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 Fabila, 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 timespan in this setting is 18.8 per 1000. It is urgent to develop appropriate service and care offers for this target group.

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
Call for participants

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

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, Ruijssenaars, 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
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

**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.

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**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 Higashiymato 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.
Published Books and Articles


