

## IASSIDD PIMD ECR Day Program: 8th October 2021

Time	Presenter	Topic
9.30 am	Michelle King and Wieneke Penninga	Welcome and Introductions
<b>Session 1: ECR Presentations</b>		
10.00 am	David Watt	A measure of social justice? The development of the curriculum and certification of young people with learning disabilities in Scotland
10.15 am	Katharine Slade	The experiences of parents caring for young people with profound and multiple learning disabilities (PMLD) during the transition years to adulthood: a qualitative evidence synthesis
10.30 am	Victoria Churchill	Developing a music therapy resource with key stakeholders, including adults with severe to profound and multiple disabilities
10.45 am	Lorene Guenot-Comairas	Objects of Reference: Self-determination support for people with Profound Intellectual Multiple Disabilities (PIMD)?
11.00 am	Hille Voss	Health practitioners' perspectives and practices of providing end-of-life care for people with profound intellectual and multiple disability
11.15 am	Session 1 Questions and Discussion	
<i>11.30 am Coffee and Chat Break</i>		
<b>Session 2: ECR Presentations</b>		
12 noon	Thomas Madhavaram Kishore & Osheen Saxena	Attitude of significant others make a difference in the life of people with PIDD
12.15 am	Rosie Rushton	Musical Play: investigating the impact of Musical Play on play experiences for children with Profound and Multiple Learning Difficulties and their supporting play-partnerships.
12.30 pm	Synne Skarsaune	Holding another carefully – exploring relations between persons with profound intellectual and multiple disabilities and professional caregivers.
12.45 am	Joao Canossa Diaz	Atypical interpersonal communication: looking for and through a different "lens"
1.00 pm	Gilles Droogmans	"Ça va?" Pathways towards more qualitative staff-client interactions in services for persons with severe to profound intellectual disabilities
1.15 pm	Magdalena Vaneva Hadzhieva	Study of the views of pedagogical specialists for the education of children with profound intellectual and multiple disabilities in Bulgaria and Belgium (Flanders)
1.30 pm	Session 2 Questions and Discussion	
<i>1.45 pm Lunch and Chat</i>		
<b>Session 3: Workshop</b>		
2.30 pm	Professor Simo Vehmas	Involving people with PIMD in research
<i>3.30 pm Coffee and Chat Break</i>		
4.00 pm	Social Session	Bingo and Networking!

## Abstracts:

**David Watt**

### **A measure of social justice? The development of the curriculum and certification of young people with learning disabilities in Scotland**

**Abstract:** Inclusive education involves a process that contributes to the goal of social justice. A core feature of an inclusive education system as outlined by United Nations Committee on the Rights of People with Disabilities General Comment No. 4 (UNCRPD 2016) was one where “(L)earners’ capacities and confidence are developed and learners receive reasonable accommodation and equality regarding assessment and examination procedures, and certification of their capacities and attainments on an equal basis with others.” Within Scotland’s Curriculum for Excellence every young person aged between 15 and 18 years is entitled to a Senior Phase that “prepares them well for achieving qualifications to the highest level of which they are capable”.

This entitlement to a Senior Phase is set within an inclusive curriculum and qualifications framework whereby young people with learning disabilities can be certificated across all curriculum areas through a set of courses and units on an equal basis with their peers. However, the entitlement to certificating the learning of young people with learning disabilities has not yet been fully utilised in the schools at secondary stages across Scotland.

This short presentation tells the story of how policy development of Scotland’s national curriculum aimed to be inclusive of all including those with profound and complex needs. It also considers the certification of their learning as part of an inclusive national qualifications framework.

**Katharine Slade**

### **The experiences of parents caring for young people with profound and multiple learning disabilities (PMLD) during the transition years to adulthood: a qualitative evidence synthesis**

**Background:** Young people with PMLD and complex health needs transition from paediatric to adult healthcare across multiple services. Transition is a complicated and a stressful time for parents, who often act as advocates. However, parental support needs remain largely unrecognised. There is limited literature exploring the experiences of those parents caring for young people (14-25) with PMLD.

**Aims:** To understand the demands parents and informal carers face in caring for their PMLD adolescent children in relation to their own well-being.

**Method:** One mixed method and 16 qualitative papers were identified. A thematic evidence synthesis on first order qualitative data was undertaken, and research poems were constructed to further the analysis.

**Results:** Parents undertake intense parenting. Three themes were identified: Parent and Child Interdependence, with parents retaining responsibility and advocacy; Sharing Responsibility, when parents and professionals work together; The Future, parents are concerned about both the short term and longer term futures, and death.

**Discussion:** Parents lose legal status at transition; an integrated model of services within adult services including the family’s contribution would ensure their knowledge is accessed. Communication with both parents and the young people is key. Encouraging healthcare professionals to undertake alternative communication training would alleviate parental concerns, and improve diagnosis and treatment. Discussions about end of life planning will help parents consider the future.

**Victoria Churchill**

**Developing a music therapy resource with key stakeholders, including adults with severe to profound and multiple disabilities**

**Abstract:** Music therapy is an allied health profession with a long history of supporting adults with severe to profound and multiple disabilities. And yet, literature is sparse and difficult to find, and training is still insufficient. This contributes to the challenges music therapists experience in supporting adults with severe to profound and multiple disabilities. Furthermore, we develop services based on our perceptions of what the person/people we are working with need, which can be influenced by the society and systems we work in. Across the world, there is now a call for disabled people, including adults with severe to profound and multiple disabilities, to be involved in the development of their services. My main research therefore aims to develop a practical resource with key stakeholders, to support better outcomes for adults with severe to profound and multiple disabilities and music therapists. Involving adults with severe to profound and multiple disabilities as key stakeholders will not only respect their right to inclusion, but also endeavour to ensure music therapy services provided are truly meaningful to them.

**Lorene Guenot- Comairas**

**OBJECTS OF REFERENCE: Self-determination support for people with Profound Intellectual Multiple Disabilities (PIMD)?**

**Abstract:** Individuals with Profound Intellectual Multiple Disabilities (PIMD) form a heterogeneous group with severe motor, perceptual and cognitive disruptions and in the construction of relationships with their physical and human environment (IReSP & CNSA, 2019). We now know that they are able to develop their potential if it is adapted to their learning abilities and based on a positive approach (HAS, 2020), especially in terms of self-determination. Its learning would be possible by repetition (Chard et al., 2013, cités dans Chard & Roulin, 2015).

The aim of this research project was to put forward the possibilities of self-determination for people with PIMD through the use of reference objects. These ones are the simplest means of signalling what is going to happen, offering choices (Golbart & Caton, 2010), responding to needs and increasing participation (Bloom, 1990, cité dans Park, 1997).

Thus, we filmed the « journey » between the presentation of object of reference of rehabilitation room to the arrival, and its return to the living unit. This 3-month research work consisted in collecting, through an observation grid, the behavioral manifestations, of acceptance or refusal, of 6 persons received at the medico-educational institute " les Mésanges ", Savoie.

The data obtained and their analysis showed great intra-individual variability and statistically insignificant results. However, the clinical observations allowed us to highlight the relevance of this tool as a support to self-determination.

## Hille Voss

**Title:** Health practitioners' perspectives and practices of providing end-of-life care for people with profound intellectual and multiple disability

**Abstract:** Due to developments in health and social care, people with profound intellectual and multiple disability (PIMD) are living longer than ever before, meaning they are increasingly experiencing life-threatening health conditions requiring palliative care. Little is known about providing end-of-life care for people with PIMD. In this presentation, results of seven in-depth semi-structured interviews with health practitioners will be shared. Questions were designed to gather information about health practitioners' experience, perceptions, and attitudes relating to people with PIMD during and at the end of their life. Inductive thematic analysis was used to analyse the data. The study provides guidance for the development of training and professional development relating to people with PIMD at the end of life. It is hoped that this will increase the accessibility of end-of-life services for people with PIMD, ensuring that a respectful and dignified death can be a reality for all humankind regardless of disability.

## Thomas Madhavaram Kishore and Osheen Saxena

**'Attitude of significant others make difference in the life of people with PIDD'.**

The presentation will look at the quality of life of two siblings with PIDD vis-a-vis the attitude of significant others.

## Rosie Rushton

**Musical Play: investigating the impact of Musical Play on play experiences for children with Profound and Multiple Learning Difficulties and their supporting play-partnerships.**

**Abstract:** We all 'play' music! Play experiences for children with Profound and Multiple Learning Disabilities (PMLD) are often compromised, lost in complex care routines, increasingly stretched timetables and a lack of suitable play interventions. There are numerous challenges supporting adults must address when facilitating and enabling playful experiences for these learners. This study investigates combining music with play, using a set of guidelines and principles, developed by the researcher, Musical Play. It evaluates the impact this has on the play experiences of both the learners and staff. This case-study approach included five primary-aged children and four teaching staff, during a five week implementation period in a UK Special School. The study collected multiple data sources to evaluate the impact of the intervention Musical Play. Results revealed that Musical Play elicited engaged, playful and creative responses, encouraging peer-awareness and interactions. The intervention allowed staff a sense of freedom from target-driven work, providing a unique opportunity to fully immerse themselves in the play experience. Further research in play, play-partnerships and music and play for people with PMLD is recommended. This small scale project forms the basis of my PhD research which further explores music and play for people with PMLD.

## Synne Skarsaune

**Holding another carefully – exploring relations between persons with profound intellectual and multiple disabilities and professional caregivers.**

**Abstract:** Reporting from the Phd project: "Self-determination without words – challenging relations between persons with PIMD and professionals" this presentation will present from the ethnographic work that is undertaken. In dialogue with an ethics of care the following question will be highlighted: what hallmarks dynamics of caring relations between persons with PIMD and professionals that advance self-determination?

## Joao Canossa Diaz

### **Title: Atypical interpersonal communication: looking for and through a different “lens”**

**Abstract:** While studying human communication, researchers and professionals may use different theoretical approaches or representative models of the process. Depending on the definition of communication and the assumption of a linear, interactional or transactional model of communication, the philosophical inclination will change, as well as the questions, hypotheses and explanations formulated by the professionals. The different conceptual orientations will, of course, influence the way the professional approaches the theme of communication and respective disorders or difficulties.

Communicative interaction may take place in different contexts; This research project focuses on communication processes within interpersonal contexts, which may become atypical when one of the parties in the exchange communicates, mainly, through pre-verbal, unconventional and, at times, peculiar behaviors. Atypical communication processes are common when someone in the dyad has a disability or condition with a significant impact on neurodevelopment.

In this research, the Complex of Continuous Communication (CCC) is formulated and presented as a theoretical model to analyze and enhance the quality of atypical interpersonal communication processes, assuming the communicative exchange as a dialogical and co-creative phenomenon and emphasizing the way in which the communication relationship can evolve within the dyads. The model is based on an extensive narrative literature review, with the purpose of determining the model's components, clarifying the relationships between them, and explaining how the communicative dynamics may grow in terms of diversity and complexity. Underlying the proposed new model is the conscious influence of the transactional communication model and the dialogic perspective of the process, recognizing the need for experimentation and considering the future analysis by a panel of experts for validation.

## Gilles Droogmans

### **"Ça va?" Pathways towards more qualitative staff-client interactions in services for persons with severe to profound intellectual disabilities**

**Abstract:** The coronavirus pandemic has shown us that high quality interactions are less self-evident and more important to our well-being than we thought. This insight might be especially important for people with severe or profound intellectual disabilities. These persons depend on others (e.g. family, volunteers or professionals) for almost all aspects in their life and often rely on specialized professional care throughout their entire life span. The quality of the interactions of clients with their supporting professionals is thus crucial. However, the development of positive staff-client interactions appears to be challenging. The aim of this project is to increase knowledge about patterns, determinants and dynamics of staff-client interactions and to provide us the opportunity to design, implement, and evaluate pathways towards more positive staff-client interactions.

This presentation will first give a general overview of the theme, intentions and directions of the project, after which the first steps taken will be outlined in more detail.

**Magdalena Vaneva Hadzhieva**

**Study of the views of pedagogical specialists for the education of children with profound intellectual and multiple disabilities in Bulgaria and Belgium (Flanders)**

**Abstract:** This paper presents the results of a comparative study of the opinions of pedagogical specialists supporting children with profound intellectual and multiple disabilities in the system of educational institutions in Bulgaria and Belgium (Flanders) for essential aspects of the organization and realization of the process of the educational support for this group of students. The data from the research show not only the similarities and differences in the vision of the pedagogical specialists from the two educational systems but the results also highlight a number of challenges in the process of providing qualitative education for children and youngsters with profound intellectual and multiple disabilities in both countries.

**Workshop Presenter:**

**Professor Simo Vehmas**

Simo Vehmas is professor of special education at Stockholm University, Sweden, and a visiting professor at Lillehammer University College, Norway. His recent publications include *Narrowed Lives: Meaning, Moral Value, and Profound Intellectual Disability* (co-authored with Reetta Mietola) and *Routledge Handbook of Disability Studies, 2<sup>nd</sup> edition* (co-edited with Nick Watson).

See a collection of his papers - <https://www.su.se/english/profiles/svehm-1.333871>

## About the IASSIDD PIMD SIRG ECR Group:

IASSIDD is the International Association for the Scientific Study of Intellectual and Developmental Disabilities, the first and only world-wide group for the research on intellectual disability. IASSIDD has several Special Interest Research Groups, or SIRGs. The PIMD SIRG is for researchers interested in Profound Intellectual and Multiple Disabilities.

### From the IASSIDD PIMD SIRG site:

The SIRG-PIMD focuses on individuals with profound intellectual and multiple disabilities (PIMD / PMLD). They form a heterogeneous group. They are characterized by very severe cognitive, neuromotor and/or sensory disabilities, which lead to very intensive support needs.

The mission of the SIRG-PIMD is:

- To provide a worldwide network for the exchange of knowledge and insights on persons with PIMD from research and practice. The SIRG-PIMD brings together researchers and practitioners with different disciplines and from different countries.
- To promote cross-national, multidisciplinary collaboration in the area of persons with PIMD.
- To provide a framework for the dissemination of information relating to the research interests, expertise, and publications of group members.
- To foster innovation and quality improvement in the support of persons with PIMD. The ultimate aim of the group is to improve the quality of life and services for people with PIMD, their carers, and their families.

Within the overall process of collaboration, the views and contributions of non-professionals, including people with intellectual disabilities and their families and friends, are a fundamental component, and will be given the priority they deserve.

We are the Early Career Researchers of the PIMD SIRG. This includes graduate researchers doing Masters or PhD work, and recent graduates in early career positions in research, industry, or academia. We are from universities and institutions all around the world. Most of us are working on PhD or Postdoctoral projects about / involving people with profound intellectual and multiple disabilities. We also welcome junior researchers and scientific staff who are new to the research field of PIMD.

You can find out about our current members and their research [here](#). [Contact us](#) if you'd like to be listed on our site!