

Minutes of PIMD SRG members meeting; 16th August 2016, Melbourne.

1. **Welcome**

2. Brief **minutes** of SIRG meeting, Malardalen, Sweden, were presented.

3. **Officers:**

a. Board changes: Bea Maes identified Board members. The meeting considered a proposal but SIRG approval was sought. Bea Maes agreed to ask Colleen Adnams if there is anyone from South Africa or elsewhere in Africa working in PIMD who would be interested joining the SIRG and the Board.

Bea Maes stated that the Board would have more regular communication – 6 monthly skype-based.

b. Representative on IASSIDD Council: Juliet Goldbart was nominated as representative on Council, with Sheridan Forster as her alternate especially for Southern Hemisphere events.

4. **SIRG activities**

a. Report 2015-6: Bea Maes presented the report submitted to Council (received by members prior to this meeting). Main activities: Round Table, Early Career Researcher (ECR) meeting, 2 newsletters, update to SIRG part of IASSIDD website. Aim is to have all presentations from the PIMD strand in conference on website.

b. Planning: Next round table August 2017 – Genevieve Petitpierre to organise at Fribourg, Switzerland. This will be combined with an ECR meeting.

A suggestion for running the next SIRG has been received from colleagues in Bulgaria (Plovdiv). This was agreed to be a good idea as we don't have many links with Eastern Europe, so this would give good reach. As yet, however, they have never been part of the SIRG, and it would be difficult for them to run a comparable event. So, it was proposed that representatives from Plovdiv should attend the Fribourg RoundTable to see what it is like. It could then be agreed that they would organise the following Round Table. Members supported this view.

Jenny Miller (PAMIS) suggested that we need to be making better use of IT to enhance access. This was agreed, and attempts to do this would be used for the ECR meeting at this conference, with the additional aim of maintaining links with PhD completers/past members. The Fribourg RT organising team will be asked to commit to more virtual connections.

Sheridan Forster has started setting up recording and distribution of conference papers. If the Plovdiv, Bulgaria team don't run the next RT, SF suggested that we could offer a workshop by members of SIRG to give input for researchers, parents etc.

SF also proposed setting up a 1 hour online or recorded discussion/workshop before the end of the year. Jenny Miller suggested linking Hannah Young (PAMIS) with SF to set this up.

RTs are usually in the year with no conference, but cycle has changed, and it was suggested that we plan the following event conference/RT by conference, when there is an opportunity.

Forthcoming IASSIDD events: 2017 - Bangkok. July 2018 Athens (European). August 2019 Glasgow. So, possible next RT Dec 2018/Jan 2019

Bea Maes explained the purpose of RTs as having focused topics and much more time for discussion. Exchanges of ideas, discussion of possible collaborations. More practice connection, more links with families. Ethical debates. More informal.

It was agreed that we need to try to organise RTs outside Europe too.

5. **Financial situation** – report 2015-6 see notes below on members and finances: Income has dropped due to IASSIDD change in allocation of money to SIRGs; only primary SIRG gets funding. So there is an urgent need to promote the SIRG. Finances are okay for next year, but will become a problem. We may need to add a small charge for activities

6. **Membership:** 2013 – 110 members, 2014 – 96, 2015- 56 subscribed, 2016 – 49 members.

7. **Newsletter & web presence:** Members were asked please to keep addresses up to date! Newsletters are currently going to ECR list and the formal IASSIDD PIMD list. Non IASSIDD members don't get information, but individuals are encouraged to forward the newsletter to their own networks.

Thanks were given to Aafke Kamstra and Sara Nijs for their excellent work on the newsletters. Leontien Bossink has taken over from Aafke – thanks for this. The newsletter team were asked to send out regular reminders to ask members to submit content.

ECRs suggest a Linked-In group to bring together and promote the community of ECR SIRG researchers. Saskia Damen suggested that this works well for her group. Gertrud Schalen proposed that this would be in parallel with main w/site allowing quick communication about conferences etc. Michael Arthur Kelly (MAK) agreed and supported a Linked-In group for the whole SIRG .Jenny Miller added that this would offer an opportunity to ask questions and to link practitioners. Gertrud Schalen and ECRs will expand the group (currently 3 people!)

8. **Award** – Carla Vlaskamp award: Congratulations to Lena Talman. Lena has her poster today, and her presentation tomorrow. Her topic is Participation in daily life of people with PIMD. Including all people living in one community of Sweden no matter where they live.

9. There was a suggestion for an **award recognising Loretto Lambe's contribution to PIMD**. It was agreed that we would set up an event at a RT and/or conference aimed at parents, to ensure we meet the needs of more parents. We will need to link with parents' organisation to make this happen.

Sheridan Forster suggested that we need to ask parents what they want, and ensure parents meet other parents at conferences and events. It was agreed that we should make conference content available to parents. Also, contributions FROM parents on what they are doing.

Petra Poppes suggested that it would be good to hear what parents' want to have researched and to hear about. More discussion is needed on this.

10. A **Special Issue of a journal on PIMD** was proposed. Ideas on a theme within PIMD should be sent to the Board. MAK supports the idea of an issue on training of support staff, capacity building and offered to be involved.

11. **PAMIS**. PAMIS works with Dundee university. It is PAMIS' 25th birthday next year and there will be a re-launch of the White Top research centre. Topics include inclusion and design, architecture and planners, toilets. Inclusion in arts. Loretto's books will be launched. There will be a conference/event 17th/18th June 2017 in Dundee. The PIMD SIRG was invited to host an event on the Wednesday.

12. Any Other Business? MAK proposed a vote of thanks for Bea Maes' leadership and her work on Council.