



**International Association
for the Scientific Study
of Intellectual Disabilities**

Special Interest Research Group Profound Intellectual and Multiple Disabilities

Newsletter - December 2015

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 and IASSID council representative*
- Juliet Goldbart, UK, *Treasurer / secretary*
- 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*
- Loretto Lambe, Scotland, UK, *Past Chair*

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 colleagues and contacts and encourage them to join our SIRG. They will find information about our mission, our

- Carla Vlaskamp, The Netherlands, *Past Chair*

Recent Conference Reports

5th Early Career Researchers Meeting SIRG-PIMD

Västerås, Sweden, September 22-23, 2015

The first day of the 5th Early Career Researchers meeting started with presentations of Gineke Hanzen (*Visio, Netherlands*) and Dinette van Timmeren (*Hanze University, Netherlands*). Next, brainstorming sessions on interesting topics in PIMD-research were conducted. Ines van Keer (*KU Leuven*) introduced her topic about small research samples in PIMD-research and Gertruud Schalen (*University of Groningen*) talked about the recruitment of participants with PIMD in a longitudinal study. We discussed the issues in subgroups and brought our ideas together. We finished the first day with a relaxed social dinner. The second day, Katherine McKenzie (*Queen's University, Canada*) presented her master thesis in Epidemiology on frailty as a predictor of institutionalization among people with ID, and asked for suggestions for further research especially in people with PIMD. Laura Jones introduced her recently started research on the influences of the language of instruction (Welsh and/or English) on access to the curriculum and inclusion. Finally, Juliane Dind told more

activities and the members of the SIRG on www.sirgpmd.be. 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](#).

Research to Practice

Several researchers of the SIRG-PIMD successfully defended their doctoral thesis. Congratulations to them all!

Mélissa Chard

Université de Savoie, Chambéry, France, December 2014. *Supervisors: prof. dr. Jean-Luc Roulin and prof. dr. Martine Bouvard*

In her thesis was stated that today, very little is known about the way each person with PIMD learn from his/her environment and develop cognitive skills. This lack of scientific knowledge is even more so remarkable when we come to adults, and pertains to a wide range of difficulties that are related to their movement limitations and absence of symbolic communication. Moreover, each person with PIMD has an idiosyncratic behavioral repertoire, which arise several issues concerning the reliability of the interpretation of one's reaction. The aim of this research project was to develop a new method for the study of the cognitive skills of persons with PIMD of any age that can take in account the complexity of their disabilities, and that is

about analysing video data and its difficulties. By using examples, we discussed about the interrater reliability in analysing video data of children with PIMD. We have had very interesting presentations and useful discussions about doing research in people with PIMD. A detailed summary and the abstracts of this meeting can be found on [the website of the ECRM-PIMD](#).

Thank you all, and we are looking forward seeing you at the next meeting!



7th Round Table Meeting SIRG-PIMD

Västerås, Sweden, September 23-25, 2015

From the 23rd till the 25th of September Mälardalen University and Swedish Family Care Competence Center hosted the 7th International Roundtable Meeting of the IASSID-Special Interest Research Group on Persons with Profound Intellectual and Multiple Disabilities (SIRG-PIMD). Various inspiring oral presentations and discussions were held around four themes: (1) social participation, (2) education, (3) development and (4) research and future. Also a general poster presentation session was organised and several early career researchers introduced themselves during short video fragments which were made during the early career researchers meeting. Thanks to **Jenny Wilder** for organising this interesting and nice meeting.

based on objective behavioral indicators. Thus, we draw our inspiration from the field of infancy research, and more specifically from habituation studies and visual habituation paradigm. The first stage of this thesis was therefore to test the feasibility and to evaluate the relevance of this approach for persons with PIMD. The second stage of our research aimed at applying the visual habituation paradigm to the study of a specific domain of competence: quantity perception. Our results suggest that person with PIMD can operate visual discrimination between two quantities of the same object when no confounding variable is controlled for, and highlight the role of objects' position in the way they build internal representations of external objects. These findings raise many issues concerning how persons with severe motor restrictions can build knowledge about their environment, without resorting to any object manipulation.

Suzanne Jansen

University of Groningen, April 2015. supervisors: prof. dr. Carla Vlaskamp and prof. dr. Annette van der Putten.

Collaboration between parents and professionals is essential in order to deliver good quality, family-centred support. Little was known about collaboration with the parents of children with intellectual disabilities, let alone children with profound intellectual and multiple disabilities (PIMD) living in residential facilities. The overall aim of this research project was to acquire knowledge about the specific content of

New projects

Appropriate symbol communication aids

Janice Murray and Juliet Goldbart (Manchester Metropolitan University), Simon Judge (Barnsley Assistive Technology Service), David Meads and Stephane Hess (Leeds University) with co-Researchers; Stuart Meredith and Liz Moulam, have been awarded £800,000 for a three-year project funded by the NIHR's Health Services and Delivery Research fund, on "Identifying appropriate symbol communication aids for children who are non-speaking: enhancing clinical decision making."

Together to School

Recently the University of Groningen has started a new research project concerning the effects of 'Together to School'. Together to School is a new project of NSGK (a Dutch foundation that promotes the wellbeing of children with disabilities). In this project children with PIMD are being placed in regular primary schools. The children stay in separate classes, but whenever it is possible, they contact with their peers without disabilities by joining the regular classes, or receiving peers in their special classroom. The aim of the new research project is to assess the effects of the 'Together to School' project on children with PIMD and children without disabilities, their parents and teachers. Moreover, we would like to determine which factors

collaboration between parents and professionals in the support of children and adults with PIMD to optimize this collaboration. Results of this study have both academic as practical implications. Recommendations for further research are made. In practice, in the support of children and adults with PIMD, two tools that resulted from this study can be used for an inventory of the actual collaboration with parents. Also, points of interest are addressed for professionals when collaborating with parents. Finally, advice for establishing collaboration with parents and eventual improvement of collaboration is given.



Sara Nijs

KU Leuven, Belgium, July 2015. *supervisor: prof. dr. Bea Maes; co-supervisor: prof. dr. Carla Vlaskamp*

She studied peer interactions of persons with PIMD. The project resulted in five manuscripts in which is focussed on how persons with PIMD interact with their peers and which factors influence the peer interactions. The results show that persons with PIMD are able to present peer directed behaviours. Their positioning, the

contribute to the success of Together to School and what motives parents of children with PIMD have to choose for such projects.

The research project is funded by NSGK and conducted by Sanne Everaarts, Anke de Boer and Annette van der Putten. For more information: [send email](#).



Implementation of structural motor activation in the support of people with PIMD

In September 2015 the University of Groningen has started with a new research project on motor activation of people with PIMD. Because people with PIMD are inactive and unable to perform physical activity independently, it is of great importance that motor activation becomes a structural part in the support of these people. However, evidence based interventions are lacking and the limited knowledge in this field is embedded in ongoing practice. Therefore, the aim of this project is to develop and implement an effective method so that motor activation can be applied more specific and structured in the support of people with PIMD. As a first step, the project members will analyze the way direct support professionals actually motor activate people with PIMD. In addition, the quality and potential of different modes of motor

direct support worker and the peer (a sibling vs a peer with PIMD) have an influence on the nature and frequency of their peer directed behaviours. A training for direct support workers was developed. An intervention study showed that this training has a positive effect on the amount of peer directed behaviours of persons with PIMD presented toward peers with PIMD.

Kirsten van den Bosch

University of Groningen, October 2015. *supervisors:* prof. dr. Carla Vlaskamp, prof. dr. Wied Ruijsenaars, prof. dr. Baskent, Deniz; *co-supervisor:* dr. Andringa, Tjeerd

Safe and Sound: Soundscape research in special needs care at the University of Groningen. The quality of the auditory environment surrounding us has a strong influence on our moods, behavior, and well-being. This unique interdisciplinary research, in which the departments Special Needs Education and Artificial Intelligence have worked together, focuses on improving the auditory environment in long-term healthcare, specifically for people with profound intellectual (and multiple) disabilities (PIMD). The high prevalence of visual impairments amongst these people and their diminished cognitive abilities, make them particularly dependent on sound in understanding the world around them. With three studies, in which use was made of soundscape tools such as a smartphone application and 3D sound, it was demonstrated that the quality of the auditory environment is indeed related to

activation will be assessed based on a fixed format. Subsequently, this knowledge will be used to develop a new method to implement specific and structured motor activation in the support of people with PIMD. This method will be implemented in practice and its feasibility and effectivity will be evaluated. The research project is funded by the 'Programmaraad Visuele sector' and conducted by Leentje van Alphen, Aly Waninge and Annette van der Putten. For more information: [send email.](#)

Upcoming event

7th World Congress IASSIDD

Melbourne, Australia, 15-19 August 2016

Members of the IASSIDD and other interested parties gather every four years for a World Congress. The 2016 meetings will mark the 15th time IASSIDD has held a World Congress. Each World Congress is comprised of daily plenary sessions at which prominent researchers from around the world speak for 30-45 minutes. The balance of the conference is a combination of paper and poster sessions, workshops, meetings of our Special Interest Research Groups, and social events. There will be a Gala Dinner somewhere in the middle of the World Congress schedule. [More information.](#)

the moods and (problem) behavior in this target group. Audible safety seems to play an important role in the quality of auditory environments: an environment should reassure and not annoy. The main recommendation we make is to increase awareness throughout the entire organization on the role of sound in the living environment of people with profound intellectual (and multiple) disabilities. Optimizing the auditory environment is important to provide the best possible care. Until this is achieved, the auditory environment will have a significant negative impact on the physical and psychological wellbeing of the residents.



Ineke Haakma

University of Groningen, December 2015.

supervisors: prof. dr. Marleen Janssen and prof. dr. Alexander Minnaert

Motivation to learn: Engaging students with congenital and acquired deafblindness. People are intrinsically motivated to learn. This also holds for children with deafblindness, even though deafblindness can negatively influence their motivation to learn. Double sensory loss can hinder the ability to explore, observe, imitate and communicate.



Announcements

Upcoming film

At the end of 2015 we will finish a (study) film, which introduces PIMD student teaching in Estonia and learning tools creation process (a research topic in my doctoral thesis). The film is in Estonian with English subtitles. **Jana Kadastik**

CAS en polyhandicap et déficience intellectuelle sévère

At the University of Fribourg a new CAS: "CAS en polyhandicap et déficience intellectuelle sévère" will be organised, from May 2016 until June 2017. More information on [the website](#).

Disability-specific English editing services

SIRG-PIMD member **Taylor Boren** is an American disability researcher, specializing in disability law with an emphasis on litigious remedies for personal injury and children with PIMD. He is now offering English editing services to fellow disability researchers seeking publication in English-

Teachers have an important role in creating an accessible and safe environment in which learning can take place. An important part of this involves teachers taking into account their students' needs. According to Self-Determination Theory, the psychological needs for competence, autonomy and relatedness influence whether people are motivated to learn. Teachers can support these needs by providing structure, autonomy support and involvement. This research explored the extent to which teachers support the needs of students with congenital and acquired deafblindness and what its effect is on student motivation. Video analysis was the most important method applied in this study. The results showed that students' motivation is generally high when teachers provide need support, suggesting that need-supporting teacher behavior does indeed influence student motivation. In general, teachers provide more structure than autonomy support and involvement. Furthermore, it appeared possible to coach teachers in need-supportive behaviors. We concluded this research with the recommendation to pay more attention to need-supportive teaching in the professionalization of teachers. The provision of autonomy support deserves particular attention, given that the teachers in this study focused least on autonomy.

Heleen Neerinckx

KU Leuven, Belgium, supervisor: prof. dr. Bea Maes
She studied joint attention in interactions

based journals. Disability articles must address their topics with care and specificity, since disability-related terminology is precise and its subject-matter both complex and sensitive. In a field where seemingly similar phrases like "societal integration" and "social inclusion" carry different meanings and subtext, an English editor possessing deep familiarity with disability terminology is critical to ensure that cutting-edge ideas are conveyed sensitively and accurately. Non-native English disability researchers seeking publication in English journals should consider Boren International Editing (www.boreninternational.com) to ensure their English language manuscripts are revised with nuance, complexity, and sensitivity when addressing disability research. Taylor Boren previously completed a Fulbright Scholarship in Sweden, researching the impacts of Scandinavian welfare policies on the social integration of children with PIMD. He lectured on the subject at the 2014 IASSIDD Conference in Vienna, and his findings will be featured in a forthcoming publication of the Journal of Policy and Practice in Intellectual Disabilities. He may be reached through the aforementioned website or directly via tboren@berkeley.edu.

Next Newsletter

We try to compose an interesting newsletter two times a year. To compose these newsletters we need your input. The following newsletter will be send to you in

with people with PIMD. The project resulted in five manuscripts in which is focussed on how persons with PIMD show joint attention behaviours in interactions, and which personal and context factors are related with these behaviours. The results show that persons with PIMD are able to present joint attention behaviours. Their developmental age, sensory disabilities (visual and auditory), motor impairments and perseverance influenced the amount and the nature of their joint attention behaviours. A structured interaction was the most motivating situation for people with PIMD to show initiatives towards their partner, while a spontaneous interaction was the most motivating situation for responding to an initiative. The familiarity of the objects used in the interaction, and the familiarity of the interaction partner did not influence person's with PIMD performances in joint attention behaviours. The responsivity of the interaction partner, however, influenced the frequency of their joint attention behaviours. Direct support workers already used successful strategies to direct the attention of the persons with PIMD, however, being directed by a person with PIMD, was still challenging for them. Direct support workers were very directive in the interactions, which became clear by the fact that they frequently used several initiatives within one single interval. No causal relationship was found between the specific initiatives of the interaction partners and the attention episodes in the interaction. An intervention to promote joint attention behaviours of people with

June of 2016. 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 November 2015).

[Send email.](#)

PIMD was developed and evaluated. An increase in the joint attention behaviours was observed when the interaction partner used adaptive communication strategies, was responsive and followed the lead of the person with PIMD, and gave him/her time to respond to or initiate a focus of attention.

Published Books and Articles

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Luijkx, J., Ten Brug, A., & Vlaskamp, C. (2015). Does the severity of disability matter? The opinion of parents about professional support in residential facilities. *Child: care, health and development*. DOI: 10.1111/cch.12297

Nijs, S., Vlaskamp, C., & Maes, B. (2015). Children with PIMD in interaction with peers with PIMD or siblings. *Journal of Intellectual Disability Research*. DOI: 10.1111/jir.12231

Nijs, S., Penne, A., Vlaskamp, C., & Maes, B. (2015). Peer Interactions among children with profound intellectual and multiple disabilities during group activities. *Journal of Applied Research in Intellectual Disabilities*. DOI: 10.1111/jar.12185

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Petitpierre, G. & Gyger, J. (2015). L'attention chez la personne avec un polyhandicap ou une déficience intellectuelle sévère. Fondation Eben-Hézer, & Université de Fribourg. [ISBN : 978-2-9700964-1-2](#).

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Van der Putten, A.A.J., Bossink, L.W.M., Frans, N., Houwen, S., & Vlaskamp, C. (2015). Motor activation in people with profound intellectual and multiple disabilities in daily practice. *Fully accepted for publication in Journal of Intellectual and Developmental Disability*

Van den Bosch, K.A., Vlaskamp, C., Andringa, T.C., Post, W., & Ruijsenaars, A.J.J.M. (2015). Examining relationships between staff attributions of soundscapes and core affect in people with severe or profound intellectual and visual disabilities. *Journal of Intellectual and Developmental Disability*. DOI:10.3109/13668250.2015.1114077

Venema, E., Otten, S., & Vlaskamp, C. (2015). The efforts of direct support professionals to facilitate inclusion: the role of psychological determinants and work setting. *Journal of Intellectual Disability Research*, 59, 970-979. DOI: 10.1111/jir.12209



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