

IASSID SPECIAL INTEREST RESEARCH GROUP PERSONS WITH PROFOUND AND MULTIPLE DISABILITIES

Meetings of the PMD SIRG

MINUTES of a meeting of the SIRG-PMD, held on 7th October 2005, in Bruges.

PRESENT: Loretto Lambe (Co-Chair)
Carla Vlaskamp (Co-Chair)
Cecilia Blank
Anne Brown
Meindert Buskermolen
Hendrike Fonteine
Barbara Fornefeld
Colette De Gier
Juliet Goldbart
Collin Griffiths
Margo Hoenders
James Hogg
Bea Maes (Secretary)
Stephanie Mueller
Han Nakken
Annette Van der Putten
Sui Sone
Annemarie Tadema
A De Vries
Jenny Wilder

1 MEMBERSHIP OF BOARD

1.1 Board members & Officers: The members and officers of the Board were confirmed as follows:

Carla Vlaskamp	co-chair & IASSID Council Representative
Loretto Lambe	co-chair
Han Nakken	past chair
Bea Maes	secretary
Mary Arnold	board member
Anne Brown	board member (parent)
Caré Fabila,	board member (parent)
Barbara Fornefeld	board member
Mats Granlund	board member
Paul Pagliano	board member
Knut Slåtta	board member

1.2 Roles & Responsibilities of Board Members: It was agreed that we would formulate the roles and the responsibilities of the board members

more clearly and would ask all current members if they wish to continue serving on the board.

Action: Carla / Loretto / Bea

1.3 Increasing the membership: It was also agreed that we will look for other members, particularly members from the Eastern and Southern parts of Europe. We still endeavour to have an equal membership on the board of researchers, practitioners and parents/relatives.

Action: Carla / Loretto / Bea

1.4 Database: The membership list has been checked. We do need more information on our members and it was agreed we will make a members card, which would be circulated to all SIRG-members requesting them to provide additional information about themselves (e.g. name, address, e-mail, fax, telephone) and about the work they do (work place, discipline). A list of topics in which members have a special interest could also be added. We will also ask all current and new members to fill in this members card, and with their agreement, this information will be disseminate to all members of the SIRG.

Action: Bea

2 COMMUNICATION WITH MEMBERS

2.1 Exchange of Information: There was a discussion as to how we could improve the communication between the SIRG-members. Possibilities that were discussed included:

- ✓ having an information exchange group or forum on the internet
- ✓ exchange of articles, projects, ideas or questions by mail. For this purpose every member should have the mailing-list available.
- ✓ an electronic newsletter about events
- ✓ exchanging national newsletters of members and/or regional platforms

2.2 Membership fee: From the beginning of 2006 we will ask a membership fee of 40 Euros. We will have a discount for parents and also for members of developing countries. This membership fee will go towards the costs of the organisation of roundtables, giving young people and parents the opportunity to attend conferences, and also cover administration etc. We will open an account by IASSID. They is a charge of 5 dollar per member for this.

3 ROUNDTABLE 2007

The venue for the next roundtable in 2007 was discussed. Dundee (PAMIS/White Top Research Unity, University of Dundee) is willing to co-ordinate the roundtable. However, James suggested we should also give other members/organisations the opportunity to host the meeting. It was agreed that

we would put a call in the next newsletter to see if other organisations are also interested.

It would also be interesting to combine the roundtable with a conference for local practitioners, for which there would be a charge. First of all this contributes to the dissemination of knowledge and expertise. Secondly, this could also be a way of raising additional funds.

4 Second European Conference of IASSID in Maastricht.

4.1 Symposia: We discuss the symposia we would be organising for the Second European Conference of IASSID in Maastricht – these are set out below for information.

Families of persons with PMD
Convenor: Loretto Lambe
A.C. Tadema, C. Vlaskamp & H. Fonteine, The time and effort in taking care for children with PMD: a study on care load.
J. Roberts & A. Brown, The impact of an intensive training and support programme on the individual and her family.
S. Sone, The role of the paediatric neurologist in supporting families with a child with profound and multiple disabilities (in Japan).

As Barbara Fornefeld's colleague has withdrawn his/her paper, we are 1 presentation short for the 'Families' symposium. Loretto agreed to contact some members to see (a) if they are attending the Conference and (b) if they wish to present a paper. If no one comes forward we will submit the symposium programme with 3 presentations.

Action: Loretto

2. Program evaluation and quality of support for persons with PMD
Convenor: Bea Maes
H. Fonteine, C. Vlaskamp & A.C. Tadema, Support model for children with profound intellectual disabilities.
K. Petry & B. Maes, Quality of support in services for persons with profound multiple disabilities.
J. Hogg, What do non-centre based services offer people with profound intellectual and multiple disabilities? A data-based critique.
C. Vlaskamp, H. Nakken, & H. Fonteine, The content of support: an overview of methods and programs that are used in supporting persons with PIMD.

3. Health and treatment programs for persons with PMD
Convenor: Han Nakken
H. Fonteine, C. Vlaskamp & A.C. Tadema, Aspects of health problems in children with PIMD: the use of medication and equipment.
A. Vanderputten, Moving towards independence? Evaluation of the MOVE-curriculum with children with profound intellectual and multiple disabilities.
J. Levy, Utilization of Coordinated Medical Care among Adults with Severe or Profound Intellectual Disabilities: Differences in Living with Families and in Group Homes.
J.Hogg, K. Juhlberg & L. Lambe, High mortality and avoidable deaths among people with profound intellectual and multiple disabilities: a 10-year longitudinal study.

4. Communication and relation between persons with PMD and caregivers Convenor: Barbara Fornefeld
C. Griffiths, Elucidating the interactions of people with profound intellectual disability: A pilot study.
B. Maes & K. Petry, Interactions between primary caregivers and persons with profound multiple disabilities during snoezelen
B. Fornefeld & Chen: Dialogue as the way to self-determination of persons with PMD – intercultural comparison on ethics
M. Wagner, On the possibility of the development of an 'educational relationship' to deaf-blind persons with mental disability.

5. Teaching children with profound multiple disabilities Convenor: Jean Ware
B. Fornefeld & U. Boeing, U., Didactic competence of teachers working with children and young adults with profound multiple disabilities
J. Ware & P. Thorpe, Helping teachers working with pupils with PMD use statistical data to inform teaching decisions
W. Lamers & T. Klauss, Educational reality of students with severe and profound disabilities
C. Anderson, Observing and coding teacher-pupil communication in preverbal exchanges

We agree to present the following papers as free papers:

L. Lambe & J. Whinnett, Healthy lifestyles – a 3 year programme on improving the health and quality of life of the person with PMLD and his/her family.

A. van der Putten & C. Vlaskamp, Aspects of health problems in adults with PIMD: the use of medication and equipment.

Carla will check with Heleen Evenhuis if these presentations could be taken in consideration for some other health symposia. **Action: Carla**

4.2. All presenters should upload their abstract electronically as soon as possible. The program committee will make a final decision about the acceptance of symposia and presentations.

Action: All presenters

4.3. Posters: We will ask the program committee of Maastricht to group the posters together, so that the topic of 'Persons with profound multiple disabilities' will be visible at the conference.

Action: Bea

5 FUTURE WORK/ PLANS OF THE SIRG-PMD

We discuss the following:

- ✓ Participation in the Second European IASSID-conference in Maastricht.

- ✓ Barbara proposes to organise a meeting for PhD students undertaking research in the field of people with profound intellectual and multiple disabilities. This could be organised before or after the Maastricht conference in Cologne. Collin agreed to think about organising such a meeting. This is very important for our SIRG as these are the potential future members of our community and they would also be very interested in exchanging ideas.
- ✓ Anne proposed the need to consider involving more parents and also some siblings. She agreed to consider organising a meeting around this topic with PAMIS and any other parent members.
- ✓ We could think of writing a publication or handbook with contributions of the SIRG-members but no firm decision was taken. Loretto, Bea and Carla agreed to discuss this further and report back to the Board.

6 IASSID WORLD CONGRESS: SOUTH AFRICA 2008

Carla reported on the next world conference of IASSID which would be held in South-Africa in 2008. The board of IASSID is intending to have a lot of people from Africa at the conference. Carla is looking for contact persons that want to help to raise funds to enable people from many African countries (states) to attend. Additional fundraising will have to take place in order to enable staff and parents from our SIRG to attend the congress. There will also be opportunities to organise pre-meetings alongside the congress.

7 DATE OF NEXT MEETING

The next SIRG-meeting will be held at the European IASSID-conference in Maastricht from August 2-5 2006.