

## **PIMD SIRG members meeting 15th July IASSIDD conference, Vienna**

### **1. Apologies**

Annette van der Putten sends apologies for absence. She is unwell.

### **2. Matters arising from Minutes of members' meeting in Groningen, 24<sup>th</sup> October 2013.**

There were no issues arising. Minutes were accepted.

### **3. SIRG – organisation and members**

a) Bea introduced Board members

It was noted that Peter Thorpe had volunteered to support the SIRG website and to be Treasurer. This offer was welcomed and accepted.

b) A financial report and an activity report (2013-2014) have been written for the council meeting (see reports in attach)

c) In 2013 111 members subscribed. In 2014, there are 93 members. This large membership generates money to support our activities.

The current balance is 6000 US dollars, some of this is being used to support the Carla Vlaskamp Early Career Researcher award and the ECR meeting.

### **4. Planning future meetings**

Forthcoming roundtable (2015): of the three proposals, it was decided that Jenny Wilder would host the next Roundtable at Mälardalen University, Västerås, Sweden. Suggested dates were early September or mid-October. Bea will discuss these options with Jenny Wilder for a final decision in the Autumn.

The date of the next Early Career Researcher's meeting will be decided on Friday 18<sup>th</sup> July, but will probably be combined with the Roundtable in Sweden.

The Asia Pacific Rim PIMD research meeting will be organized by Nan Chieh on Saturday 18th October 2014. It will have a parallel conference for local people and a separate room for the internet based conference (see further on).

### **5. Cooperation with Academy**

A joint pre-conference workshop had been proposed on PIMD and mental health. Unfortunately the SIRG missed the opportunity as there were already ten workshops agreed. The Academy has suggested separate event on this topic or one combined with a next conference.

A range of options was discussed including: adding the workshop to the Melbourne conference, or the Pacific Rim roundtable, or the conference of the European Association of Mental Health in Intellectual Disability (EAMHISD) in Rome, or a free standing meeting.

A proposed alternative was a series of linked seminars projected around the world. This could be a staggered series which could then be repeated for different areas or time zones.

Bea will contact the chair of the mental health SIRG to ask members from both SIRG's for concrete propositions.

It was agreed that Darren Chadwick would be co-opted to support planning.

Nan-chieh Chen suggested trialling this as a webinar/teleconference within the PIMD SIRG. Nan-chieh Chen's university colleague (Secretary General) will obtain information on this idea for the Asia Pacific meeting. Nan-chieh Chen asked each speaker to send a pre-recorded version (or, at Darren Chadwick's suggestion, and audio track added to the powerpoint) so there is a back-up in case of internet problems.

Peter Thorpe proposed adding a webinar session on PIMD and Mental Health to the next Round Table.

## **6. Melbourne IASSIDD World Congress**

a) The next World Congress will be in Melbourne, August 15 – August 19, 2016.

b) Keynote speakers. It was agreed that we sought speakers from a broader range of disciplines to reflect on the implications of research in their fields for people with ID e.g. philosopher, science, engineering . Any suggestions should be sent to Bea Maes asap.

Juliet Goldbart suggested Dr Karen Dodd, clinical psychologist, to speak on her work on training staff to recognise and manage pain in people with ID.

A further suggestion was for a speaker on music and ID. Members in Japan might be able to suggest someone. Katrina McFerran might be another possibility.

c) Programme for 2016: There was a general feeling that we wanted more discussion-based symposia. It was proposed that each SIRG should identify some themes, which could follow the format of two brief presentations on a topic followed by more extensive discussion. This would be particularly relevant to some of the challenging themes/issues.

Suggestions for discussion topics:

Reciprocal relationship between research and practice and the related topic of effecting real changes in generic services (health, education, social services); cross-SIRG topics; relevance and problems in using developmental ages; discussion of different approaches to education in different countries (in this area we would need to avoid a polarised inclusion debate and make it more strategy oriented); new developments in health (to include medical doctors).

Again, feedback on these ideas should be sent to Bea Maes as soon as possible.

d) It was proposed that the poster presentations be made more important. Suggestions included having smaller groups of posters in each session, and having the authors speak briefly on their poster in turn.

## **7. Outcome of the COST funding bid PIMD Action**

Unfortunately the bid narrowly missed the threshold for funding, achieving 32/35 and needing 33/35.

Feedback was limited but supportive, so the bid will be revised, based on guidance received and re-submitted . More information will be needed on the broader implications beyond PIMD.

Other potential collaborators from Europe should contact Bea for further information.

The next date for submission will be early 2015. Stage 1 involves a short pre-proposal. Stage 2 is longer and more detailed. Jean Ware suggested that we need to work on both stages ahead of the call for submission, so we are ready for the second stage if we reach it.

## **8. Publications**

A draft position paper on euthanasia is in preparation in advance of the meeting at this conference. The authors will continue after the meeting and circulate the next draft.

A special issue of a journal on a PIMD-related topic was proposed.

Carla Vlaskamp suggested the need to plan a team of people for this as editing a special edition is very time consuming.

Possible topics were: Health and wellbeing; Participation and inclusion and what these mean for people with PIMD; Different approaches to staff training.

## **8. Carla Vlaskamp Early Career Researcher award**

The members enjoyed a short talk from the award winner, Magdalena Birtha, a sociologist based at NUI Galway, Ireland. She thanked the SIRG for the award. Magdalena has worked on monitoring institutions, she has an activist background as well as being a researcher. Her work concerns legal and monitoring issues regarding the UN Convention on the Rights of Persons with Disabilities. Implementation is uneven. People with PIMD are excluded from discussion with government and also often from inclusion.

She has been meeting people with ID about ideal levels of participations: major factors and success criteria. She stated that there is a need to reduce exclusionary factors, but also to avoid tokenism.

## **9. Any Other Business**

Newsletter:

Aafke Kamstra was thanked for her work on the newsletter. The most recent edition was very good. Items for the next edition should be sent to Aafke: [aafke.kamstra@rug.nl](mailto:aafke.kamstra@rug.nl)

The aim is for two per year. Juliet Goldbart suggested that the next edition include a couple of commentaries on this conference.