fulfil and make a recommendation to the President concerning this.  
  
(Note: currently, there are four Vice Presidents with roles which cover SIRG co-ordination, Publications, WHO and International Affairs, and Constitutional Affairs, Awards and Recognition. The VP for Publications is the Editor of the Journal of Intellectual Disability Research. In addition, the Immediate Past President acts as the Association's webmaster.)
5. The trend towards greater democratic accountability to the membership is maintained.
6. There are 26 Council positions not filled by the four Officers (the Immediate Past President is supernumerary). It is recommended that:
  - a) the current formula for the direct election of Council members by individual members is maintained up to a maximum of 8
  - b) each SIRG should be represented by a nominated officer  
(Note: the recommendations about SIRG development which follow foresee the number of SIRGs growing to a possible total of about 14)
  - c) the remaining positions should be filled equally by research centre or organisational members so as to maximise international representation
  - d) the officers of SIRGs be elected by individual members affiliated to SIRGs

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

### **Development of SIRGs**

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

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

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

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

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

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

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

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

#### Recommendations:

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

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

### **Finance Developments**

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

#### Recommendations:

1. A council sub-group should be appointed to:
  - (a) review the benefit packages for individual, research centre and organisational members<sup>2</sup>
  - (b) create a virtual membership pack which can be sent electronically to all new members in each category
  - (c) draw up a proposal to increase membership.

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

Appendix 1 Meeting Executive and Council Costs from Fee Income

Cost of Council Meeting

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

Cost of 2 Additional Executive Meetings

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

Total Cost

\$36,000

Fee Income (full member and research centre member)

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

Target breakeven membership = 720

## Appendix 2 SIRG Themes and Content Areas

### Biological and Biobehavioural Understanding

Genetics  
Syndromes  
Biobehavioural processes  
Behavioural Phenotypes  
Brain Research/Neurotransmitters  
Risk Factors for ID  
Developmental and Behavioural Neurotoxicology

### Challenging Behaviour

Challenging Behaviour  
Forensic Issues  
Psychological Intervention & Other Therapies

### Mental Health

Mental Health  
Diagnosis/Assessment and Classification Systems  
Psychopharmacology  
Psychological Intervention & Other Therapies

### Cognitive, Behavioural and Social Development

Adaptive Behaviour  
Cognitive Development  
Communication and Language  
Early Intervention  
Social Skills/Impairment  
Autism  
Down's Syndrome

### Physical Health

Physical Health  
Medical Intervention/Medication/Dentistry  
Sensory and Physical Disabilities  
Epilepsy

### Profound Multiple Disabilities

Profound Intellectual Disability  
Sensory and Physical Disabilities  
Epilepsy  
Assistive Technology

### Families

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

### Parenting

Early Intervention/Pre-school Provision  
Schooling  
College  
Transition

### Employment

Transition  
Employment  
Day Occupation Supports  
Careers  
Retirement

Ageing

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

Quality of Life and  
Community Living

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

Individual Rights

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

Comparative Policy and Practice

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

### Appendix 3 Alternative Clustering of SIRG coverage

- **Aetiology, Health and Psychopathology**

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

- **Behavioural, Cognitive and Social Development**

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

- **Family Life**

- to include: Families, Parenting

- **Adult Life**

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

- **Civil Rights**

- to include: Ethics, Empowerment, Law