



**International Association
for the Scientific Study
of Intellectual Disabilities**

Special Interest Research Group Profound Intellectual and Multiple Disabilities

Newsletter - June 2016

The purpose of a SIRG is to provide opportunities for international and multidisciplinary networking between researchers and members of IASSIDD within the same area of interest. In this way, they may create opportunities for sharing information, developing initiatives, identifying new colleagues and being visible to newcomers in the field. Through the SIRGs, groups of researchers in the field may easily collaborate on common themes of interest.

Introducing the Board

- Bea Maes, Belgium, *Chair and IASSIDD council representative*
 - Juliet Goldbart, UK, *Treasurer / secretary*
 - Annette van der Putten, The Netherlands, *Member*
 - Nan-Chieh Chen, Taiwan, *Member*
 - Sheridan Forster, Australia, *Member*
 - Krysti De Zonia, US, *Member*
 - Gare Fablila, Mexico, *Member*
 - Carla Vlaskamp, The Netherlands, *Past Chair*
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Membership

If you are not yet an official IASSIDD-member, you may still start or renew your membership fee (see www.iassidd.org). Remember to click the box under the section SIRG for the SIRG Profound and Multiple Intellectual Disabilities. As you know part of the membership fee is given to the SIRG's to organize meetings and roundtables! Please speak to your colleagues and contacts and encourage them to join our SIRG. They will find information about our mission, our activities and the members of the SIRG on

Loretto Lambe

1943-2015

Tireless and effective advocate for people with PIMD and their families

It is with great sadness that we report the death, in October 2015, of Loretto Lambe; a passionate and effective campaigner for the rights of people with PIMD and their families.

Loretto started working for the UK campaigning charity Mencap in 1975, going on to run the highly successful Profound Disability Project in Manchester from 1985, developing training materials for families and practitioners. In 1990, Loretto and her husband James Hogg moved to Dundee, in Scotland where she set up Pamis; *Promoting A More Inclusive Society*, an organisation committed to working with people with profound disabilities and their families.

As many SIRG members will know, Loretto built Pamis into a well-funded and multifaceted organisation, developing research, training, a network of skilled and experienced coordinators providing family support and, perhaps above all, campaigning for much needed rights and services. It is a tribute to Loretto's skill and commitment that Pamis' work has informed and influenced the Scottish Government's strategy for learning disabilities over many years. Loretto's work with the *Changing Places Consortium* has led to 838 fully accessible Changing Places toilets in the UK, and the number is still increasing.

www.sirgpmd.be. Members are key to the continued success and development of our activities. If people are interested, please ask them to send a mail to [Bea Maes](#).

Research to Practice

Short summary of a PhD thesis

David Haines

University of Brighton, UK. *Supervisors Dr Jon Wright and Dr Huguette Comerasamy*

When circumstances such as poor support result in people with profound intellectual and multiple disabilities doing very little at home, occupational injustice arguably results, impacting on wellbeing and quality of life. Support to engage in occupations (meaningful activities) is underpinned by research evidence and theory from occupational therapy, occupational science and active support and occupational therapists claim to support people with complex needs to engage in ways that are authentic and meaningful. Exactly *how* and whether their methods differ from others' remains unclear, however.

Using a qualitative case study methodology (from an interpretivist and social constructionist stance) and ethnographic methods (participant observation, interviews and document analysis), David explored a single purposively selected case over one year. In this, occupational therapist Esther worked with Matt, Steve, Becky, Jane and Harold, five people with severe and

Loretto was, for many years, a co-chair of the PIMD SIRG. Colleagues will remember her contributions to committee meetings, round tables and conferences with great warmth. In the midst of discussion of research methods, funding opportunities and journal articles, Loretto ensured that central to all our work was our commitment to the lives of people with profound disabilities and their families.

Awards

Carla Vlaskamp Early Career Award

The Carla Vlaskamp Early Career Award has been established by the SIRG-PIMD. It has been established to support the participation of a young researcher at the European or World Conference of IASSIDD. With this year's award an early career researcher get the chance to finance their participation in the IASSIDD world congress in Melbourne.



The Carla Vlaskamp Early Career Award was awarded to **Lena Talman** of the Mälardalen University in Sweden. She is doing research on participation in everyday life for persons with profound disabilities. During the word conference she will give a presentation entitled: Insufficient

profound intellectual disabilities and their support workers to increase engagement in occupation at home.

The case is illustrated with three ethnodramatic vignettes, constructed from field notes and interview transcripts. Its story has two overarching themes: the impact of shifting support and leadership cultures on engagement and characteristics of occupational therapy, which: aimed to create and sustain cultural change; had a particular understanding of authentic occupational engagement; and sought to work with the staff team in a collaborative and empowering way.

The case illustrates: (1) that authentic engagement in occupation is possible for those with profound intellectual disabilities (essentially meaning engaging in co-occupations at a sensory level, without necessarily *physically* doing anything); (2) how occupational therapy sought to address occupational injustices not only for those with profound intellectual disabilities, but also for those supporting them, for whom role ambiguity risked burnout; and (3) how occupational therapy sought to sustain a different way of supporting engagement by collaborating with and empowering the staff team.

"*Petite generalisations*" (credibly transferable when contextualised to the case) are suggested: (1) organisational culture may impact on whether people are supported effectively to engage in occupation; (2) recognising the level at which people can engage in occupation seems necessary for support to engage

documentation of participation: A study of contents in implementation plans (IPs) for adults with profound intellectual disabilities (PID) during the symposium on Social participation and inclusion of persons with PIMD. She will also present a poster on Participation for adults with profound intellectual disabilities (PID): Perceptions of officials and staff during the congress.

Ds. Visscherprijs

In March 2016 Kirsten Ten Bosch received the ds. Visscherprijs. The prize is awarded every two years to the author of a highly valuable dissertation in the interests of people with intellectual disabilities defended at a university in the Netherlands or Flanders. Two members of the SIRG-PIMD were awardee. **Dr. Kirsten van den Bosch** of the University of Groningen received the first prize for her dissertation: Safe and Sound Soundscape research in special needs care; **dr. Sara Nijs** of the KU Leuven received the second place for her dissertation: Experience Together: Peer interactions in persons with profound intellectual and multiple disabilities.



authentically; (3) “independence”, “choice” and “personalisation” are everyday words, but how they are meaningfully relevant to people may not be fully understood; (4) occupational therapists should focus on facilitating sustained cultural change in support of occupational engagement at home.

Upcoming Events

ISAAC Conference 2016

Toronto, Canada, 6-13 August 2016

The ISAAC Conference 2016 will be held at the Westin Harbour Castle hotel in Toronto, Canada, from August 6 – 13, 2016.

7th World Congress IASSIDD

Melbourne, Australia, 15-19 August 2016

Members of the IASSIDD and other interested parties gather every four years for a World Congress. The 2016 meetings will mark the 15th time IASSIDD has held a World Congress. Each World Congress is comprised of daily plenary sessions at which prominent researchers from around the world speak for 30-45 minutes. The balance of the conference is a combination of paper and poster sessions, workshops, meetings of our Special Interest Research Groups, and social events. [More information](#)

The Early Career Researchers Meeting during the IASSIDD World Congress 2016

Past Event

EMB Today

The Netherlands , June 2, 2016

's Heeren Loo and the University of Groningen organized together the congress 'EMB Today'. Researchers, professionals and families shared actual knowledge on people with PIMD. The day was filled with interactive workshops of Dutch and Belgian SIRG-members.

In addition, Suzanne Jansen and Petra Poppes introduced the expertise centre on PIMD, which will focus on training, consultation and the development and use of scientific knowledge in practice. The expertise centre on PIMD is a collaboration between 's Heeren Loo and the University of Groningen.



Announcements

New job for Vera Munde

Based on my new position as a manager of corporate development of the Lebenshilfe Berlin (the Berlin department of an NGO supporting individuals with intellectual disabilities and their families in Germany),

Melbourne, Australia, 19 August 2016

The 6th early career researchers meeting of the SIRG-PIMD will take place on **Friday the 19th of August, 2016**. All early career researchers with interest in PIMD are invited to attend this meeting. So if you have any colleagues working on PIMD, please let them know about the meeting. Of course, all senior researchers are also welcome to participate! [Subscribe here](#)

It has become a tradition to go for dinner with all early career researchers, therefore on **Wednesday the 17th of August** we would like to go for dinner in Melbourne. Let's join it!

Roundtable Meeting of the SIRG-PIMD 2017

Fribourg, Switzerland, 29-30 August 2017

Genevieve Petitpierre and Juliane Dind are pleased to invite you to the next 8th Roundtable Meeting of the SIRG-PIMD from the 29th (since morning) until the 30th (until the end of afternoon) of August 2017 at the University of Fribourg, Switzerland. The early career researcher meeting (ECRM) will take place on the 28th of August (full day) and on the 31th (morning).

Next Newsletter

We try to compose an interesting newsletter two times a year. We would welcome any feedback on this newsletter and content for the next edition. The following newsletter will be send to you in

I am involved in several projects (for example one about realizing quality of life in individuals with PIMD in clinical practice). If there are any ideas for international collaboration, I am very amenable for it! *Vera Munde*

December of 2016. Please send us your information on: Past & Upcoming Events, finished doctoral theses, new projects, interesting books, articles and announcements with regard to the group of persons with PIMD (after May 2016). [Send email to Sara Nijs.](#)



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