

**IASSID SPECIAL INTEREST RESEARCH GROUP
PERSONS WITH PROFOUND INTELLECTUAL AND MULTIPLE
DISABILITIES**

Meetings of the PIMD SIRG

MINUTES of a meeting of the SIRG-PIMD, held on Friday 9th November 2007, in Dundee, Scotland.

Present:

Loretto Lambe (Co-chair)	Juliet Goldbart
Carla Vlaskamp (Co-chair)	James Hogg
Bea Maes (Secretary)	Nicola Maier
Mary Arnold	Vera Munde
Monica Björkman	Kate Mure
Nelleke Boer	Han Nakken
Marjo Brinkman	Katja Petry
Anne Brown	Mauren Phillip
Meindert Buskermolen	Sui Sone
Nan-Chieh Chen	Anna Strimbold
Lisa Curtice	Jenny Wilder
Gare Fabila	Jenny Whinnett

Apologies for absence were received from:

Nicola Grove and Jean Jacques Detraux.

1. Membership

Loretto Lambe asked individual members and members of organisations/institutions, for example PAMIS and the respective universities, who already subscribe as members of IASSID, to indicate participation at the SIRG-PIMD. In this way, a part of the membership fee will be redistributed to the SIRG-PIMD.

2. Board members

The meeting agrees that Mrs Chen will become a board member, and will represent the Asian countries on the board.

3. Involvement of parents

We are very pleased that parents are also involved in our SIRG. Their presence and contribution is very important for researchers and practitioners to keep in mind their perspective. Representatives of organisations and universities present were encouraged to try to find support for family carers to become more involved.

It was agreed that one of the parent members would write a piece for the next newsletter about the contribution of parents to the SIRG and the benefit to them of

involvement. Members are asked to publicise this letter to other parents or parents' organisations in their own country.

We need to seek funds to provide parents with the possibility to attend conferences and roundtables. We keep asking IASSID for a special rate for parents to become a IASSID-member and also for a reduction of the conference fees – as is in place for people with intellectual disabilities. PAMIS has successfully negotiated this in the past but as yet this is not made clear in IASSID literature.

4. IASSID- World congress in Cape Town

We discussed the idea of organising several symposia about persons with PIMD at the next world conference in Cape Town. This would make our visibility even greater.

We agreed upon the following themes. Under each theme some persons have already proposed giving a presentation at the Cape Town Conference. If we have too many presenters in 1 symposium, we may always split up the symposium. Each symposium includes 3 presenters (each 15 minutes) and discussion (15 minutes).

- **PIMD - Forgotten Citizens of the World**
 - Lisa Curtice – To what extent are Western ideas of citizenship inclusive of people with PIMD?
 - Chen – From Forgotten to being remembered
 - Barbara Fornefeld – Migration
 - James Hogg
- **Emotional and Mental Well-being of persons with PIMD/Behavioural problems**
 - Sarah Dero - Comparison of different methods in measuring subjective well-being of persons with PIMD
 - Nicola Grove: Memory, dreams and imagination in people with PIMD
- **Health Issues in persons with PIMD**
 - Sui Sone - Lifelong diseases of adults with PIMD
 - Darren Chadwick - Oral tasters for people who are non-orally fed
 - PAMIS
- **Communication/Interaction with persons with PIMD**
 - Ine Hostyn: Measuring emotional availability in support workers interacting with persons with PIMD
 - Katja Petry: Influencing factors in the interaction between support workers and persons with PIMD
 - Sheridan Foster: What's happening in the interaction: looking at the interaction from different coding perspectives
 - Brinkman
- **Educational and Therapeutic Interventions for persons with PIMD**
 - Barbara Fornefeld - Dydactics for children with PIMD
 - Bea Maes - Sensory story telling
 - Care Fabila – New opportunities for PIMD
 - Carla Vlaskamp
 - Juliet Goldbart: speech and language therapy
- **Family Life of persons with PIMD**
 - Jenny Wilder & Mats Granlund: Children with PIMD and participation in family life

- Krysti DeZonia: Transition to adulthood for students with PIMD from the perspective of parents and teachers
- **Service Delivery for persons with PIMD / Staff Training**
 - Jacqueline Walker and Mary Arnold: Ensuring PIMD program success utilizing a summative evaluation approach
 - Anna Strimbold - Benefits and challenges of personal assistance service
 - Terry Collard: Effectiveness of clubhouse programs

This list is only preliminary. Other members will be asked to add their contribution. Bea Maes will send out a mail in mid November to all SIRG-members to ask them to suggest other presentations, to confirm whether they will attend the Cape Town Conference and give a presentation and, ask them to send the title of the presentation. When a final proposal has been drawn up, this will be sent to all members. After this, members must remember to send in their abstracts twice:

(1) to bea.maes@ped.kuleuven.be

and (2) via the weblink of the conference: http://www.uct-cmc.co.za/Conferences/conf-main.asp?Conf_ID=56&Page=Home

All abstracts still need to be approved by the scientific committee of the conference. People could also send in a free paper, when they feel that their paper does not fit in the suggested themes.

5. Pre-conference for African delegates before the IASSID - World congress in Cape Town 2008

Carla Vlaskamp has agreed to organise a pre-course for African delegates before the IASSID - World congress in Cape Town.

We agreed that the pre-course should focus on the following topics: (1) basic knowledge; (2) practical aspects of working with persons with PIMD; and (3) possibilities for networking between African delegates.

The themes of health, communication and quality of life could also be included in the program. Topics should be discussed in a very concrete practical way.

It was agreed that information on all the contacts that each of the SIRG-members has with people/organisations in African countries that are working in the field of PIMD should be sent to Carla.

Juliet Goldbart, Mary Arnold, Jacqueline Walker, Bea Maes, Katja Petry and Carla Vlaskamp agreed to further prepare this workshop. Carla will formulate a proposal.

6. Financial statement

Bea Maes presented a financial report of the income and expenditure of the SIRG-PIMD.

At present the SIRG has 212 Euro deposited at the European bank account and 1414 USD at the IASSID bank account.

The following suggestions for using some of these funds were put forward:

- prize(s) for an excellent paper in the field of persons with PIMD
- publication of position papers of the SIRG-PIMD
- prize(s) for a student paper in the field of persons with PIMD
- supporting parents to attend roundtables/congresses

No decision was taken on this and this item would be discussed further in due course.

7. Website

Our website is www.sirgpmid.be

You can access the website by using 'specialist' as password.

Bea Maes asked all SIRG-members to please fill in the membership card on the website. 152 persons are subscribed to the mailing list, but only 20 persons have filled in the membership card at this moment. This card gives more details about how to contact SIRG-members, their background and their interests.

It was agreed that we would try to share more information by means of the newsletter and to also include a new section on the website about current research projects and publications. A format to send in abstracts about current projects and new publications will be send to all SIRG-members.

Any members who wishes to share information, should send a mail to bea.maes@ped.kuleuven.be. We will then include this information in the newsletter, send it to the mailing list, and/or put it on the website.

8. Roundtable

About 30 participants attended the 3rd Roundtable of the SIRG-PIMD in Dundee. There were also additional members of PAMIS staff and local professionals who attended individual sessions. The introductions and the discussions were very interesting and inspiring for our future work. We thank Loretto Lambe, James Hogg, Lynne Wilson and all the parents of PAMIS who worked very hard to organise this roundtable. We appreciated very much their hospitality and their perfect organisation of this roundtable!

Bea Maes
20 November 2007