



International Association  
for the Scientific Study  
of Intellectual Disabilities

## Special Interest Research Group Profound Intellectual and Multiple Disabilities

*Newsletter - June 2017*

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.

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### Introducing the Board

- Bea Maes, Belgium, *Chair*
- Juliet Goldbart, UK, *Treasurer / secretary and IASSIDD 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*

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### New projects

**iParticipate: Using technological devices in persons with PIMD**

*dr. Sara Nijs – sara.nijs@kuleuven.be*

### Membership

Please do consider to start or renew your IASSIDD Membership for 2017. If you do so, please do remember to select the SIRG Profound and Multiple Intellectual Disabilities as your "primary" SIRG. 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 [the IASSIDD website](#). Members are key to the continued success and development of our activities. If people are interested, please ask them to send an email to [Bea Maes](#) (SIRG Chair).

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At the parenting and special education unit of the KU Leuven we started the iParticipate project in which we are carrying out a survey study on assistive technology. We want to spread this survey in European countries and would like to have the input of paid professionals working with persons with profound intellectual disabilities (teachers, direct support workers, staff, policymakers, therapists,...). It would be a great help for is you could spread our survey in your country. We want to have as much input as possible, do not hesitate to send this e-mail to contacts or organisations who on their turn can send it to their contacts. [If you have questions, please do not hesitate to contact me.](#)

The survey is translated in various languages: [Dutch](#), [German](#), [Portuguese](#), [Spanish](#), [French](#) & [English](#).

### **Assessing alertness and engagement in children with profound and multiple disabilities**

dr. Kathleen Tait - [kathleen.tait@mq.edu.au](mailto:kathleen.tait@mq.edu.au)  
or [kathleen.tait@gmail.com](mailto:kathleen.tait@gmail.com) and dr. Jeff Sigafos - [jeff.sigafos@vuw.ac.nz](mailto:jeff.sigafos@vuw.ac.nz)

Children with profound and multiple disabilities often appear to have fluctuating levels of alertness and limited engagement in instructional activities. Consequently, a major educational priority for such children is to increase their levels of alertness and engagement so that they are then more likely to benefit from instruction. One barrier to increasing alertness and engagement is the difficulty of determining when a child is in fact sufficiently alert and engaged.

There is still room for presentations during the Roundtable Meeting 2017. **The deadline is extended for the abstract submission until the 15th of May**, and the **deadline for the registration until the 10th of June**. The date of the acceptance notification doesn't change, it remains the 31th of May.

*Juliane Dind*

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## **Upcoming events**

### **PAMIS International conference**

*Dundee, UK, 14-16 June 2017*

In June 2017 the PAMIS international conference will take place. [More information.](#)

### **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

This current project is to evaluate a new and potentially easy and practical approach for distinguishing between two ends of the alertness/engagement continuum in children with profound and multiple disabilities, that is: (a) alert and engaged versus (b) not alert and not engaged. Along these lines, we observed five children with profound multiple disabilities when they were receiving frequent social and sensory stimulation versus when they were alone and receiving no such stimulation. We hypothesized that if certain behaviours (e.g., body movements, eyes movements, facial expression) were more evident under the stimulation condition compared to the alone condition then these behaviours might be valid indicators of alertness and engagement. If so, then observers might be able to quickly and reliably determine when a child was alert and engaged by comparing the child's general demeanor to a photograph of the child's body movements, eyes movements and facial expressions when receiving social and sensory stimulation versus photographs of the child's general demeanor when they were left alone without stimulation. This project is significant because this approach could point to a reliable, yet practical and easy method for determining the child's level of alertness and engagement. A reliable, yet practical and easy method for alertness and engagement would prove useful to professionals and carers with respect to increasing the child's alertness and engagement for instructional purposes.

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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 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). [More information.](#)

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**Australia and Japan  
continue progress on**

# Summary Online Survey ECR Meetings

To explore the wishes and ideas of SIRG PIMD Early Career Researchers about the ECR Meeting, we asked in the previous newsletter to fill out an online survey. Fourteen Early Career Researchers finished the survey with detailed and informative answers. Many thanks for taking the time and effort!

Overall, the previous meetings (social dinners and informative meetings) were rated as (very) good. Participants liked the informal atmosphere, interactive presentations and room for discussions with peers. The presence of senior members was also one of the positive key points, especially in summarizing different opinions and guiding discussion. Points of attention were early planning of date and providing of program and further information, to stay international, and a mix of discussions in smaller and a larger group. In addition, when it is possible, a preference for the meeting before IASSIDD conference was described so early careers can easily meet during the conference as well. Finally, opinions about online attendance were asked. The overall idea was that online attendance can be an important tool to include researchers who are not able to attend in real life, but also some issues to take into account were mentioned. For example, how to deal with time differences, how to ensure these attenders are actively involved in the discussions and the need to have direct access to IT support in case of trouble.

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# international research collaboration

*Naoki Onodera & Michael Arthur-Kelly*

**Naoki:** April in Japan, cherry blossoms are in full bloom everywhere and their petals are dancing in spring wind like a flower shower. My dear colleague Dr. Michael Arthur-Kelly of The University of Newcastle has been visiting Japan with his family in this romantic season. He observed some Japanese residential facilities and special schools in which the complex health care needs of people with PIMD are addressed in an integrated way. Moreover he had an occasion to exchange opinions at the National Institute of Special Needs Education in Japan (NISE). Japanese research teams have been honored to share stimulating discussions with him, and through this experience we have learned much together about supporting people with PIMD in community living and with respect to the best methods of training professionals engaging with them. Our network among the members of the SIRG-PIMD grows globally now and it is important that researchers and practitioners of every country collaborate with each other in our shared efforts to create an inclusive society and world. I hope that the friendship between Australia and Japan will grow and lead to a program of joint international research in the near future. I would like to express our great thanks to the SIRG-PIMD board, as their efforts to promote interaction are the origin of our friendship.



# Interesting PIMD articles

(published after November 2016)

Amor-Salamanca, A., & Menchon, J.M. (2017). Pain underreporting associated with profound intellectual disability in emergency departments. *Journal of Intellectual Disability Research*, 61, 341-347. doi:10.1111/jir.12355

Bossink, L.W.M., van der Putten, A.A.J., Waninge, A., & Vlaskamp, C. (2017). A power-assisted exercise intervention in people with profound intellectual and multiple disabilities living in a residential facility: A pilot randomised controlled trial. *Clinical Rehabilitation*, doi:10.1177/0269215516687347

Chan, J.S.L., & Chien, W.T. (2017). A randomised controlled trial on evaluation of the clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities: a pilot study. *Journal of Intellectual Disability Research*, doi:10.1111/jir.12377

Haines D. Brown A. (2017) Health professionals working effectively with support workers to enhance the quality of support for adults with intellectual disabilities: A meta-ethnography. *Journal of Applied Research in Intellectual Disabilities*.

Haines D. (2017) Ethical considerations in qualitative case study research recruiting participants with profound intellectual disabilities. *Research Ethics Review* [accepted for publication, in press]

Hanzen, G., van Nisperen, R.M.A., van der Putten, A.A.J., & Waninge, A. (2017).



**Michael:** After a superb 10 weeks based in Leuven, Belgium working with Professor Bea Maes and her impressive team, I was very happy to spend 2 weeks in Japan on the way home to Australia, connecting with valued colleagues there. I would like to express my deep gratitude to Mr. Naoki Onodera and Professor Shigeru Suemitsu who hosted my visit and ensured I learnt so much about support for people with PIMD in Japan. I was impressed with the unified approach to education, daily living and medical care. Also I especially impressed with the harmonious way in which professionals from various human service disciplines worked seamlessly together to seek the highest quality life outcomes for people with PIMD in their care. I learnt a great deal about schooling and community living supports as well as the various types of living arrangements on offer for people with PIMD in Japan. I am very keen to investigate the effectiveness of different approaches to designing and delivering programs of professional learning for staff working in a range of settings in collaboration with my colleagues there. The opportunity to learn from each other, across cultures, stimulated by the initiatives of this SIRG is a key element in achieving continuous improvement in our shared efforts to maximize life quality

Participation of adults with visual and severe or profound intellectual disabilities: Definition and operationalization. *Research in Developmental Disabilities*, 61, 95-107.

Jansen, S.L.G., van der Putten, A.A.J., & Vlaskamp, C. (2017). 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*, 21, 53-67. doi:10.1177/1744629516641843

Jansen, S.L.G., van der Putten, A.A.J., Post, W.J., & Vlaskamp, C. (2017). Do they agree? How parents and professionals perceive the support provided to persons with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*. doi:10.3109/13668250.2017.1287885

Kamstra, A, van der Putten, A.A.J., & Vlaskamp, C. (2017). Efforts to increase social contact in persons with profound intellectual and multiple disabilities: Analysing individual support plans in the Netherlands. *Journal of Intellectual Disabilities*, 21, 158-174

Luijkx, J., Putten, A. A. J., & Vlaskamp, C. (2017). Time use of parents raising children with severe or profound intellectual and multiple disabilities. *Child: Care, Health and Development*. doi:10.1111/cch.12446.

Van keer I., Colla, S., Van Leeuwn, K., Vlaskamp, C., Ceulemans, E., Hoppenbrouwers, K., Desoete, A., & Maes, B. (2017). Exploring parental

outcomes for children and adults with PIMD. I am very excited about moving forward in this journey and wish the SIRG a productive Roundtable in Switzerland later in 2017.

Our sincere thanks to the followings:  
Dr. Suemitsu and Mr. Habara (Asahigawa-so Medical Welfare Center, Okayama)  
Dr. Kaga, Dr. Iwasaki and Ms. Kihara (Tokyo Metropolitan Tobu Medical (Ryoiku) Center, Tokyo)  
Dr. Wakui, Dr. Ikoma and Mr. Munekata (the National Institute of Special Needs Education, Kanagawa)

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## Interesting Twitter account

[@ResearchEMB](https://twitter.com/ResearchEMB)

The PIMD research group of the University of Groningen is active on twitter. This might be interesting to follow for some of you. For example, we share ongoing research projects, visits to conferences and recent research results. Although most of the messages are in Dutch, Google Translate can be your best friend.



**Distribution Next Newsletters**

behavior and child interactive engagement: A study on children with a significant cognitive and motor developmental delay. *Research in Developmental Disabilities*, 64, 131-142.

Van der Putten, A.A.J., Bossink, L.W.M., Frans, N., Houwen, S., & Vlaskamp, C. (2017). Motor activation in people with profound intellectual and multiple disabilities in daily practice. *Journal of Intellectual & Developmental Disability*, 42, 1-11.

doi:10.3109/13668250.2016.1181259

Van Timmeren, E.A., van der Schans, C.P., van der Putten, A.A.J., Krijnen, W.P., Steenbergen, H.A., van Schrojenstein Lantman-de Valk, H.M.J., & Waninge, A. (2017). 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*, 61, 30-49.

Zaal-Schuller, I.H., Willems, D.L., Ewals, F.V. van Goudoever, J.B., & de Vos, M.A. (2016) How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Research in Developmental Disabilities*, 59, 283-293.

From now on, all members of the SIRG PIMD will receive the newsletter as a PDF document by email. This to ensure that all paying member receive the newsletter at any case. We will also continue with sending the newsletter to the mailing list of MailChimp to other interested parties. Everyone interested in research with PIMD is able to subscribe to this list.

If you are paying member of the SIRG and don't like to receive the newsletter twice, please click at "**unsubscribe from the list**" at the bottom of this email.

All past issues of our newsletter are also available on the website of [IASSIDD \(SIRG-PIMD; Documents and Publications\)](#).

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#### 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 **December of 2017**. 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 2017).

[Send email](#)

