



International Association
for the Scientific Study
of Intellectual Disabilities

Special Interest Research Group Profound Intellectual and Multiple Disabilities

Newsletter - December 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*
- Juliet Goldbart, UK, *Treasurer / secretary and IASSID council representative*
- 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*

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

- Carla Vlaskamp, The Netherlands, *Past Chair*

Past Events

The 6th Early Career Researchers Meeting

Melbourne, Australia , August 19, 2016

A short report can be found [on the updated website!](#)

Social Dinner Early Career Researchers

Melbourne, Australia , August 17, 2016

Social dinner with all early career researchers during the IASSIDD and/or SIRG activities has become a tradition. Last summer, 13 early career researchers went for dinner on the 17th of August during the IASSIDD World congress in Melbourne.



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 the IASSIDD website. 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](#).

Announcements

Saskia Damen (University of Groningen) has received a grant from Inzicht/ZonMW fund in the Netherlands for a project in which we will implement the High Quality Communication intervention. This intervention aims to enhance the quality of communication of individuals with sensory and intellectual disabilities, by supporting their communication partners. In the implementation project two Dutch Universities (the University of Groningen, VU Amsterdam) and three service providing organizations (Bartiméus, Royal Dutch Kentalis and Visio) collaborate in developing a course for professionals and in the publishing of a book with video materials.

Communication in the Context of Congenital Deafblindness

Groningen, The Netherlands, November 15-17, 2016

A three days international conference was held on congenital deafblindness at the University of Groningen. With this conference the university is celebrating the 10 years anniversary of the international master communication and deafblindness at the department of special education and youth care.

Roundtable Meeting PIMD during the IASSIDD World Congress

Melbourne, Australia, August 17, 2016

During the IASSIDD World Congress, an evening roundtable was held on the developing of training programs for Professional Care Coordinators (PCC) for PIMD. Below, a report written by *S.Suemitsu, N.Onodera, Y.Iwasaki, T.Matsubasa*.

There are about 40,000 people with PIMD in Japan, and 25,000 (62.5%) of them are living with their family. In addition, the number of newborn babies in NICU with severe disabilities has increased recently. The promotion of their discharge from NICU

The **Han Nakken Price 2016** is awarded to **Kirsten van den Bosch** for her article about the role of sound in residential facilities for people with profound intellectual and multiple disabilities, published in the Journal of Policy and Practice in Intellectual Disabilities. **Prof. Bea Maes** (Catholic University of Leuven) will pronounce the Han Nakken Lecture on December 9, 2016, titled "The crucial role of supervisors in supporting social interaction and participation of people with PIMD".

New LinkedIn Group

During the last Early Career Researchers Meeting we discussed about future opportunities for international networking such as LinkedIn and conference call. Recently, we created a new LinkedIn group. This group is open to any student or researcher (junior, senior) with interest in PIMD. We would like to invite you (and your colleagues) to join the LinkedIn group '[ECR SIRG PIMD Network](#)'. If you have any questions (or troubles with joining the group) please contact by [e-mail](#). We are looking forward to your membership and if you know anyone who should join us,

is also becoming a PIMD support issue, and so there is a situation in which the health care needs of PIMD are becoming more complex and severe in Japan.

Japanese study teams have been developing training programs for Professional Care Coordinators (PCC) for

PIMD community living. We therefore announce the contents of this training program and plans for improvement of the quality of the future training programs for PCC. Last year at the 7th SIRG-PIMD roundtable meeting in Sweden, the importance of PCC engaging with people with PIMD gained international and universal recognition. Again in this August at the World Congress in Melbourne, we had a roundtable meeting on PCC training methods in cooperation with Dr. Arthur-Kelly of The University of Newcastle, Australia. According to his summarization of the meeting as a moderator, the following issues were discussed by the larger group;

- The importance of providing training in the core areas in ways that connect theory and good practice. This point was mentioned in relation to the changes in the PCC delivery approach in Japan including more support in the field and care for families who include people with PIMD.

please spread the word!



Online Survey

To explore the wishes and ideas of SIRG PIMD Early Career Researchers about the ECR Meetings, we would like to ask **all Early Career Researchers** to fill out an online survey. Also if you did not attend the last Meeting in Melbourne. The survey is meant to inform ourselves about the wishes and ideas of the SIRG PIMD Early Career Researchers. It will only take a couple of minutes of your time, and will provide us with a lot of information. Thank you very much in advance!

Leontien Bossink, Gertruud Schalen & Juliane Dind

[Click here for the Survey](#)

Upcoming events

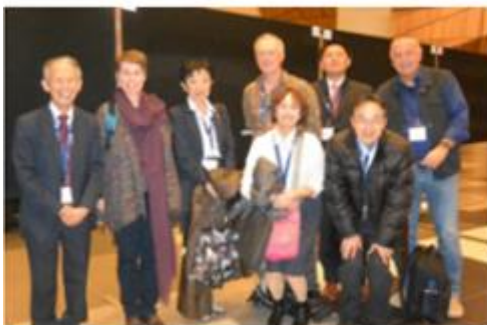
AGOSCI

Melbourne, Australia, 17-20 May 2017

Sheridan Forster, Hilary Johnson and

- The cultural variations across the world in terms of how people with PIMD are assisted to maximize their quality of life.
- How to ensure training staff have suitable experience and expertise and the model of training is effective in building the skills of participants in community care and support.
- The challenges of effectively assessing the skills, knowledge and attitudes of PCC staff working in different situations and with clients who can have vastly differing and often complex needs.

Many countries are working on how to effectively train PCC. We plan to publish a book of the Japanese current programs for training PCC which will be translated to an English version next year. Through a pioneering action in Japan we hope that it will assist a discussion for international standardization of the training programs. We would like to express our great thanks to SIRG-PIMD colleagues and Dr. Arthur-Kelly. See you in Fribourg!



Meredith Prain will be running a workshop at the AGOSI conference next year in Australia: Communication with People Who Don't Use or Seem to Understand Speech or Symbols: Connect, Explore, Thrive. This workshop will be about people, in particular adults, who don't use or seem to understand speech or symbols. Sometimes these people are referred to as having a profound intellectual disability, or being emergent or preintentional communicators. The theme of the conference is Ready, Set, Aaction, but we've put our own twist on it for thinking about supporting people who don't use or seem to understand speech or symbols. Ready = Connect with the person - Exploring features of environments/cultures that can aid connection, and practical strategies for making individual connections Set = Explore preferences and choice - Strategies for supported decision making and supporting individuals within NDIS and other choice based environments AAction = Thrive in ongoing interaction - exploring how to deepen and enrich interactions using video and goals building on current

skills, and considering the outcomes that can arise from high quality interactions. Interaction is possible with this population and meanings can be cocreated. [More information about the conference.](#)

PAMIS International conference

Dundee, UK, 14-16 June 2017

Interesting PIMD articles

(published after May 2016)

Aherne, C., & Coughlan, B. (2016). A preliminary investigation of the suitability of aquatics for people with severe and profound intellectual disabilities. *Journal of Intellectual Disabilities*. doi: 10.1177/1744629516646513

Antaki, C., Crompton, R. J., Walton, C., & Finlay, M. (2016). How adults with profound intellectual disability engage others in interaction. *Sociology of Health and Illness*, 1-18. doi: 10.1111/1467-9566.12500

Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2016). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 409-421. doi: 10.1111/jar.12200

Boren, T., Granlund, M., Wilder, J., & Axelsson, A. K. (2016). Sweden's LSS and social integration: An exploration of the relationship between personal assistant type, activities, and participation for children with PIMD. *Journal of Policy and Practice in Intellectual Disabilities*, 13(1), 50-60. doi: 10.1111/jppi.12146

In June 2017 the PAMIS international conference will take place. [More information can be found on the website.](#)

Vision 2017

The Hague, The Netherlands, 25 - 29 June 2017

The [12th International Low Vision Research and Rehabilitation \(ISLRR\) congress](#) will be organized in the Netherlands, in the Hague on 25th -29th of June 2017. During this congress, a symposium will be organized on the theme 'Participation and Health in persons with multiple disabilities and visual impairment (MDVI)', by Royal Dutch Visio and the Hanze University in close collaboration with the University of Groningen, Department of Special Needs Education and Youth Care. It is estimated that visual and severe or profound

intellectual disabilities affect 10,000 to 15,000 adults in the Netherlands, which is approximately 0.05-0.08% of the Dutch population. People with severe or profound intellectual disabilities and visual impairment (MDVI) encounter numerous physical health problems simultaneously. In addition, they have lower physical activity and physical fitness levels compared to the general population. As a consequence, their ability to perform activities of daily living is decreased. Last but not least, persons with MDVI appear to be at risk of decreased participation.

The symposium 'Participation and Health in persons with multiple disabilities and visual impairment (MDVI)' is scheduled on

Brug, A., Van der Putten, A., Penne, A., Maes, B., & Vlaskamp, C. (2016). Making a difference? A comparison between multi sensory and regular storytelling for persons with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research, 60*(11), 1043-1053. doi: 10.1111/jir.12260

Cluley, V. (2016). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *British journal of learning disabilities, n/a-n/a*. doi: 10.1111/bld.12174

Dijkhuizen, A., Hilgenkamp, T. I. M., Krijnen, W. P., van der Schans, C. P., & Waninge, A. (2016). The impact of visual impairment on the ability to perform activities of daily living for persons with severe/profound intellectual disability. *Research in Developmental Disabilities, 48*, 35-42. doi: 10.1016/j.ridd.2015.10.001

Griffiths, C., & Smith, M. (2016). You and me: The structural basis for the interaction of people with severe and profound intellectual disability and others. *Journal of Intellectual Disabilities*. doi: 10.1177/1744629516644380

Haring, N. G. (2016). Republication of "Educational Services for the Severely and Profoundly Handicapped1". *The Journal of Special Education*. doi: 10.1177/0022466916651465

Thursday, 29 June 2017. Research will be presented concerning the following topics: participation, physical health problems, optometric issues, motor activation, and measuring muscle strength of persons with MDVI.

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).

Finished PhD thesis



The right to supported decision-making for people rarely heard

Joanne Watson

Deakin University, Australia. Supervisors Dr. Erin Wilson and Dr. Nick Hagiliassis

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) represents an important step towards promoting, protecting and ensuring human

Harshaw, J. (2016). Finding accommodation: Spirituality and people with profound intellectual disabilities. *Journal of Disability & Religion, 20*(3), 140-153. doi: 10.1080/23312521.2016.1203694

Jansen, S. L., van der Putten, A. A., & Vlaskamp, C. (2016). Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: A multiple case study. *Journal of Intellectual Disabilities. doi: 10.1177/1744629516641843*

Johnson, H., Bigby, C., Iacono, T., Douglas, J., Katthagen, S., & Bould, E. (2016). Increasing day service staff capacity to facilitate positive relationships with people with severe intellectual disability: Evaluation of a new intervention using multiple baseline design. *Journal of Intellectual & Developmental Disability, 1-12. doi: 10.3109/13668250.2016.1246656*

Kamstra, A., van der Putten, A. A., & Vlaskamp, C. (2016). Efforts to increase social contact in persons with profound intellectual and multiple disabilities: Analysing individual support plans in the Netherlands. *Journal of Intellectual Disabilities. doi: 10.1177/1744629516653037*

rights for people with disability. Article 12 of the Convention mandates that all people with disability be recognized before the law on an equal basis with others and importantly be supported to exercise that legal capacity. In so doing, it challenges the use of substitute decision-making. In response to the UNCRPD, supported decision-making is emerging as an alternative paradigm in lieu of substitute decision-making.

Tension exists around the relevance and application of Article 12 for those who communicate informally, and sometimes unintentionally: people with severe or profound intellectual disability. Due to the interdependent nature of their lives, autonomous decision-making is obviously challenging. However, if signatory nations to the UNCRPD are to live up to their obligations under Article 12 attention needs to be paid to how best to support people with severe or profound intellectual disability to have their preferences reflected in the decisions that are made about their lives.

This thesis reports on a study that used an interpretative, multiple case study design. Five people with severe or profound intellectual disability and their circle of support participated in a supported decision-making process, targeting a range of life decisions. Interview, focus group, questionnaire and observation data were collected and analysed. A primary aim of the study was to

Luijkx, J., van der Putten, A. A. J., & Vlaskamp, C. (2016). "I love my sister, but sometimes I don't": A qualitative study into the experiences of siblings of a child with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability, 41*(4), 1-10. doi: 10.3109/13668250.2016.1224333

Nagra, M. K., White, R., Appiah, A., & Rayner, K. (2016). Intensive Interaction training for paid carers: 'Looking, looking and find out when they want to relate to you'. *Journal of Applied Research in Intellectual Disabilities, n/a-n/a*. doi: 10.1111/jar.12259

Poppes, P., van der Putten, A., Post, W., Frans, N., ten Brug, A., van Es, A., & Vlaskamp, C. (2016). Relabelling behaviour. The effects of psycho-education on the perceived severity and causes of challenging behaviour in people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research, n/a-n/a*. doi: 10.1111/jir.12299

Poppes, P., van der Putten, A. A., ten Brug, A., & Vlaskamp, C. (2016). Staff attributions of the causes of challenging behaviour in children and adults with profound intellectual and multiple disabilities. *Research in Developmental Disabilities, 48*, 95-102. doi: 10.1016/j.ridd.2015.10.014

characterize supported decision-making for people with severe or profound intellectual disabilities. Addressing this aim, supported decision-making was characterized in terms of the existence of two distinct but interdependent roles. The thesis describes the roles played by (a) the person with a disability (supported), and (b) the circle of support (supporters) in a supported decision-making process. The role of the person with a disability in this dynamic is their expression of preference, and the role of supporter(s) is to respond to this expression of preference by acknowledging, interpreting and acting on this expression. Within this decision-making dynamic, supporter responsiveness, as opposed to focus people's expression of preference, is the component that is amenable to change through structured practice guidance, making the enablement of responsiveness a crucial strategy for supporting decision-making.

A secondary aim of the study was to identify and discuss factors that underlie supporter responsiveness and therefore supported decision-making for people with severe or profound intellectual disability.

Five themes and ten sub themes, characterizing supporter responsiveness are identified and explored.

The thesis furthers understanding of what supported decision-making looks like for people with severe or profound intellectual disability. These findings give a focus for practice and policy efforts for ensuring

Poppes, P., van der Putten, A. J. J., Post, W. J., & Vlaskamp, C. (2016). Risk factors associated with challenging behaviour in people with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, n/a-n/a. doi: 10.1111/jir.12268

Schönewolf-Greulich, B., Stahlhut, M., Larsen, J. L., Syhler, B., & Bisgaard, A.-M. (2016). Functional abilities in aging women with Rett syndrome – the Danish cohort. *Disability and Rehabilitation*, 1-8. doi: 10.3109/09638288.2016.1170896

Steel, E. J., Layton, N. A., Foster, M. M., & Bennett, S. (2016). Challenges of user-centred assistive technology provision in Australia: shopping without a prescription. *Disability and Rehabilitation: Assistive Technology*, 11(3), 235-240. doi: 10.3109/17483107.2014.941953

Ten Brug, A., Van der Putten, A. A., Penne, A., Maes, B., & Vlaskamp, C. (2016). Making a difference? A comparison between multi-sensory and regular storytelling for persons with profound intellectual and multiple disabilities. *Journal of Intellectual Disability Research*, 60(11), 1043-1053. doi: 10.1111/jir.12260

Vaan, G., Vervloed, M., Peters Scheffer, N., Gent, T., Knoors, H., & Verhoeven, L.

people with severe and profound disability receive appropriate support in decision-making, a clear obligation of signatory nations under the UNCRPD.

Interesting links

The **PMLD Link magazine** from the UK (www.pmldlink.org.uk) contains practice, theoretical, and ethical discussions as well as what is happening in the UK.



Blog of **Sheridan Forster** in which she discusses many practice based issues, with a reflection on research and ethics, for example, this piece entitled Communicative (cognitive) absolutism. [Click here](#)

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 **June of 2017**. Please send us your information on: Past & Upcoming Events, finished doctoral theses, new projects, interesting books, articles and

(2016). Behavioural assessment of autism spectrum disorders in people with multiple disabilities. *Journal of Intellectual Disability Research*, 60(2), 101-112. doi: 10.1111/jir.12206

van den Bosch, K. A., Andringa, T. C., Başkent, D., & Vlaskamp, C. (2016). The role of sound in residential facilities for people with profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 13(1), 61-68. doi: 10.1111/jppi.12147

Van keer, I., & Maes, B. (2016). Contextual factors influencing the developmental characteristics of young children with severe to profound intellectual disability: A critical review. *Journal of Intellectual & Developmental Disability*. Doi: 10.3109/13668250.2016.1252458

van Timmeren, E., van der Putten, A., van Schroyensteen Lantman de Valk, H., van der Schans, C., & Waning, A. (2016). Prevalence of reported physical health problems in people with severe or profound intellectual and motor disabilities: A cross sectional study of medical records and care plans. *Journal of Intellectual Disability Research*, 60(11), 1109-1118. doi: 10.1111/jir.12298

announcements with regard to the group of persons with PIMD (after November 2016). [Send email to Sara Nijs.](#)

van Timmeren, E. A., van der Schans, C. P., van der Putten, A. A. J., Krijnen, W. P., Steenberg, H. A., van Schroyensteen Lantman-de Valk, H. M. J., & Waning, A. (2016). Physical health issues in adults with severe or profound intellectual and motor disabilities: a systematic review of cross-sectional studies. *Journal of Intellectual Disability Research*, n/a-n/a. doi: 10.1111/jir.12296

Walton, C., & Kerr, M. (2016). Severe intellectual disability: Systematic review of the prevalence and nature of presentation of unipolar depression. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 395-408. doi: 10.1111/jar.12203

Young, H., Hogg, J., & Garrard, B. (2016). Making sense of bereavement in people with profound intellectual and multiple disabilities: Carer perspectives. *Journal of Applied Research in Intellectual Disabilities*, n/a-n/a. doi: 10.1111/jar.12285



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