



International Association
for the Scientific Study
of Intellectual Disabilities

Special Interest Research Group Profound Intellectual and Multiple Disabilities

Newsletter - June 2018

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 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 Fabllila, Mexico, *Member*

New research project

Palliative Care for persons with intellectual and multiple disabilities, PiCarDi

*Catholic University of Applied Sciences
NRW Dep. of Social Sciences | Munster,
Germany*

Background: Persons with PMID are up to now underrepresented in palliative care services in Germany. The research project explores the situation both in palliative and disability services with a special view on the service users and their relatives. The multi-perspective design includes data collection, semi-structured interviews with experts, service users and relatives, focus group discussions with service users and concepts of person-centred planning. Participatory research is guaranteed by a supervisory board of service users. The results of a initial secondary analysis of existing data show, that the number of persons with ID dying in residential homes is increasing. The death rate in the analyzed group in this setting is 18.8 (per

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 success and development of our activities. If people are interested, please ask them to send an email to [Bea Maes](#) (SIRG Chair).

Upcoming events

5th IASSIDD Europe Congress

*July 18, 2018 - July 20, 2018 | Athens,
Greece*

In July 2018 the 5th IASSIDD Europe Congress "Diversity & Belonging: Celebrating Difference" will be organized in Athens. Call for papers is open till January 15th. [More information](#). Before the IASSIDD Europe Congress the **ECRM PIMD of 2018** will be organised on Tuesday 17th of July 2018 in Athens (Greece). You can enroll for the meeting by completing [this form](#) (before the 31st of May). Please also send the link to all people who might be interested.

Raising The Bar II

*November 2, 2018 | Birmingham, United
Kingdom*

analyzed group in this setting is 20,9 (per thousand), while the death rate in the general adult population in Germany is 13,4. But still, professional capacity in many cases does not yet meet special needs of persons with PMID in end-of-life care sufficiently. Group discussions with persons with ID on the other hand show quite clear concepts of dying and wishes according to adequate support in this vulnerable situation. All in all, crossing network lines between the support systems seems to be crucial for adequate capacity building. Pedagogical expertise is needed to ensure participation esp. for persons with profound and multiple disabilities, which is a core subject corresponding to the human rights in the end of life. For more information or questions you can contact: [Prof. Dr. Sabine Schäper](#)

Call for participants

Questionnaire about assessment for professionals who work in support of people with PMID

We would like to invite you to complete a questionnaire about assessment in people with Profound Intellectual and Multiple Disabilities (PIMD). Assessment is defined in this study as: The systematic collection, ordering and interpretation of information about a person and his or her situation, to obtain an adequate representation of the person (De Bruyn, Ruijsenaars, Pameijer, & van Aarle, 2009). This questionnaire is part of a PhD project, performed at the University of Groningen (under supervision of Prof. dr. Annette van der Putten and dr. Muirne Paap) about assessment in people with PIMD. In this study we would like to obtain an overview of what instruments or other types of assessments are used in practice, what aspects are measured, the reasons for conducting these assessments and the barriers which are encountered in assessing people with PIMD. For this study, we are looking for professionals (for example therapists, physicians, support professionals, developmental psychologists or teachers) who work in support of people with PIMD.

We would like to ask you to fill in the questionnaire by clicking [here](#). If you have any questions or comments about the questionnaire, please contact Marleen Wessels (m.d.wessels@rug.nl). Thank you for your help!

Past events

First National Virtual Disability

Last year's Raising the Bar saw parents and practitioners from around the UK meeting together to launch the new Core and Essential Service Standards for Supporting People with Profound and Multiple Learning Disabilities (PMLD) a document created with the intention of raising the bar with regards to what best practice care looks like for people with PMLD. The atmosphere in the room was like no other conference any of those in attendance had been to that year. The drive to create a better life for the people we care about was palpable and in the year since the launch everyone has been working hard to see those changes happen. Raising the Bar II will be a

chance to hear about the progress of the Standards and to learn from inspirational speakers from a range of backgrounds. Delegates will also be able to select from a rich array of workshops on offer throughout the day to further develop their skills and abilities in supporting people with PMLD. The conference will be of interest to those working in the fields of education, health and social care, as well as to families, charities and CICs who support people with PMLD. The Core Service Standards are aimed at Commissioners and Providers of services to ensure equity of support and service provision. They are a valuable tool for those looking to advocate for better care. The conference will also interest service providers, health/social care/education professionals and family carers. We look forward to welcoming you to Raising the Bar II. [More information](#).

Polyhandicap et processus d'apprentissage" (PIMD and learning process)

March 2019 | Paris, France

Nowadays, there is a consensus on the need to integrate the learning dimension into the individualized projects of children or teenagers identified with "polyhandicap" (in French) or "profound intellectual and multiple disabilities" (PIMD). Access to learning for people with PIMD is only now starting to be discussed. This puts emphasis on cognition, pedagogy and learning places, including school. What do we mean by learning for young people with PIMD? What are the characteristics of a student with PIMD? What socio-emotional and sociocognitive processes are mobilized? How could we support their learning?" The conference will take place in Nanterre University (close to Paris) in March 2019. It will bring together researchers, but also professional and families in order to meet three objectives: developing scientific knowledge, supporting innovative methodology and approaches, and promoting the dissemination of

Conference

March 21, 2018 | Australia

The first National Virtual Disability Conference was held in Australia on the 21st March, 2018. The conference comprised four streams: health and well being, community living, lifelong education, and meaningful occupation. It was pleasing to see some papers specifically addressing the needs of people with profound intellectual and multiple disabilities. These included:

- A pain awareness intervention for adults with severe or profound intellectual disability
- Positive behaviour support: how do we know we are making a difference
- Using intensive interaction to support communication, learning, and emotional well being with people with complex intellectual disabilities.

It is still possible to access the conference presentations:
<http://virtualdisability.conferenceworks.com.au/> or email nvd-conference@unimelb.edu.au

Congress about disability and pediatrics

April 23-27, 2018 | Buenos Aires, Argentine

The Argentine Society of Pediatrics (Sociedad Argentina de Pediatría) has organized a Congress about Disability and Pediatrics April 23 to 27 in Buenos Aires. It was expected to be attended by a diverse audience including families. People come from all over the country and from neighboring countries such as Bolivia, Chile, Uruguay and Paraguay. The program includes some activities devoted to PIMD: lectures, testimonies and videos. More information: congresos@sap.org.ar or www.sap.org.ar



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 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

knowledge and practices on society. Call for papers will be open in September on the website of INSHEA (<http://www.inshea.fr/>), and communications may be in French or English.

IASSIDD World Congress

August, 2019 | Glasgow

The next World Congress will take place in Glasgow, Scotland in August, 2019. More information will be provided in the next newsletter.

Miscellaneous

Policy and practice of healthcare delivery to persons with profound intellectual and multiple disabilities by unregistered assistive personnel in foreign countries

Sui Sone (Tokyo Metropolitan Higashiyamato Medical Center for Developmental/Multiple Disabilities) & Tadashi Matsubasa (Kumamoto-Ashikita Medical Center for The Severely Disabled).

We compared practices of the delivery of four kinds of healthcare to persons with profound intellectual and multiple

disabilities by unregistered assistive personnel (UAP) among nine countries including Japan. We then compared the policies for healthcare delivery via support workers in four countries including Japan. Airway suctioning, tube feeding, inhalation and nebulization and tracheal suctioning were delivered by UAP, although the kinds of healthcare delivered by each paid UAP category differed among the countries. Parents delivered the aforementioned healthcare in nine countries, except for tracheal suctioning, which was forbidden in three countries. Four countries required UAP to obtain additional licenses for delivering healthcare. Finding UAP for healthcare delivery was difficult in three countries. Regarding policies for delivering healthcare via support workers, training and supervision of UAP by registered nurses (RN) was required in all countries studied except for Japan, and more kinds of healthcare were delivered by UAP in these countries than in Japan. Comparing practices among those countries was difficult because of the differing healthcare systems in each country. However, this comparison revealed the importance of revising and improving Japan's UAP healthcare delivery policy by adding training and supervision by visiting RN, as well as developing a policy for decreasing the burden of these RN.

persons with PIMD (after May 2018). [Send email](#)

Published Books and Articles

Arthur-Kelly, M., Foreman, P., Maes, B., Colyvas, K., & Lyons, G. (2018). Observational data on socio-communicative phenomena in classrooms supporting students with profound intellectual and multiple disabilities: Advancing theory development on learning and engagement through data analysis. *Advances in Neurodevelopmental Disorders*, 2, 25-37.

Camberlein, P.(dir.) & Ponsot, G.(dir.). (2017). *La personne polyhandicapée* Paris, France: Dunod

Crawford, H., & Wilkinson, H. (2018). The novel use of life grids in a Phenomenological study of family carers of people with profound intellectual and multiple disabilities and dysphagia. *Quality Health Research*, doi: 10.1177/1049732318761028.

Degache, F., Bonjour, A., Michaud, D., Mondada, L., & Newman, C.J. (2018). The effects of tandem skiing on posture and heart rate in children with profound intellectual and multiple disabilities. *Developmental Neurorehabilitation*, doi: 10.1080/17518423.2018.1462268

Gauthier-Boudreault, C., Couture, M., & Gallagher, F. (2018). How to facilitate transition to adulthood? Innovative solutions form parents of young adults with profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31, 215-223. doi: 10.1111/jar.12394

Haines D., Wright J., Comerasamy H. (in press) Occupational therapy empowering support workers to change how they support people with profound intellectual disabilities to engage in activity. *Journal of Policy and Practice in Intellectual Disabilities*.

Hall, S.A., & Rossetti, Z. (2018). The roles of adults siblings in the lives of people with severe intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31, 423-434. doi: 10.1111/jar.12421

Ikeda, A., Tsuji, M., Goto, T., & Lai, M. (2018). Long-term home non-invasive positive pressure ventilation in children: Results form a single center in Japan. *Brain and Development*, doi: 10.1016/j.braindev.2018.03.006

Lancioni, G.E., Singh, N.N. O'Reilly, M.F., Sigafoos, J., Alberti, G., Campodonica, F., Perilli, V., Chiariello, V., & Zimbaro, C. (2017). A technology-aided program to support basic occupational engagement and mobility in persons with multiple disabilities. *Front Public Health*, doi: 10.3389/fpubh.2017.00338

Lancioni, G.E., Singh, N.N., O'Reilly, M.F., Sigafoos, J., Campodonico, F., Oliva, D., Alberti, G., & D'amico, F. (2018). Using microswitch-aided programs for people with multiple disabilities to promote stimulation control and mild physical exercise. *Journal of Intellectual & Developmental Disability*, 43, 242-250, doi: 10.3109/13668250.2016.1253831.

Nijs, S., Vlaskamp, C. & Maes, B. (2018). Promoting Social Scaffolding Behaviors in Staff Members and Peer-Directed Behaviors Among Persons With Profound Intellectual and Multiple Disabilities: An Intervention Study. *Journal of Policy and Practice in Intellectual Disabilities* doi: 10.1111/jppi.12251

Roemer, M., Verheul, E., & Velthausz, F. (2017). Identifying perception behaviours in people with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, doi: 10.1111/jar.12436

Robertson, J., Bained, S., Emerson, E., & Hatton, C. (2018). Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 31, 11-28, doi: 10.1111/jar.12325

Wosinski, B., & Newman, C.J. (2018). Physicians' attitudes when faced with life-threatening events in children with severe neurological disabilities. *Developmental Neurorehabilitation*, doi: 10.1080/17518423.2018.1461946

Zaal-Schuller, I.H., Willems, D.I., Ewals, F., van Goudoever J.B., & de Vos, M.A., (2018). Involvement of nurses in end-of-life discussions for severely disabled children. *Journal of Intellectual Disability Research*, 62, 330-338. doi: 10.1111/jir.12473

Zaal-Schuller, I.H., Willems, D.I., Ewals, F., van Goudoever, J.B., & de Vos, M.A. (2018). Considering quality of life in end-of-life decisions for severely disabled children. *Research in Developmental Disabilities*, 73, 67-75, doi: 10.1016/j.ridd.2017.12.015

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