

Newsletter March 2025

UPCOMING EVENTS

Title: Early Career Researchers Meeting and SIRG's roundtable

Date: April 22-24, 2025

Place: Cork, Ireland

We are pleased to invite you to the 2025 Early Career Researchers Meeting and Roundtable of the SIRG PIMD, titled '***Profound Partnerships: Working in Partnership to Advance Research and Support for Persons with Profound Intellectual and Multiple Disabilities.***'

The Early Career Researchers Meeting will take place on **22nd April 2025** (from 08:30 to 16:00), followed by the SIRG's Roundtable on **23rd April** (from 08:30 to 16:30) and **24th April 2025** (from 09:00 to 15:30). We plan to offer a hybrid format, allowing both in-person and online participation.

Registration and the call for abstracts will open at the beginning of January. More information will be available soon on [PIMD EARLY CAREER RESEARCHERS - Home](#).

NEW PROJECTS

Title: Komma. Ensuring successful communication of ageing people with PIMD. Overview and preliminary findings of a research project on the communicative needs of an often-overlooked population

Researchers:

- Prof. Dr. Tobias Bernasconi (University of Cologne)
- Timo Dins (University of Cologne)

Project description:

With increasing age, communication often becomes challenging for individuals with (profound) intellectual disabilities due to factors like dementia, loss of familiar communication partners, and frequent changes in professional caregivers. The Komma research project (10/2023–09/2027) aims to develop research-based knowledge and tools to improve communication and support caregivers in adapting their approaches sensitively.

The project begins with a review of existing research, followed by an exploratory data collection phase, including participant observations in day-care and residential settings and focus group interviews with caregivers. The findings will identify key factors for enhancing communication opportunities and inform the development of diagnostic and support materials. These materials will be tested in practice settings to evaluate their effectiveness and applicability.

Based on the results, the materials will be refined to ensure their quality and usability in improving communicative processes for this target group.

Contact:

komma-koeln@uni-koeln.de

<https://gkb.uni-koeln.de/forschung/komma-engl/>

Title: Faces of Loneliness

Researchers: Consortium consisting of both research and social partners, including the Academic Collaborative Centre for PIMD

Institution: University of Groningen, Open University, Rotterdam University of Applied Sciences

Project description:

In this research project funded by the Dutch Research Council (NWO), we aim to investigate loneliness among a specific group of informal caregivers who provide care for a person with intensive support needs. For example, parents or young adult siblings of a child with PIMD. The unique challenges for these informal caregivers is that they have this intensive care duty in an unusual phase of life. Other people may find it difficult to connect with them, because they do not understand the challenges that come with the informal care duty. This lack of connection and acknowledgement is associated with loneliness. In this project, we are interested in how these informal caregivers experience loneliness, how social networks and stigma influence these experiences, what their coping strategies are, and what they identify as their needs. This knowledge will then be used by us to develop interventions to reduce or prevent loneliness.

Link to website:

www.eenzaamheidbijmantelzorg.nl (work in progress)

<https://www.linkedin.com/company/eenzaamheidbijmantelzorg/>

Title: The Prevailing Paradigm: Complex Additional Learning Needs, Special Schools and Capacity Building in Welsh Local Authorities

Research (doctoral candidate): Simon Anderson

Doctor of Education Programme

University of Bangor

Commencing January 2025

Supervisor: Dr. Jean Ware

Project description:

The increasing prevalence of complex ALN among children and young people is a significant challenge facing educational systems globally. This research focuses on the specific context of Wales, examining the escalating demand for complex educational provision, particularly in special schools, and the capacity of local authorities (LAs) to meet these needs.

Contact:

s.p.anderson1@gmail.com

Title: The Mandala project: stress and stress regulation in children with profound intellectual and multiple disabilities

Researchers:

- Emma Vanroye (PhD student)
- Prof. Dr. Bea Maes
- Prof. Dr. Sara Nijs
- Dr. Sien Vandesande

**Research group:**

[Parenting and Special Education Research Unit](#)

INOVHO (<https://ppw.kuleuven.be/ogop/inovho>)

Institution: Catholic University of Leuven (Belgium)

Project description:

The project's main aim is to unravel the role and mechanisms of stress regulation in children with profound intellectual and multiple disabilities (PIMD). First, the way in which these children experience sensory stimuli and respond to them, as well as how these contribute to their general stress level will be studied. Secondly, it will be evaluated in which way high quality interactions which are attuned to the needs of persons with PIMD can diminish their stress levels. The third aim is to test the association between stress levels and stress regulation on the one hand and the children's general wellbeing, engagement and problem behaviours on the other hand. Data will be collected in real life situations. Data on environmental stimuli, staff's interaction style and behavioural indicators of stress will be collected through continuous video observation. A physiological indicator of the child's stress will be registered through the galvanic skin response.

Link to the website and contact information:

Link to the website: <https://ppw.kuleuven.be/ogop/medewerkers/00156013>

Contact information: emma.vanroye@kuleuven.be

Title: Lighthouses of participation for people with PIMD (LINKED)

Headed by:

- Dr. Caren Keeley (University of Cologne)
- Prof. Dr. Teresa Sansour (Carl von Ossietzky University Oldenburg)

Funded by:

German Federal Ministry of Labour and Social Affairs (BMAS)

Project description:

Adults with PIMD are still to a great extent excluded from participation in all areas of life and professionals working with the group of people often struggle to develop participation-oriented services. Addressing this situation, the LINKED research project aims at finding and analyzing existing participation-oriented services and identifying successful moments of participation for adults with PIMD. A central aim represents the derivation of fundamental aspects for an understanding of participation which includes adults with PIMD. Moreover, factors that contribute to the emergence of participation are analyzed to develop a guideline for the design of participation-orientated programs. Thus, disability care facilities are involved in the project at various stages including four multi-method field studies. The identified examples of good practice will also be presented online to provide inspiration for the development of participation-oriented services for facilities and professionals.

Link to the website and contact information:

More information can be found on our website: <https://blog.uni-koeln.de/linked/>

Contact: linked@uni-oldenburg.de

FINISHED DOCTORAL THESES

Candidate: Dr. phil Meike Engelhardt

Supervisors: Prof. Dr. Peter Zentel, Prof. Dr. Teresa Sansour

Title: Assistive Technologien in der Interaktion mit unvertrauten Menschen mit schwerer und mehrfacher Behinderung – Perspektiven anhand eines qualitativ-rekonstruktiven Zugangs (Assistive Technologies in Interaction with Unfamiliar People with Profound Intellectual and Multiple Disabilities – Perspectives Using a Qualitative-Reconstructive Approach)

Date (of defense): May 16, 2024

Institution: Ludwig Maximilian University Munich

Contact: meike.engelhardt@edu.lmu.de

Link:

[https://www.researchgate.net/publication/383422179 Assistive Technologien in der Interaktion mit unvertrauten Menschen mit schwerer und mehrfacher Behinderung - Perspektiven anhand eines qualitativ-rekonstruktiven Zugangs](https://www.researchgate.net/publication/383422179_Assistive_Technologien_in_der_Interaktion_mit_unvertrauten_Menschen_mit_schwerer_und_mehrfacher_Behinderung_-_Perspektiven_anhand_eines_qualitativ-rekonstruktiven_Zugangs)

Abstract: The study investigates the potential of assistive technologies to enhance interactions with individuals with PIMD, focusing on challenges such as uncertainty and communication mismatches. It employs Grounded Theory methodology, integrating creativity-enhancing methods from design thinking (e.g., persona development, Disney method) to explore innovative solutions. These approaches foster an in-depth understanding of user needs and contextual dynamics, enabling more effective and personalized technological implementations.

The research highlights the importance of balancing human and technological support, addressing personalization, resource limitations, and interdisciplinary collaboration. Practical strategies are proposed to support educators and caregivers in improving interaction quality, promoting both user autonomy and relational understanding.

Candidate: Dr. phil Torsten Hammann

Supervisors: Prof. Dr. Peter Zentel, Prof. Dr. Teresa Sansour

Title: Analyse des Emotionsausdrucks von Menschen mit schwerer und mehrfacher Behinderung als forschungsethische Herausforderung und Indikator für Lebensqualität (Analysis of the Emotional Expression of People with Profound Intellectual and Multiple Disabilities as a Challenge in Research Ethics and an Indicator of Quality of Life)

Date (of defense): April 30, 2024

Institution: Heidelberg University of Education

Contact: torsten.hammann@ph-freiburg.de

Link:

https://www.researchgate.net/publication/380817987_Analysis_of_the_Emotional_Expression_of_People_with_Profound_Intellectual_and_Multiple_Disabilities_as_a_Challenge_in_Research_Ethics_and_an_Indicator_of_Quality_of_Life

Abstract: Emotions have an impact on thinking, learning, and quality of life (QoL), making emotional competence (i.e., regulating, expressing, and understanding emotions) crucial, especially when interacting with people with profound intellectual and multiple disabilities (PIMD). Due to mostly limited verbal or alternative communication, interpreting their emotions relies on behaviours, which poses challenges for caregivers and researchers. This dissertation explores QoL, research ethics, and emotional expression in people with PIMD. Paper I reviewed QoL studies, emphasizing active inclusion of individuals in decision-making. Paper II addresses ethical challenges in research, proposing solutions to ensure consent, protection, and participation. Papers III and IV analysed emotional expressions through behavioural signals and physiological data (i.e. skin conductance, heart rate (variability), and movement data), confirming emotional arousal insights using statistical and machine learning methods. These findings highlight the value of physiological measures. Future studies should deepen research in QoL and emotional competence through long-term, real-life approaches.

Candidate: Dr. Linn Johnels

Supervisors: Prof Jenny Wilder, Prof Simo Vehmas, Prof Shakila Dada (opponent for public defense: Prof Vera Munde)

Title: Musical Interaction with Students with Severe/Profound Intellectual and Multiple Disabilities

Date (of defense): October 18, 2024

Institution: Department of Special Education, Stockholm University

Contact: linn.johnels@gu.se

Link: <https://lnkd.in/dRn6ntCM>

Abstract: The aim was to investigate how musical interaction could support interactive engagement in students with S/PIMD, in three sub-studies. In study 1, a scoping review was conducted to summarise the evidence base on musical interaction with children with S/PIMD. In study 2, a pedagogical approach – MultiSensory Music Drama (MSMD) – was evaluated for its effectiveness and social validity in school settings for students with S/PIMD. In study 3, a teacher and her student with S/PIMD working with MSMD were followed in a longitudinal case study. Conclusions highlight the importance of finding motivating pedagogical activities to support interactive engagement in the population, and that musical interaction can play an important role in this regard.

Below: Vera Munde and Linn Johnels engage in a discussion during the public defense. Also pictured are the scientific committee members—Associate Professor Shruti Taneja Johansson, Professor Stephan Hau, and Professor Eva Bojner Horvitz—together with Linn and Vera following the defense.



Candidate: dr. Siméon T.A. Lahaije

Supervisors: prof. dr. A.A.J. van der Putten, dr. J. Luijkx, Dr. A. Waninge

Title: Supporting families with a child with profound intellectual and multiple disabilities

Date: October 10, 2024

Institution: University of Groningen

Contact: s.t.a.lahaije@gmail.com

Link: <https://research.rug.nl/en/publications/supporting-families-with-a-child-with-profound-intellectual-and-m>

Abstract: Supporting persons with profound intellectual and multiple disabilities (PIMD) is a complex and intensive task. Family members of a person with PIMD play a significant and lifelong role in this support. Due to this role and because family members together form a system, it is important to support the entire family. However, to targeted and appropriate support more knowledge is needed.

The goal of this dissertation is therefore to gain knowledge about the lives and needs of families with a child with PIMD and to support them (with it). It was found that families have on average

a positive experience of their family quality of life, though appear to need (additional) support to relieve stress. Additionally, the support needs of these families in all levels of the system surrounding the family, and the specific needs per life stage of the child with PIMD have been inventoried. Furthermore, it was found that families have on average a positive experience of their family resilience, and that it has a positive effect on their family quality of life. Finally, based on the input of parents, a product (an online training course for WMO-consulenten) was developed to support them. With this knowledge and the product developed, families with a child with PIMD can be appropriately supported so that they may lead a positive and meaningful life in a way that is important to them.

INTERESTING BOOKS, ARTICLES, ... WITH REGARD TO THE GROUP OF PERSONS WITH PIMD

Dhondt, A., Van keer, I., van der Putten, A., Maes, B. (2023). Changes in the early communicative behaviors of young children with significant cognitive and motor developmental delays in a two-year span. *Journal Of Communication Disorders*, 104, Art.No. 106337. [doi: 10.1016/j.jcomdis.2023.106337](https://doi.org/10.1016/j.jcomdis.2023.106337)

Dhondt, A., Van Keer, I., Ceulemans, E., van der Putten, A., Maes, B. (2023). Describing the communicative profiles of young children with a significant cognitive and motor developmental delay. *Augmentative And Alternative Communication*, 39 (2), 84-95. [doi: 10.1080/07434618.2022.2138780](https://doi.org/10.1080/07434618.2022.2138780)

Dhondt, A., Van keer, I., van der Putten, A., Maes, B. (2023). Analysis of Early Expressive Communicative Behaviour of Young Children with Significant Cognitive and Motor Developmental Delays. *British Journal Of Learning Disabilities*, 51 (1), 24-37. [doi: 10.1111/bld.12440](https://doi.org/10.1111/bld.12440)

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>

Engelhardt, M. (2024). *Assistive Technologien in der Interaktion mit unvertrauten Menschen mit schwerer und mehrfacher Behinderung. Perspektiven anhand eines qualitativ-rekonstruktiven Zugangs (Assistive Technologies in Interaction with Unfamiliar People with Profound Intellectual and Multiple Disabilities – Perspectives Using a Qualitative-Reconstructive Approach)*. Dissertationsschrift zur Erlangung des Doktorgrades (Dr. phil), Ludwig-Maximilians-Universität München. https://edoc.ub.uni-muenchen.de/33922/1/Engelhardt_Meike.pdf

Hanley, E., Dalton, C., Lehane, E. and Martin, A.-M. (2024), Communication Partners' Perceptions of Their Roles and Responsibilities in the Design, Planning and Use of

Augmentative and Alternative Communication With Individuals With Severe or Profound Intellectual Disability: A Qualitative Descriptive Study. *British Journal of Learning Disabilities*. <https://doi.org/10.1111/bld.12620>

Hanley, E., Martin, A., Dalton, C., & Lehane, E. (2023). Communication partners experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review. *Disability and Rehabilitation, Assistive Technology* 19(7), 2454-2470. <https://doi.org/10.1177/17446295221115914>

Hanley, E., Martin, A., Dalton, C., & Lehane, E. (2023). Communication partners experiences of communicating with adults with severe/profound intellectual disability through augmentative and alternative communication: A mixed methods systematic review. *Journal of Intellectual Disabilities*, 27(4), 1107-1134. <https://doi.org/10.1177/17446295221115914>

Lahaije, S. T. A., Luijkx, J., Waninge, A., & Van der Putten, A. A. J. (2024). Family Resilience Affecting Well-being of Families With a Child With Profound Intellectual and Multiple Disabilities. *Intellectual and Developmental Disabilities*, 62(2), 101-113. <http://doi.org/10.1352/1934-9556-62.2.101>

Lahaije, S. T. A., Luijkx, J., Waninge, A., Van der Putten, A. A. J. (2023). Well-being of Families With a Child With Profound Intellectual and Multiple Disabilities. *Research and Practice for Persons with Severe Disabilities*, 48(2), 63–78. <http://doi.org/10.1177/15407969231173916>

Martin, A.-M., Nilsson, L., & Andrews, T. (2024). Classic grounded theory: A rigorous methodology for research involving participants with severe/profound intellectual disabilities: A discussion of classic grounded theory as a way of undertaking rigorous, credible research involving participants with severe/profound intellectual disability. *British Journal of Learning Disabilities*. <https://doi.org/10.1111/bld.12635>.

Murphy, M., & Martin, A.-M. (2024). We became their beginning, their middle and their end. *British Journal of Learning Disabilities*, 52(2), 225-235. <https://doi.org/10.1111/bld.12565>

Slade, K., Shaw, R.L., Larkin, M., & Heath, G. (2023). Care-giving experiences of parents of young people with PMLD and complex healthcare needs in the transition to adulthood years: A qualitative poetic synthesis. *Arts & Health*. <https://doi.org/10.1080/17533015.2023.2288058>

Van keer, I., Maes, B. (2024). Our path together: Development of the inclusive parenting goals questionnaire. *Journal of Intellectual Disabilities*. [doi: 10.1177/17446295241304463](https://doi.org/10.1177/17446295241304463)

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.

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 **July 2025**. 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 webside 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