

## **Activity Report of the IASSIDD Profound Intellectual and Multiple Disabilities - Special Interest Research Group (SIRG-PIMD)**

**2014**

### **1. Members**

The SIRG-PIMD had 96 subscribed members in 2014 (14 less compared to 2013).

### **2. Board**

A board meeting and a members meeting have been organized at the IASSIDD European conference in Vienna. The board members have been confirmed: Bea Maes (Chair), Juliet Goldbart (Secretary, Treasurer), Annette Van der Putten, Sheridan Forster, Nan-Chieh Chen, Krysti De Zonia, Gare Fabila, Loretto Lambe, Carla Vlaskamp and Peter Thorpe (webmaster).

### **3. Activities**

#### **3.1. International conference, Tokyo**

A 2nd international symposium has been hold in Tokyo, with the topic 'Pain of persons with PIMD'.

#### **3.2. Vienna Conference**

The SIRG-PIMD coordinated the preparations for the Vienna conference. 15 symposia were organized next to the poster presentations and one discussion symposium about end-of-life issues and euthanasia in persons with PIMD (Carla Vlaskamp & Paulien Rijkhoek). We plan to make a position paper based on this discussion symposium.

#### **3.3. Early career research meetings**

There has been an early career research meeting on Friday the 18<sup>th</sup> of July after the IASSIDD conference in Vienna. The topic was 'writing and publishing scientific articles'. About 20 early career researchers attended the meeting.

They also set up a website for this group, see [ecrmpimd.weebly.com](http://ecrmpimd.weebly.com)

### **4. Other initiatives**

We launched the *Carla Vlaskamp Early Career Award* (€ 750). It has been established to support the participation of a young researcher at the European or World Conference of IASSIDD. Carla Vlaskamp is one of the founders of the SIRG-PIMD and played an important role in the 'visibility' of persons with PIMD and in generating knowledge for science and practice about those people. The award provides the reimbursement of eligible expenses incurred to attend the Conference. The first award has been given to Magdalena Birtha (Hungary/Ireland) who is working on advocacy and citizenship rights of persons with severe disabilities.

The members of the SIRG-PIMD have submitted a *European COST-proposal*: Supporting development, participation and wellbeing of persons with profound intellectual and multiple disabilities (PIMD-ACTION). We proposed a European network of research groups and practice-oriented organizations to encounter the problems experienced in family life, education, health care, and support for children and adults with PIMD, as well as to deal with the challenges of doing research about this target group. The proposal has not been accepted, but we will try again in the beginning of 2015.

## **5. Communication**

An *electronic newsletter* has been re-launched in the beginning of 2014. We plan at least 2 newsletters per year. The newsletter includes announcements and reports of conferences, current research projects, questions of members to cooperate in certain projects, new publications etc. Krysti DeZonia and Aafke Kamstra are coordinating the newsletter.

We still need to transfer our own *website* of the SIRG-PIMD: <http://www.sirgpmid.be> to the new IASSIDD-website and to update the format and the contents. Peter Thorpe volunteered to manage the new IASSIDD-website.

## **6. Plans for the future**

From 23<sup>rd</sup> to 25<sup>th</sup> September 2015 the 7<sup>th</sup> *Roundtable Meeting* of the SIRG-PIMD will take place in Mälardalen University. Our hosts are the Jenny Wilder of the Mälardalen University and the Swedish Family Care Competence Center. Topics are Early development, Education, Social Participation, and Future collaborative research.

Just before the roundtable an *early career researchers meeting* will be organized from 22<sup>nd</sup> to 23<sup>th</sup> September 2015, also in Mälardalen, Sweden.

At the *IASSIDD world conference in Melbourne* (15<sup>th</sup>- 19<sup>th</sup> of August 2016) the SIRG-PIMD will organize several symposia with current research with regard to persons with PIMD. The planning will be made at the next roundtable. We plan to have some joint symposia with other SIRG's, such as ethics, health, and challenging behavior/mental health.

Submitted by:

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