From: IASSIDD
To: Bea Maes
Subject: IASSIDD | SIRG PIMD Newsletter Update - April 2023
Date: vrijdag 14 april 2023 1:47:15

Dear Bea,

Please see the following updates:

Past events

Successful edition of the SIRG PIMD ECRM and Roundtable in Leuven

On the 6th-8th February 2023 an Early Career Researchers Meeting and a Roundtable of the SIRG PIMD have taken place at the University of Leuven (Belgium). It was a very successful edition. About 80 researchers had subscribed for the ECRM and about 65 for the roundtable. About half of them were in Leuven, and the other half were attending online. Thanks to the organizing team in Leuven, we managed to realize a good hybrid event, where the people in Leuven and online could participate in an equal and qualitative way. The evaluation of the organization was very positive. Also the quality of the contributions were considered to be high, thanks to all the participants. With the following links, you can still access the presentations of the ECRM and the roundtable. People enjoyed the group discussions and the social events. For the future, the participants even asked for more interactive parts and more time for discussion in the program. It might also be useful to make a clearer distinction in the goals and approach between the ECRM and the roundtable. Several participants were willing to organize a next edition of the ECRM and the roundtable. We will make further arrangements with them, and announce a save the date in the next newsletter.

Roundtable: Program

After a short welcome word by Bea Maes, we started with two invited keynote speakers: Edward Hall and Virginie Cobigo. They shared their views on participation and inclusion of people with disabilities and provided starting points to think about these topics in people with PIMD. These introductory talks were followed by a symposium on the same topic by researchers focusing on persons with PIMD (Gineke Hanzen, Mélodie Bourger-Bouveret and David Haines). As these presentations gave as a lot of food for thought, we went for a lunch at the 'Alma' (the university canteen). Right after, the group was divided into a couple of smaller groups to brainstorm about how to realize participation and inclusion for people with PIMD. This resulted in a fruitful exchange, focusing on the concept of belonging and what this entails. To round of the day, a second symposium took place, in which the senses of persons with PIMD were the central topic. The importance of odours, sounds (music) and touch were beautifully illustrated by the four speakers (Juliane Dind, Rosie Rushton, Kathleen Julia Barnes and Sarah Weber).

Our second day started with a round of poster pitches, which entailed the researchers taking turns in standing in front of the room and summarizing their poster in approximately 2 minutes. This was a new, but warmly welcomed way of capturing the most important messages of the presented research and provided a good basis for further discussion (standing in front of the poster with a cup of coffee or tea). The online participants were able to follow the pitches and to take a look at the posters in pdf-format on their computer. A warm thanks to Gemma Testerink, Annelies Colliers, Lotte Piekema, Annemieke Enninga, Anouk Mol-Bakker, Marleen Wessels and Jean Ware for such wonderful poster presentations. Our day proceeded with a symposium on tacit knowledge, prepared by Marga Nieuwenhuijse, Kasper Kruithof and Maartje Hoogsteyns and a symposium on supporting families of persons with PIMD (by Siméon Lahaije, Nicole Luitwieler and Naomi Dorsman). Approaching the end of the conference, the organizing team had prepared a surprise lunch: a real Belgian 'frietkot' (yes indeed, French fries are not really French!). After the lunch, we concluded the conference with an interesting symposium on health problems (by Caren Keeley, Sui Sone, Aly Waninge, Vivette van Cooten and Akiko Nagae).

Roundtable: Social Program

Tuesday evening, we gathered for a nicely filled social program, starting with a visit to the library of KU Leuven. Not only the beautifully arranged collection of books were the spectacle of the evening, but foremost the guided tour by Luc Rombouts in the belltower of Leuven. Luc is a specialized 'carilloneur' and allowed us to choose the songs he played for us, including a piece of Bach, Lady Gaga and Harry Potter! Going back down the tower afterwards, we were treated to a beautiful sunset! We proceeded walking towards the destination of the evening: restaurant 'De Hoorn'.

Roundtable: Summary

The meeting was a productive and inspiring way of sharing ideas with other early career researchers in the field of PIMD. The hybrid model required some technical organisation but it meant we could enjoy the benefits of both face-to-face and remote conference experiences. It was a wonderful opportunity to hear from so many researchers from around the world.

We would like to thank the SIRG PIMD for sponsoring the Roundtable and all the participants for making it such an interesting experience. For more information about the SIRG PIMD and ECRM, including newsletters, we refer to the following websites:

www.iassidd.org/profound-intellectual-and-multiple-disabilities

www.ecrmpimd.weebly.com

Kind regards,

The Roundtable organising committee of 2023,

Bea Maes and Sara Nijs

Sien Vandesande, Ines Van keer and Gilles Droogmans

Early Career Researchers Meeting: Preface

On 6th February 2023 we gathered at KU Leuven (Leuven, Belgium) for the 11th Early Career Researchers Meeting. For the first time, the meeting was hosted in hybrid form, both live in Leuven and online. As a result, the ECRM welcomed 51 researchers from all over the world (10 online and 41 in person).

In this report we would like give participants or others who were not able to attend a glimpse of how the day proceeded.

Early Career Researchers Meeting: Program

After a short welcome word, we began the day with a quick Mentimeter survey to find out a bit more about the group. Around half the participants were about to enjoy their first ECRM while the others had attended before. Many of the group were PhD students. Participants were attending from all around the world including Japan, Iceland, Canada, Belgium, the Netherlands, Sweden, Ireland, UK, Bulgaria and several other locations. Participants also shared their diverse views on research into PIMD.

For our first activity, participants were placed in small groups and given a research-based challenge. Using their shared ideas and respective strengths they had to design a hypothetical research project. They then had to represent this creatively on paper and pitch it to the group as a whole. This turned out to be a great way of getting to know each other leading to some serious discussion, adventurous ideas, interesting art work and fair bit of laughter. Study ideas included a 'living lab' carrying out action research to enable people with PIMD to flourish, a 'mind reading' machine to explore their personal perspectives and a study exploring what small differences might make big differences to personhood and individuality.

Having got to know each other better, we settled down to listen to the first of two sets of presentations. Maartje van Uffelen started the first set by telling us about her study looking at the assessment of motor behaviour in young children with PIMD. Edina Hanley described her PhD work, presenting an integrative review of factors influencing communication partners use of Augmentative and Alternative Communication. Pála Kúld presented the findings of a systematic review and meta-analysis of intervention studies aimed at promoting self-determination of persons with severe or profound intellectual disabilities. Michiru Sasaki joined us (in person) all the way from Japan to tell us about the process of developing a decision aid to facilitate communication between physicians and parents of children with PIMD.

Busy discussion continued over lunch with those attending in person enjoying a university canteen to themselves since the students were on holiday. Lunch was followed by a second set of presentations beginning with an online presentation from Lynn LeVatte and Kristin O'Rourke from Australia, telling us about their project fostering inclusion, communication and engagement through creative & visual arts with youths with Down Syndrome during Covid-19. Sanne Nieuwenhuis & Amber Decoen then shared their experience of taking an interdisciplinary approach to studying personhood of non-verbal participants. Julia Barnes outlined some different methodological approaches to capturing 'photovoice' for people with PIMD. Rosie Rushton concluded the early career research presentations by describing her approach to engaging proxies as co-researchers as a means of developing participatory research.

For the final part of the afternoon, boosted by coffee and some delicious pie, we were entertained and inspired by Professor Dr. Elke Emmers. Elke cleverly used the teachings of Bob Ross (popular artist) to get us thinking about how we might truly engage people with intellectual disabilities in participatory research. Her introductory presentation was then followed by some whole group discussion of how we might relate this to a population with PIMD.

Early Career Researchers Meeting: Social Program

In the evening we enjoyed a walking tour around Leuven, expertly guided by Gilles followed by dinner at a local restaurant. The evening ended (for those who remained…) enjoying traditional Belgian beer at the 'longest bar in Europe'.

Early Career Researchers Meeting: Summary

The meeting was a productive and inspiring way of sharing ideas with other early career researchers in the field of PIMD. The hybrid model required some technical organisation but it meant we could enjoy the benefits of both face-to-face and remote conference experiences. It was a wonderful opportunity to hear from so many researchers from around the world.

We would like to thank the SIRG PIMD for sponsoring the ECRM and all the participants for making it such an interesting experience. For more information about the SIRG PIMD and ECRM, including newsletters, we refer to the following websites:

www.iassidd.org/profound-intellectual-and-multiple-disabilities

www.ecrmpimd.weebly.com

Kind regards,

The ECRM organising committee of 2023,

Gilles Droogmans Lucy Pepper

New projects

Christine Pacitti: Use of pain medication in people with intellectual disabilities

I am investigating pain medication in adults with learning disabilities and relationships with polypharmacy and impact on health-related outcomes. My research is being hosted at the University of Glasgow with funding from The Baily Thomas Doctoral Fellowship. My supervisory team are also based at the University of Glasgow –

<!--[if !supportLists]-->1. <!--[endif]-->Dr Barbara Nicholl, Senior Lecturer, University of Glasgow, General Practice & Primary Care, School of Health & Wellbeing, University of Glasgow

<!--[if !supportLists]-->2. <!--[endif]-->Professor Deborah Cairns, Professor of Health and Neurodevelopmental Conditions, University of Glasgow, Scottish Intellectual Disabilities Observatory, School of Health & Wellbeing

<!--[if !supportLists]-->3. <!--[endif]-->Dr Laura Ward, Research Associate, University of Glasgow, Mental Health, School of Health & Wellbeing, University of Glasgow.

I am examining the use of pain medication in people with intellectual disabilities who frequently experience multiple long-term conditions and take multiple medications. Health inequality experienced by people with learning disabilities includes differences in how pain is expressed, and painful conditions appear to be under-treated. Communicating pain can be challenging and pain can present as challenging or self-injurious behaviour. There is existing evidence on prescribing patterns of anti-depressants and anti-psychotics used inappropriately to manage challenging behaviour, however, there is a lack of evidence on patterns of prescribing pain medications and how this affects people with learning disabilities. This study aims to increase understanding of how pain is managed from a medication perspective and hopefully inform clinical practice. My initial work is on a systematic literature review to establish current knowledge prior to secondary data analysis of prescribing patterns with a matched comparator group from the general population.

Intensive Interaction for children and young people with profound and multiple learning disabilities: INTERACT trial

A team of leading researchers from UK Universities (Kent, York, Sheffield, Newcastle, Bangor) have secured funding to understand and support the communication abilities of children and young people with Profound Intellectual and Multiple Disabilities (PIMD). The research team will work together with key stakeholders to evaluate Intensive Interaction in educational settings. Despite its wide use, there is limited evidence on if and how Intensive Interaction works. This research will seek to understand the impact of Intensive Interaction on children and young people's communication, education and quality of life. Parents/carers and practitioners who support children and young people with PIMD will be trained to deliver Intensive Interaction. The research will identify their experiences of using Intensive Interaction and impact on their lives.

For more details contact J.Bradshaw@kent.ac.uk

INSPIRE

(Interaction Skills for Nursing Practice through Immersion: Research and Education)

School of Nursing and Midwifery and ASSERT,

University College Cork, Ireland.

PI: Dr. Anne-Marie Martin (a.martin@ucc.ie)

Team: Dr Brendan Noonan; Dr Pat Henn; Mr. Kevin McGuire, Dr. Mohamad Saab, Dr. Johnny Goodwin, Ms. Claire Hayes, Ms. Anne McAuliffe, Dr. Patrick Cotter, Mr. Damien Drohan, Mr. David Murphy

Project Overview: Empathy is the ability to share and understand another person's internal state. It is a core skill among health and social care professions that facilitates the development of therapeutic relationships and provides the basis for personalised care. Yet many experience difficulty empathising in their practice.

Research regarding carer empathy for people with intellectual disability is limited particularly regarding people with profound intellectual disability. It may be harder to empathise if people have difficulty expressing their perspectives/thoughts, as is the case with people with profound intellectual disability. Carers are challenged to understand their feelings, thoughts, and perspective. It is important that undergraduate intellectual disability nurses enhance their empathic skills in order to develop therapeutic relationships and provide person centred support.

It is recommended that innovative ways of teaching empathy and supporting students to develop an empathic understanding are developed with the literature advocating that teaching strategies should involve active participation of students and experiential approaches are most effective.

Therefore, this study seeks to examine the effect of immersive simulation on intellectual disability nursing students' empathy towards people with profound intellectual disability and explore the usability/feasibility of immersive technology as a teaching and learning tool.

Finished doctoral theses

Esther Atlan (defended on December 12 2022). Les initiatives des élèves en situation de polyhandicap en contexte de classe [Initiatives of students with multiple disabilities in a classroom setting]. PhD thesis defended in Paris Nanterre and INSHEA under the supervision of Minna Puustinen and Regine Scelles.

Abstract: The objective of this thesis is to identify and analyze the initiatives of seven young people with multiple disabilities, aged 6 to 13, who were enrolled in a teaching unit. Three questions guided this work, in an inductive and exploratory approach. The first was to learn more about the classroom context in which the young students were enrolled. The second sought to identify and characterize the initiatives produced by the students in this context. The third aimed to show to what extent the professionals present in the classroom reacted or responded to the students' initiatives. The youth were filmed in classrooms within two different medical-educational institutes. Analysis of one filmed learning session per institution allow to identify over 1,000 initiatives. The results concerning the context revealed a great diversity in the organization of the pedagogical situations (e.g., the distribution of roles between professionals present in the classroom), with however common points in the structuring of time and the sensory experiences proposed.

Interesting books, articles, with regard to the group of persons with PIMD

Dins, T., & Keeley, C. (2022). Recognising Basic Health Literacy Capabilities: An Explorative Study on the Relevance of Health-Related Information in the Support of People with Profound Intellectual and Multiple Disabilities. International Journal of Environmental Research and Public Health, 19(24). https://doi.org/10.3390/ijerph192416874

Hammann, T., Valič, J., Slapničar, G., & Luštrek, M. (2022). The missing piece. Physiological data as a factor for identifying emotions of people with profound intellectual and multiple disabilities. International Journal of Developmental Disabilities, 1–17. https://doi.org/10.1080/20473869.2022.2154928

Lahaije, S. T. A., Luijkx, J., Waninge, A., & Van der Putten, A. A. J. (2023). Support needs of families with a child with profound intellectual and multiple disabilities. International Journal of Developmental Disabilities. DOI: 10.1080/20473869.2023.2168718

Maes, B., Nijs, S., Vandesande, S., Van Keer, I., Arthur-Kelly, M., Dind, J., Goldbart, J., Petitpierre, G., & Van der Putten, A. (2021). Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities. Journal of Applied Research in Intellectual Disabilities (JARID), 34(1), 250-262, DOI: 10.1111/jar.12803

Petitpierre, G., & Dind, J. (2023). Measuring olfaction in children and young people with profound intellectual and multiplte disabilities. In: M. Bensafi (ed.), Basis protocols on emotions, senses, and foods. Methods and protocols in food science. Springer, https://doi.org/10.1007/978-1-0716-2934-5_10

Petitpierre, G., Dind, J., Domeniconi, D., & Diacquenod, C. (2022). L'évaluation des habilités visuelles des personnes polyhandicapées. Motricité Cérébrale, 43(3), 92-97, https://doi.org/10.1016/j.motcer.2022.07.001

Skarsaune, S. N., & Hanisch, H. M. (2023). Holding and Professional Care: On Self-Determination for Persons With Profound Intellectual and Multiple Disabilities. Research & Practice for Persons with Severe Disabilities, 48(1), 25-40. https://doi.org/10.1177/15407969231153579 (URL: https://journals.sagepub.com/doi/10.1177/15407969231153579)

Van Cooten, V., Gielissen, M., van Mastrigt, G., den Hollander, W., Evers, S., Smeets, O., Smit, F., & Boon, B. (2022). Smart continence care for people with profound intellectual and multiple disabilities. Protocol for a cluster randomized trial and trial-based economic evaluation. JMIR Res Protoc, 11(11):e42555, DOI: 10.2196/42555 (URL: https://www.researchprotocols.org/2022/11/e42555)

Miscellaneous

Akiko NAGAE (Biwakogakuen Kusatsu Medical and Welfare Center for Disabilities) & Sui SONE (Tokyo Metropolitan Higashiyamato Medical Center for Developmental/Multiple Disabilities): Japanese original connectors may be more useful than enfit for enteral nutrition

In Japan, original connectors, which have funnel shape and larger in diameter than ENFit, had been used for enteral nutrition (EN) for a long time. The Japan Ministry of Health, Labour and Welfare (MHLW) made a special research group and compared usefulness and safety between Japanese original connectors and ENFit through May 2022, when the MHLW allowed the use of Japanese connectors after adopting ENFit because it may reduce the QOL of patients with EN. The MHLW has recognized some conditions which require the Japanese connectors including frequent gastric venting dependent and blenderized tube feeding or semi-solid nutrients dependent pathology. Moreover, Japanese connectors were revealed to be more useful for feeding highly viscous food with syringes without any electric pumps, which is common way of EN for Japanese home caregivers. The implementation of ENFit may not only decrease the QOL of the patients but also place additional burdens on caregivers.

Link to website and/or contact information:

https://www.mhlw.go.jp/content/10800000/000941626.pdf

Platform Ik ga EMB: inspiration for active participation of young people with PIMD!

The Dutch platform ‘Ik ga EMB’ is an online meeting point for young people with PIMD, their parents (i.e. carers) and professionals. It is a place where people can meet, share inspiration and exchange ideas. The platform aims to increase the active participation of young people with PIMD in everyday life activities (e.g. daily care, household, leisure activities, transport) and relationships.

The platform was founded around five years ago by Nicole van den Dries-Luitwieler (PhD-student, professional and mother of a now 19-year-old daughter with PIMD). Today, many other parents and professionals are connected with the platform. They share their stories and movies on the Ik ga EMB social media (e.g. Facebook, and Instagram) and an online inspiration box (www.embinsipratiebox.nl). Examples of inspiring activities you can find here are: peeling an apple or blow-drying your hair by pressing a large button, turning toys on and off with eye control, making art with an EazyHold Strap (grip aid) or voice-activated robot and much more …

Learn more about the platform Ik ga EMB: www.ikgaemb.nl

Information on the PIMD SIRG position paper

The PIMD SIRG position paper “Looking back, looking forward: Methodological challenges and future directions in research on persons with profound intellectual and multiple disabilities” authored by Bea Maes, Sara Nijs, Sien Vandesande, Ines Van Keer, Michael Arthur-Kelly, Juliane Dind, Juliet Goldbart, Geneviève Petitpierre and Annette Van der Putten was a “Top Cited Paper” for Journal of Applied Research in Intellectual Disabilities (JARID) 2021-2.

Announcement of Anna Pella

My name is Anna Pella and I am a Swedish author, journalist writing about my own and others experiences about being a relative to a child with PIMD. My own daughter Agnes is 19 again all odds, and recently my second book ”Väntesorg” (Anticipatory grief) came out in Sweden. I also write children’s books about siblings experiences and in december they became a theatre now touring in Swedish schools. It is called ”Stop staring operation” and is mainly about how we treat each other different, and what we should do about it. Unfortunately, nothing of my work is translated yet, though I have hade some discussions with editors abroad.

I also do workshops under the name ”Gott liv - för alla?” (Good life, for everybody?) together with another mum who is an educator, speaking about how to make the whole family healthy. Our workshop can be hold in English and is addressed to both professionals and relatives.

If you would like som more information, please don’t hesitate to contact me.

My home pages:

www.gottlivforalla.se

www.funkisfamiljen.se

www.nardulerstannartiden.se

www.vantesorg.se

Deafblind Information Australia

The complex needs and changing nature of the population of people with deafblindness often results in poor recognition of deafblindness and associated inadequate or inappropriate service provision.

Deafblind Information Australia (DBIA) is a consortium of SensesWA, Able Australia and Deafblind Australia, formed to deliver a project, funded by the National Disability Insurance Agency.

It is in the final year of the 4 year project with several focus areas, one of which is building skills and knowledge of the Australian disability services sector in congenital deafblindness.

Face-to-face workshops, a webinar series and the distribution of information on the DBIA website are several ways in which DBIA is addressing this service shortfall.

All resources have been developed with an Australian context in mind, however much of the content has a global reach.

To learn more about deafblindness visit the Deafblind Information Australia website. The DBIA News page contains details of workshops and webinars.

DBIA website: https://www.deafblindinformation.org.au/

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 sent to you in November 2023. Please send us your information on:

- Past events (title, date and place; report of maximum 150 words; link to a website or contact information)
- Upcoming events (title, date and place; report of maximum 150 words; link to a website or contact information)
- Finished doctoral theses (Name of doctoral candidate; name(s) of (co)supervisor(s); title, date and institution; report of maximum 150 words; link to website or contact information)
- New projects (Project title; name(s) of research group; institution; project description of maximum 150 words; link to website or contact information)
- Interesting books, articles,… with regard to the group of persons with PIMD, published after November 2019 (in APA format and if available a link to a webpage)
- Miscellaneous (Title; names; institution; description of maximum 150 words; link to website

and/or contact information)

Please consider the specified guidelines and send your input for our next newsletter to - i.keijzer@rug.nl

Kind regards,

IASSIDD Office
www.iassidd.org
office@iassidd.org