

Newsletter July 2025

PAST EVENTS

Title: ECRM and Roundtable Meeting SIRG PIMD

Date: April 22-24, 2025

Place: Cork, Ireland

We welcomed over 30 delegates from 13 countries to Cork for the 12th Early Career Researchers' Meeting on 22 April, hosted in a hybrid format. The day began with an icebreaker — followed by a visit from My Canine Companion Promoting Academic Wellbeing and Support @UCC. An engaging in person workshop followed oral and poster presentations.

The momentum continued with the Roundtable Meeting on 23–24 April, bringing together over 74 delegates from 15 countries, online and in person. The theme was Profound Partnerships: Working in partnership to advance research and support of persons with profound intellectual and multiple disabilities. We were reminded of the importance of partnering with individuals with PIMD, their families and caregivers.

Both events were hosted at the School of Nursing and Midwifery, University College Cork. Thank you to the SIRG PIMD and the Health Research Board Ireland Conference and Event Sponsorship Scheme 2024 for their support.

UPCOMING EVENTS

Title: IASSIDD European Congress

Date: July 29-31, 2026

Place: Munich, Germany

Local Host: Ludwig Maximilian University of Munich (Prof. Peter Zentel, Chair of Intellectual and Developmental Disabilities)

We are pleased to invite you to the 2026 European Congress in Munich, Germany. The pre-conference will take place on **28th July 2026**, followed by the main conference from **29th July to 31st July 2026**. The conference theme **real.time** invites exploration of the many dimensions of reality and the digital realm – encouraging us to look forward with a mindful regard for the past and to consider the empowering potential of participation through Assistive Technology. It will serve as a guiding thread throughout the program while also leaving space for broader perspectives and cross-cutting ideas.

Regular updates will be posted on the conference website, including first key info already available now. Gradually, you'll find further announcements: keynote speakers, call for contributions, venue details, and more – all also shared via our linked social media channels.

We look forward to your interest, your active participation, and to welcoming many of you in person in Munich!

Conference Website: <https://iassidd2026.com>

FINISHED DOCTORAL THESES

Candidate: Dr. Joanna Grace

Supervisors: Prof Melanie Nind, Dr Jo Hope

Title: Recognizing the belonging of people with profound intellectual and multiple disabilities in research through a collaborative exploration of identity

Date (of defense): November 22, 2024

Institution: University of Southampton

Contact: www.TheSensoryProjects.co.uk/contact

Link: <https://eprints.soton.ac.uk/497372/>

Abstract: This study explored how to meaningfully conduct research with people with profound intellectual and multiple disabilities, challenging traditional approaches that have excluded them. The research took place in a UK special school over a school year. Grounded in Merleau-Ponty's phenomenology and inactivist philosophy, and inspired by sensory ethnography, participant observation was used to develop a way of collaborating with four young people with profound intellectual and multiple disabilities. The method of "Being With" was developed through which participants took on researcher roles. Identity was experienced as embodied, and at times shared. Data were collected in the form of vignettes and memos, and analysed thematically. Photographs were taken to increase the impact of the work. The study argues that recognizing the belonging of people with profound intellectual and multiple disabilities in research addresses the epistemic injustice of their exclusion and supports a fuller understanding of human identity and experience.

INTERESTING BOOKS, ARTICLES, ...

Droogmans, G., Nijs, S., & Maes, B. (2024). Capturing staff perspectives on quality interaction with clients with intellectual disability. A diary study. *Intellectual and Developmental Disabilities*, 62(5), 376-391. <https://doi.org/10.1352/1934-9556-62.5.376>

MISCELLANEOUS

Building a Network for PIMD Researchers

At the Chicago meeting, we discussed the importance of creating means of connecting, sharing, and learning about each other's work. A particular challenge for our field is knowing who is working on PIMD and what topics they are studying.

To address this, we identified [Padlet.com](https://padlet.com) as an excellent solution. Padlet allows researchers to add, edit, or delete their own information independently, eliminating the need for someone to actively manage the platform. This self-organizing structure encourages collaboration and keeps the information up-to-date with minimal effort.

We've created a Padlet to kickstart this initiative. You can view it here: [PIMD Researchers Padlet](#). Feel free to add your information and help expand this valuable network!

Let's build a stronger, more connected community for PIMD research.

International Communication Rights Alliance – Call for committee members

The International Communication Rights Alliance is a group of organisations and individuals working to uphold the communication rights of people with disability and operationalise the United Nations Convention on the Rights of Persons with Disability with regard to communication rights.

The committee meets bi-monthly, and members include representatives from the International Society for Augmentative and Alternative Communication, Deafblind International, the World Federation of the Deafblind, and International Council of Educators of the Vision Impaired. We are very keen to have representation from IASSID, and would welcome a member of the IASSID PIMD SIRG to join the committee. You would be welcome to sitting in on a meeting before committing to join. We are also calling for general members, who we keep informed of our activities. For further information please contact the ICRA Chair – Dr Meredith Prain – meredith.prain@ableaustralia.org.au

The Skies We're Under: A podcast for practitioners and parents.

Supporting a family member with complex, profound and multiple disabilities can be exhausting, confusing, emotional and often lonely. Families can feel overwhelmed by the

services they need to navigate, and practitioners can feel that they don't have the skills to work in this complex context.

That's where 'The Skies We're Under Podcast' helps.

Hosted by Rachel Wright, a qualified nurse and parent of a young man with complex disabilities with Sarah Clayton and Lucy Parr. They share experience as parent carers and professionals, giving a perspective from both sides of the bed. Their irreverent, funny, authentic, useful and hopeful conversations, and the podcast guests, help families feel less alone and more understood.

There are over 100 episodes available covering topics including, feeding, epilepsy, parent/caregiver trauma, holidays, communication and more.

You can listen wherever you get your podcasts.

The Skies We're Under
Parenting Disabled Children Podcast
With Rachel Wright

www.bornattherighttime.com
podcast@bornattherighttime.com

100+ EPISODES AVAILABLE

Diagnosis
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Trauma
Support
Community
Wellbeing

"This podcast is such a breath of fresh air."
"Parent carers - subscribe to this!"

Lorna & Cat

"Helping families feel a little less alone and a little more understood"

<https://www.bornattherighttime.com/the-skies-we-are-under-podcast/>

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 at the beginning of **2026 (call for input in January 2026)**. Please send us your information on:

- **Past events** (*title, date and place; report of maximum 150 words; link to website or contact information*)
- **Upcoming events** (*title, date and place; report of maximum 150 words; link to 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 take into account the specified guidelines and send your input for our next newsletter to ***meike.engelhardt@edu.lmu.de***