

IASSID Asia Pacific Region Summary Report and Proposals for Consideration

(prepared by Keith McVilly – Co-VP for Asia Pacific)

This report covers five areas of activity in the Asia Pacific Region, as noted below. It concludes with some project proposals and seeks in-principle approval for an indicative budget to progress negotiations in the region. However, some budget items will require further evaluation over the next few months, between the March Executive Meeting and the Full Meeting of Council, at Rome in October. Questions, comments and suggestions are invited.

1. 2nd Asia Pacific Conference - Singapore, June 24 to 27, 2009
2. 3rd Asia Pacific Conference – Japan (Tokyo), July 4th to 6th, 2013
3. 4th Asia Pacific Conference – India, 2017
4. New Delhi Meeting, 13th March 2010
5. Regional Development Proposal – from 2010

(1) 2nd Asia Pacific Conference - Singapore, June 24 to 27, 2009

Delegates:

362 Delegates

Approximately 30% from Singapore; 25% from Australia & New Zealand, 25% from the Asia Pacific, remainder from USA, Central & South America, UK, Europe and Africa.

Programme:

7 Key Note Papers

236 Plenary Papers (distributed over 7 to 9 streams each day)

Regional Research to practice Round Table

Academy Workshops (pre and post conference):

8 at Singapore (195 attendees)

1 at Hong Kong

1 in Malaysia

Note: in the lead up to the conference, there were Academy workshops in 2008 & early 2009. A full outline of the Academy events is included in the Academy Report, prepared by Academy Chair Prof. Roy Brown.

SIRG and Affinity Group Meetings:

Ageing

Behaviour & Mental Health

Down Syndrome

Parenting

Physical Health

Profound & Multiple Disability

Quality of Life

Meetings of Affiliated Associations:

Australasian Association of Doctors in Developmental Disability Medicine

Down Syndrome International (Regional Meeting)

ISAAC (Regional Meeting)

Singapore Budget Summary:

(Note – full accounts have been provided to the IASSID Treasurer)

Total Expenses: SING \$ 211,757

Exchange Estimates -

US Dollar = 150,000

Pounds = 100,635

Euro = 111,755

Australian Dollar = 165,000

Funds transferred to the IASSID: SING \$ 172,401

Exchange Estimates -

US Dollar = 123,000

Pounds = 81,900

Euro = 90,985

Australian Dollar = 134,000

Less Funds transferred to the Academy: SING \$ 17, 932.50

Exchange Estimates -

US Dollar = 12,910

Pounds = 7,920

Euro = 8,750

Australian Dollar = 14,065

Funds available for regional development activities (see proposals at item 5 of the current report): approximately SING \$ 150,000

Exchange Estimates -

US Dollar = 106,700

Pounds = 71,600

Euro = 80,000

Australian Dollar = 117,000

(2) 3rd Asia Pacific Conference – Japan (Tokyo), July 4th to 6th, 2013

Local Organizing Committee:

Hitoshi Hara, Chairperson (President of JASDD)
Atsushi Kanno, Co-chairperson (Vice-President of JASDD)
Souichi Hashimoto, Treasurer (Chief Secretary of JASDD)
Shigeru Suemitsu, (Council Members of JASDD)
Kiyoshi Otomo, (Council Members of JASDD)
Hidetsugu Nozaki, (Council Members of JASDD)
Akiko Hayashi, (Council Members of JASDD)
Tomoko Takamura, (Professor, Ochanomizu Women's University)
Chiyoiko Numata, (Chief Secretary of Japan League on Developmental Disabilities)

The last day of the conference will overlap the first day of the 48th annual meetings of the Japanese Association for the Study of Developmental Disabilities (JASDD).

Two candidate hotels have been identified: Keio Plaza Hotel in Shinjuku and Four Season Hotel Tokyo at Chinzan, in Mejiro. To be confirmed by June 2011 (when the second JASDD Council Meeting is held).

The conference theme is not decided, but discussions currently are focusing on the issue of 'diversity'

Hoping to use sponsorship to assist in supporting delegates from developing countries across the region.

Yet to determine international Key Note Speakers, but already exploring possibilities with local leaders.

The total expense of the conference is roughly estimated at US \$ 200,000. JASDD has some reserve funds for commissioning of the conference and is seeking donations.

A draft budget for initial consideration will be prepared for the Rome meeting.

Academy events conducted from 2011 would assist with building both interest and local capacity.

We need to develop a Memorandum of Understanding between the local committee (JASDD) and IASSID. The MOU could be built upon the correspondence prepared in the early phases of the Singapore planning and issues that arose during the preparations for Singapore.

(3) 4th Asia Pacific Conference – India, 2017

Following from discussions during the Singapore conference and a recent meeting at New Delhi, on 13th March 2010 (see notes at item 4 of the current report), it is anticipated we will be receiving a proposal for regional conference to be hosted in India in 2017.

A series of Academy events, possibly commencing in 2011, would precede the conference and assist with building both interest and local capacity.

(4) New Delhi Meeting, 13th March 2010

25 people from across India attended a half day meeting at New Delhi – including people from several universities, and people involved with the Asian Federation (of service providers), Inclusion International and WHO.

IASSID allocated 45,000 Indian Rupee (approx US \$ 1000 / Euro 750 / UK Pounds 650 / Aus \$ 1080).

Mrs Pramila Balasundaram of SAMADHAN (a large service provider organisation) convened the meeting on behalf of IASSID.

Mrs Rekha and Mr Rami RamaChandran, sponsors from the Singapore conference, provided some sponsorship to assist with expenses.

Dr Singh, from Singapore was at New Delhi and chaired the meeting.

Keith McVilly (IASSID) and Prof. Libby Cohen (Singapore National Institute of Education & Co-Chair from the Singapore Conference Scientific Programme Committee) attended via SKYPE.

Currently awaiting minutes from the meeting, but the key issues included:

- Acknowledgement of previous IASSID activity in India, dating back to the 1985 conference.
- Lack of prevalence information and limited capacity to distribute limited resources where most needed
- Absence of culturally sensitive assessment tools – cognitive assessment; adaptive behaviour; communication. It's not sufficient to just translate tools!
- Lack of training among professionals – need to support generic professionals to develop skills: teachers and health workers.
- Lack of an effective national network of specialist in the field of ID (compared with other disability networks).
- Questions about accommodation developments (inc. post parents and independent living), health promotion, education, employment and social enterprise, legal capacity, ageing issues, person-centred planning.
- The need to develop self advocacy; need to bring forth the voice of people with intellectual disability to challenge social stereotypes, prejudices and taboos, and influence policy makers.
- Need to develop family support.
- Wanting to mobilise the ICF framework in assessment, service planning and evaluation – identification of barriers and facilitators.
- Need to raise the profile of people with intellectual disability in the eyes of state and national governments / policy makers.
- Looking for options for international researchers and educators to work with regional and national bodies such as the Rehabilitation Council of India.
- Development of a mentorship programme for local professionals being linked to international researchers to bolster local consultancy and educational capacity.
- Access to literature, both in original scientific format and in plain language summaries.
- Seeking a programme of IASSID Academy workshop over the next few years – based on local needs and possibly linked to a mentorship programme for the follow-up.
- Possibility of developing a proposal for an IASSID regional conference in 2017.

(5) Regional Development Proposal – from 2010

Discussion has identified the need to think broadly (it's a BIG region, with diverse needs), but to plan for small and achievable activities. It is clear that success will be dependent upon the formation of strategic partnerships: WHO, UNESCAP, WB, ADB, OECD, Pacific Forum. It is also noted that the Asian Federation, Disabled People International and Inclusion International are very active in the region, and have well established networks through which we could work.

Note our IASSID Asia Pacific region traverses two WHO Regions: (1) South East Asia - mhGAP targeted countries = Bangladesh, India, Indonesia, Nepal, Sri Lanka, Thailand, Timor-Leste; and (2) Western Pacific - mhGAP targeted countries = Cambodia, China, Lao, Mongolia, Philippines, Solomon Islands, Vietnam.

From the Singapore Research-to-Practice Round table, conducted over 3 days of the conference, and subsequent discussions with key stakeholders, three principals have emerged to guide IASSID's engagement in the region:

- (a) support and encourage existing expertise within the region, and foster the on-going development of current good practices;
- (b) provide a conduit to enable good practices currently in the region to be disseminated within the region and across the rest of the world;
- (c) provide mechanisms to bring international expertise to support the development of new research and evidence-based practices in the region.

Consistent with IASSID's mission as primarily a network of scientists, project merit are proposed to be considered in terms of their contribution to:

- a) Developing research networks
- b) Enhancing research capacity
- c) Promoting the translation of research into policy (gaining high-level influence)
- d) Fostering the use of research through the application of evidence-based practice
- e) Demonstrating the value of research through practical evidence-based projects and the application of research in conjunction with service developments and educational activities

The priorities established during the Research-To-Practice Round Table at the Singapore conference give us strong direction as to where people in the region want to go with respect to research, the development of evidence-based practice and education.

- Measurement
 - ICF
 - Indigenous or adaptation of instruments
 - Population level/census & longitudinal trend data (also check on preexisting datasets)
- Dissemination
 - IASSID website (email, discussion groups, videoconferencing)
 - Networking via the identification of persons in respective countries
 - IASSID Academy
- Study replications & comparative research

- European studies
- Asia-Pacific studies
- Demographic standardization
- E.g., policy & practice, human rights based legislation, existing practices (and trend data)
- Research-practice-policy alignment
 - Consensus statements
 - Politically relevant agenda (e.g., health)
 - WHO initiatives
- Parent/family advocacy and support
- Research approaches
 - Basic & locality-based research
 - Building capacity for research
 - Mentorship (in research, and in cultural aspects)

It has been noted that it would be advantageous to align some of our activities with issues and priorities already identified for the region by WHO. These could include, but not necessarily be limited to, strategies and projects to:

- (a) Identify children at risk of developmental delay
- (b) Implement evidence-based community rehabilitation programmes designed to promote health and wellbeing
- (c) Provide parent education

We also know that there are a number of low and middle income countries across the region that have already been prioritised by WHO, and we would be wise to consider these when setting IASSID priorities and planning pilot projects.

We know that in 2010 there will be a further World Bank sponsored report on disability, which could influence our emerging agenda.

Indicative Budget for in-principle approval:

Note – there is approximately SING \$ 150,000 available
(Exchange Estimates: US = 106,700; UK= 71,600; Euro= 80,000; Aus= 117,000)

Japan, 2013 – Sing \$10,000

(Exchange Estimates US=7,000;UK=4,700; Euro=5,300; Aus =7,800)

Seeding funds to support the initiation of the 3rd Asia Pacific Conference. To be provided to the Japanese association on approval of their indicative budget.

India, 2017 – Sing \$ 10,000

(Exchange Estimates US=7,000;UK=4,700; Euro=5,300; Aus =7,800)

Seeding funds to support the initiation of the 4th Asia Pacific Conference. Funds to be allocated for specific approved activities over the next 4 years. These activities would need to be part of an overall strategy that contributed to the development of local community capacity and the formulation of a conference proposal. Events could be held in conjunction with and leverage off IASSID Academy activities.

Regional Network Development Project – Sing \$ 5000

(Exchange Estimates US=3,500;UK=2,300; Euro=2,600; Aus =3,900)

A census to be conducted across the region to identify researchers working in the field of intellectual and developmental disability, and related issues; a data base to be developed which catalogues current research and publications, demonstration projects and evidence-based service initiatives; the availability of venues in sub-regional hubs and IT facilities to support local and pan regional symposium and the development of communities of practice. Budget allocation over about 2 years, with a review thereafter.

Scholarship Programme – Sing \$20,000

(Exchange Estimates US=14,200;UK=9,500; Euro=10,600; Aus =15,600)

A Scholarship programme to be established with an approved selection criteria and a pan-regional committee to review applications. Scholarship would primarily assist people from developing countries in the region to attend IASSID conferences and associated SIRG round tables, etc. Budget allocation would spread over 4 years.

Note – An additional SING \$ 30,000 remaining from the Singapore conference surplus after the current indicative budget has been acquitted could be invested, with the view to establishing a longer-term regional scholarship fund, to be added to following each regional conference and / or via donation.

Mentorship Programme – Sing \$ 10,000

(Exchange Estimates US=7,000;UK=4,700; Euro=5,300; Aus =7,800)

This project would link experts both from within the Asia Pacific region and from outside the region to researchers, policy makers, practitioners and leading service providers in Asia Pacific region. There would be a particular emphasis on leveraging off expertise from within IASSID Special Interest Research Groups - SIRGs. It is envisaged that the majority of contact would be via electronic means. However, face-to-face meetings could be conducted in conjunction with IASSID Academy events, which could be used to help off-set travel and associated expenses. Further development is required. However, the indicative budget allocation is anticipated to cover 4 years.

Regional Strategic Partnerships Fund – Sing \$50,000

(Exchange Estimates US=35,500;UK=23,800; Euro=26,600; Aus =39,000)

This fund would be preserved for conducting or, preferably, co-sponsoring (e.g., with WHO, ADB, UNESCAP, WB, OECD, Pacific Forum, II, etc) research and evidence-based pilot projects that included a research and evaluation component. A set of guidelines would be prepared (for approval by IASSID Council) and a regional committee established that would be responsible for calling for and reviewing project submissions. Priority would be given to projects in low-infrastructure countries, already prioritised by WHO, etc. Projects could leverage off the Mentorship Programme (as noted above) and / or conducted in conjunction with IASSID Academy activities. Linkages with SIRGs would be encouraged, to foster project development and implementation consistent with the requirements of best practice in research. Project progress and findings would be reported to the 2013 Conference and at regional and other IASSID events after that. Budget allocation would spread over 4 years.

Virtual Network Project for People with Intellectual Disability – Sing \$ 10,000
(Exchange Estimates US=7,000;UK=4,700; Euro=5,300; Aus =7,800)

A project brief is currently being developed that would build a virtual (on-line) community to link people with intellectual disability from across the region. This project would include at least two research components – how best to implement such a venture in an on-line, multi-lingual, cross cultural environment; and what are the issues impacting the lives of people with intellectual disability in the Asia Pacific, based on their personal lived experience. There are potential partners for this project with Inclusion International and Down Syndrome International. The indicative budget allocation is anticipated to cover 4 years. However, a fully costed project proposal and budget is yet to be developed and reviewed.

Regional Administration Fund – Sing \$5,000
(Exchange Estimates US=3,500;UK=2,300; Euro=2,600; Aus =3,900)

To provide for incidental costs associated with networking, information dissemination and meetings, etc. All expenses to have prior approval from the IASSID Treasurer. Budget allocation would spread over 4 years.