



International Association  
for the Scientific Study  
of Intellectual Disabilities

## Special Interest Research Group Profound Intellectual and Multiple Disabilities

*Newsletter - December 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 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 Fabilla, Mexico, *Member*

### Membership

Please do consider to start or renew your IASSIDD Membership for 2018. 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. Information about our mission, our activities and the members of the SIRG can be found on [the IASSIDD website](#). Members are key to the continued



**Annette van der Putten**, board member of our SIRG-PIMD, has been appointed associate professor with *ius promovendi* of the special needs education focusing in particular on people with profound multiple disabilities at the Faculty of Behavioural and Social Sciences of the University of Groningen, the Netherlands. Annette will hold her inaugural lecture on April 10, 2018.

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## New research project

### Assessment in people with PIMD

July 2017, Marleen Wessels started her PhD- project about assessment in people with PIMD at the university of Groningen under supervision of prof. dr. Annette van der Putten. Assessment is essential for gathering information about needs, wishes, abilities and preferences of people with PIMD and adapting support to them. However, there are few instruments or assessment methods specifically developed for people with PIMD and many instruments or assessment methods that are available were not studied for

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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## Upcoming events

### 5th IASSIDD Europe Congress



#### 5th IASSIDD Europe Congress

*Athens, Greece, 18-20 July 2018*

In July 2018 the 5<sup>th</sup> IASSIDD Europe Congress "Diversity & Belonging: Celebrating Difference" will be organized in Athens. Call for papers is open till January 15<sup>th</sup>. [More information](#).

#### IASSIDD World Congress

*Glasgow, United Kingdom, August, 2019*

The next World Congress will take place in Glasgow, Scotland in August, 2019. More information will be available in 2018.

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## Miscellaneous

psychometric qualities. The current project will start with an inventory of assessment instruments and assessment methods that are used in practice in people with PIMD, to what goals these instruments and methods are used and what barriers professionals experience in assessment of people with PIMD. Moreover, the project will focus on determining the psychometric qualities of several assessment instruments that are used in support of people with PIMD. For more information send an e-mail to [m.d.wessels@rug.nl](mailto:m.d.wessels@rug.nl).



### Overview of protocols to assess the cognitive functioning

During the Roundtable meeting in Fribourg the question was raised to compose an overview of the various available assessment protocols to determine the level of cognitive functioning of persons with PIMD. In order to make a useful overview, we would like to ask you to fill in this questionnaire where you can provide us with information about one or various assessment protocol(s). [Link to questionnaire](#). Together with the next newspaper in June 2018 the overview will be send to you. If you have further questions please contact [Sara Nijs](#).

### LinkedIn Group: ECRM SIRG PIMD Network

We want to point your attention to the LinkedIn group: [ECR SIRG PIMD Network](#). This group is open to any student or researcher (junior, senior) involved in or interested in research in the field of profound intellectual and multiple disabilities (PIMD). This Linked-In group has originated from the Early Career Researchers Meetings that have been organized alongside international IASSID congresses and roundtables of SIRG-PIMD. With this group we aim to create a platform with a low communication threshold in order to facilitate interaction and exchange of information among all researchers with interest in PIMD. This group is not meant to be an isolated group beside the current activities of the SIRG-PIMD activities. For more information

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## Past events

### Roundtable Meeting of the SIRG-PIMD 2017

*Fribourg, Switzerland, 29&30 August 2018*

During these two days various interesting oral presentations and discussions were held around four themes: (1) People with PIMD and their families' development during the course of the lifespan, (2) Context, supports and assistive technology, (3) Functioning and development, and (4) Current state of research in the field of PIMD and perspectives. Besides, various posters were presented and discussed in smaller groups. Some of the presentations can be

found on the [IASSIDD website](#). Thanks to Genevieve and Juliane for organising this interesting Roundtable and for showing us around in a beautiful part of Switzerland.



Group photo Roundtable 2017

### Early Career Researchers Meeting

*Fribourg, Switzerland, 28&31 August 2018*

Before the start of the Roundtable meeting of the SIRG PIMD the early career researchers and some senior researchers gathered for the ECRM. After a short introduction, some early career researchers had the chance to present their PhD research to the group. Guided by the senior researchers, various topics were furthermore discussed in smaller groups:

- (1) (Video)coding, behavioural approach,
- (2) Integration of the families in the health path/impact of research on families, and
- (3) Impact of neurological impairments, input of the neurosciences in the understanding of PIMD functioning.

During the second day we discussed issues like sample size/control group/ missing data/comparative research and approaching the end of a PhD: thesis defence + what to do after a PhD in PIMD? We were pleased to see many familiar faces and to welcome the new early career

about the SIRG-PIMD and ECRM, including newsletters, and archive we refer to the following websites:

[www.iassidd.org/content/profound-multiple-disabilities](http://www.iassidd.org/content/profound-multiple-disabilities) and [ecrmpimd.weebly.com](http://ecrmpimd.weebly.com).



### Distribution Next Newsletters -

#### REMINDER

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](#)).

**Next Newsletter**

researchers! A more detailed report can be found on [the website of the Early Career Researchers](#).



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 2018**. 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 December 2017). [Send email](#)

## Published Books and Articles

Antaki, C., Crompton, R.J., Walton, C., & Finlay, W.M.L. (2017). How adults with a profound intellectual disability engage others in interaction. *Sociology of Health & Illness*, 39, 581-598. DOI: [10.1080/20473869.2016.1158511](https://doi.org/10.1080/20473869.2016.1158511)

Benford, F., (2017). Us of powered mobility for a young adult with profound and multiple learning disabilities: a pactice analysis. *Britisch Journal of Occupational Therapy*, 80, 517-520. DOI: 10.1177/0308022617698169

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

Candeias, A.A., Grácio, M.L., Satagoca, M.J., Pires, H. (2017). Training needs of Portuguse practitioners working with children and young people with complex and intense support needs. *Journal of Intellectual Disabilities*, DOI: 10.1177/1744629517735230

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

Cluley, V., (2017). Using photovoice to include people with profound and multiple learning disabilities in inclusive research. *Britisch Journal of Learning Disabilities*, DOI: 10.1111/bld.12174.

Gauthier-Boudreault, C., Gallagher, F., & Couture, M. (2017). Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing? *Research in Developmental Disabilities*, 66, 16-26. DOI: [10.1016/j.ridd.2017.05.001](https://doi.org/10.1016/j.ridd.2017.05.001)

Graffiths, Cl., Smith, M. (2017). You and me: The structural basis for the interaction of people with severe and profound intellectual disability and others. *Journal of Intellectual Disabilities*, 21, 103-117.

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*. DOI:[10.1177/1747016117711971](https://doi.org/10.1177/1747016117711971)

Hanzen, G., van Nisperen, R.M.A., van der Putten, A.A.J., & Waninge, A. (2017). Participation of adults with visual and severe or profound intellectual disabilities: Definition and operationalization. *Research in Developmental Disabilities*, 61, 95-107.

Hully, M., Brisse, C., Bredillot, M., Bruilt, R., Lhermitte, Y., Coiffier, C. et al. (2017) Patients with Profound Intellectual and Multiple Disabilities (PMID) and access to the pediatric neurologist: An opportunity for Telemedicine? *European Journal of Paediatric Neurology*. DOI: [10.1016/j.ejpn.2017.04.1097](https://doi.org/10.1016/j.ejpn.2017.04.1097)

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

Lancioni, G.E., Singh, N.N., O'Reilly, M.F., Sigafoos, J., Alberti, G., Perilli, V., & Campodonico, F. (2017). Promoting functional activity engagement in people with multiple disabilities through the use of microswitch-aided programs. *Front Public Health*. DOI: 10.3389/fpubh.2017.00205

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Luijckx, 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.

Luijckx, J., Van der Putten, A.A.J., & Vlaskamp, C. (2017). A valuable burden? The impact of children with profound intellectual and multiple disabilities on family life. *Journal of Intellectual & Developmental Disability*. DOI: [10.3109/13668250.2017.1326588](https://doi.org/10.3109/13668250.2017.1326588)

Lyons, G., De Bortoli, T., & Arthur-Kelly, M. (2017) Triangulated Proxy Reporting: a technique for improving how communication partners come to know people with severe cognitive impairment. *Disability and Rehabilitation*, 39, 1814-1820. DOI: 10.1080/09638288.2016.1211759

- Mietola, R., Miettinen, S., & Vehmas, S. (2017) Voiceless subjects? Research ethics and persons with profound intellectual disabilities. *International Journal of Social Research Methodology*, 20, 263-274. DOI: 10.1080/13645579.2017.1287872
- Morimoto, M., Satomura, S., Hashimoto, T., & Kyotani, S. (2017). A study of oxidative stress and the newer antiepileptic drugs in epilepsy associated with severe motor and intellectual disabilities. *Journal of the Chinese Medical Association*, 80, 19-28. DOI:[10.1016/j.jcma.2016.10.005](https://doi.org/10.1016/j.jcma.2016.10.005)
- Nieuwenhuijse, A.M., Willems, D.L., Van Goudover, J.B., Echteld, M.A., & Olsman, E. (2017). Quality of life of persons with profound intellectual and multiple disabilities: A narrative literature review of concepts, assessment methods and assessors. *Journal of Intellectual & Developmental Disability*. DOI: [10.3109/13668250.2017.1388913](https://doi.org/10.3109/13668250.2017.1388913)
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- Seliner, B., Latal, B., & Spirig, R. (2017). Effectiveness of a nurse-led preadmission intervention for parents of children with profound multiple disabilities undergoing hip-joint surgery: A quasi-experimental pilot study. *Journal for Specialists in Pediatric Nursing*. DOI: 10.1111/jspn.12184
- Talman, L., Gustafsson, C., Stier, J., & Wilder, J. (2017) Staffs' documentation of participation for adults with profound intellectual disability or profound intellectual and multiple disabilities. *Disability & Rehabilitation*, 21, 1-11. DOI: 10.1080/09638288.2017.1340979
- Van keer I., Colla, S., Van Leeuwn, K., Vlaskamp, C., Ceulemans, E., Hoppenbrouwers, K., Desoete, A., & Maes, B. (2017). Exploring parental 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 den Bosch, K.A., Andringa, T.C., Peterson, W., Ruijsenaars, W.A.J.J.M., & Vlaskamp, C. (2017) A comparison of natural and non-natural soundscapes on people with severe or profound intellectual and multiple disabilities, *Journal of Intellectual & Developmental Disability*, 42, 301-307. DOI: 10.3109/13668250.2016.1250251
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