

ECR-MEETING SIRG-PIMD

22nd – 23rd September 2015

Västerås – Sweden

Program Tuesday, 22nd of September

Program Wednesday, 23rd of September

Abstracts presentations

Topics of the brainstorming sessions

Early Career Researchers - meeting 2015

Program Tuesday, 22nd September 2015

- 13.00 **Welcome** with coffee and tea
- 13.15 **Introduction round**
- 13.45 **Presentations and discussion**
- Gineke Hanzen
- Dinette van Timmeren
- 14.55 **Break**
- 15.15 **Introduction brainstorming sessions**
- 15.30 **Brainstorming sessions**
- Ines van Keer *Small research samples*
- Gertruud Schalen *Recruitment of participants in a longitudinal study*
- 17.00 **End**
- 18.30 **Social program – Dinner with the ECR's**
*Restaurant Å
Slotssgatan 6
722 11 Västerås*
-

Program Wednesday, 23rd September 2015

- 9.00 **Welcome** with coffee and tea
- 9.15 **Skype style presentation and discussion**
- Dreenagh Lyle
- 9.45 **Presentation and discussion**
- Katherine McKenzie
- 10.15 **Break**
- 10.30 **Brainstorming sessions**
- Laura Jones: *Analysing video data*
- Stephy Colla: *Longitudinal data analyses*
- 12.00 **Lunch**
- planning next ECRM
-

Abstract Presentations

Operationalization concept Participation of adults with visual and severe or profound intellectual disabilities: perspectives of parents, professionals, and experts.

Gineke Hanzen

The objective of our study is to define and operationalize the concept Participation of adults with visual and severe or profound intellectual disabilities. We asked parents/relatives, professionals, and experts of adults with visual and severe or profound intellectual disabilities for perspectives and statements about the concept Participation. Subsequently, we asked them to sort and rank these statements. Online concept mapping was used to obtain this information.

In my short presentation, I would like to tell something about the background and design of the study, what's done up to now, the upcoming plans, and if possible, the first results.

Physical health issues in persons with severe or profound intellectual and motor disabilities (SPIMD)

Dinette van Timmeren

Introduction: People with SPIMD encounter numerous physical health problems. There is a risk for these problems to go unrecognized, which can lead to discomfort and pain. There are several studies reporting the need for health screening for people within the ID population. Given the interrelatedness of the disabilities in people with SPIMD and the different prevalence of physical health problems compared to people with less severe ID, the need for an adjusted health screening for people with SPIMD, is evident.

Objective: 1) to determine the prevalence of physical health problems in adults with SPIMD; 2) to compare the results with data of our previous systematic review.

Method: We conducted a cross-sectional study, using data obtained from medical and support records. A sample of adults with SPIMD was recruited in eight settings of five residential care providers for people with ID. Prevalence rates and 95% confidence intervals were calculated.

Results: Medical and support records of 99 participants with SPIMD were included. A wide range of recorded physical health problems were found, with a mean of twelve problems per person. Very high prevalence rates (>50%) were found for constipation, visual impairment, epilepsy, spasticity, deformations, incontinence, and reflux. Compared with our previous systematic review a lower prevalence was found for anemia, thyroid dysfunction, parkinsonism, hypertension, osteoporosis and fractures and a higher prevalence was found for epilepsy, spasticity, visual impairment, constipation and reflux.

Discussion/Conclusion: A strength of the study is the use of medical and support records: therefore, we could provide an overview of a broad range of physical health problems. However, the reliance on reported physical health problems may cause an underestimation of the prevalence rate.

Given the interrelatedness of the complex disabilities in people with SPIMD, further research regarding adjustment of measurements of physical health problems for people with SPIMD is necessary.

After the presentation I would like to discuss the impact of these physical health problems and how to set priorities for screening.

Policy to Practice: A critical analysis of Valuing People policy *Dreenagh Lyle*

Happy to give a skype style presentation outlining my tool for including people with PIMD in consultation. This was a central feature of my research for my PhD thesis, 'Policy to Practice: A critical analysis of Valuing People policy'.

Link to PhD thesis: <http://eprints.mdx.ac.uk/15731/>

Frailty as a predictor of institutionalization among adults with intellectual and developmental disabilities.

Katherine Mc Kenzie

Background: Frailty typically develops earlier and more frequently in adults with intellectual and developmental disabilities (IDD) compared to the general population, and subsequently, this population is at risk for higher care needs. Despite a shift towards community-based care to meet increasing demands, the population of individuals with IDD is at risk for admission, or re-admission, into long-term facilities.

Methods: 3,034 individuals (aged 18 to 99 years) living in Ontario, Canada and assessed with the Resident Assessment Instrument – Home Care were followed during a four-year period. A frailty index, specific to persons with IDD, characterized individuals as frail, and the interRAI Changes in Health, End-stage disease, Signs and Symptoms (CHES) scale, identified individuals with health instability. Cox proportional hazard models determined differences in rates of admission to long-term care.

Results: Almost a quarter (22%) of the sample was admitted to long-term care. Controlling for age, sex, rural status, caregiver status, living situation, and cognition level, frail individuals had rates of admission two times greater than non-frail individuals (HR=2.19, 95% CI: 1.81-2.64). Using the CHES, adults who were unstable had a greater risk of institutionalization compared to those who were stable (HR=1.52, 95% CI: 1.29-1.79).

Conclusions: The frailty index specific to persons with IDD can predict institutionalization in adults of all ages and is a comparable measure of health vulnerabilities. Future areas of research include assessments of the feasibility of implementation of the frailty index as a routine indicator in health care settings.

Topics of the brainstorming sessions

Small research samples

Ines van Keer

Often, research on persons with PIMD is criticized because of small research samples, lack of statistical power. Maybe it would be interesting to discuss this well-known criticism and what we can learn from it. Especially finding the balance between accepting the 'inevitable' shortcomings of our studies and trying to accomplish a 'golden standard' research design.

Recruitment of participants in a longitudinal study

Gertruud Schalen

For the one of brainstorm sessions during the ECRM meeting, we would like to introduce the topic of recruitment of participants in a longitudinal study. We would like to discuss ways to recruit children with PIMD and their parents for longitudinal studies, hereby focussing on a young age group. We are eager to learn from you about ways of recruitment in different countries, ethical issues and the use of terminology.

Analysing video data

Laura Jones

I would like to ask for suggestions on how to analyse video data in order to measure access to the curriculum and inclusion.

Longitudinal data analyses

Stephy Colla

Early Career Researchers – meeting 2015

Kirsten van den Bosch

Institution: University of Groningen

Contact: k.a.van.den.bosch@rug.nl

Website: <http://www.rug.nl/staff/k.a.van.den.bosch/>

Research topic: Auditory environments of people with (profound) intellectual disabilities

This research addresses the lack of knowledge about the quality and effect of soundscapes for people with profound intellectual and multiple disabilities (PIMD). A soundscape is defined as an environment of sound, with an emphasis on how it is perceived by an individual or society (Schafer, 1977). We developed a theoretical framework based on the concepts core affect and audible safety. Our research has confirmed the hypothesis that soundscapes indeed affect the behavior and mood of people with PIMD. In addition, we developed an assessment procedure by which the quality of soundscapes can be assessed. We are currently developing a digital version of this procedure, in the form of a smartphone application called MoSART (Mobile Soundscape Appraisal & Recording Technology). The goal is to raise awareness about the importance of safe soundscapes and improve quality of life for people with PIMD.



Leontien Bossink

Institution: University of Groningen, the Netherlands

Contact: l.w.m.bossink@rug.nl

Website: <http://www.rug.nl/staff/l.w.m.bossink/>

Research topic: Motor activation in people with profound intellectual and multiple disabilities.



My research project focuses on the motor activation of people with profound intellectual and multiple disabilities (PIMD). Recently, we analysed the extent to which these people are motorically activated in daily practice. Based on this results, it can be concluded that motor activation is a minor part of the support provided to people with PIMD. Given the high degree of dependence of these people, direct support persons are to a great extent responsible for including motor activation in their daily routine. To reduce inactivity in the daily lives of people with PIMD, insight into facilitators and barriers to motor activation as perceived by direct support persons is needed. Therefore, we are developing an instrument for systematically identifying the facilitators and barriers to motor activate people with PIMD. Furthermore, although studies in people with PIMD reporting beneficial effects of motor interventions, they seem to be difficult to maintain by direct support persons. We need more knowledge with regard to the content of potential interventions and its effectiveness for more focused and structural implementation. Therefore, we will also analyse two interventions developed and implemented by daily practice.

Stephy Colla

Institution: KULeuven (Belgium)

Contact: stephy.colla@ppw.kuleuven.be

Personal website: <http://www.kuleuven.be/wieiswie/en/person/00086749>

Project website: www.ojko.be

Research topic: Communicative development in young children with a severe cognitive and motor developmental delay

In my doctoral research project, I will focus on the communicative development of young children (between 6 months and 4 years at the start of their participation) with a severe cognitive and motor developmental delay. This study is part of a broader research project on the development of these children. In this project information on various



developmental domains (cognitive, motor, communicative and social-emotional domain) and influencing child and context factors is collected by six monthly administrations.

The aim of my project is to gain insight in the early communicative development of very young children with PIMD. This will deliver us a framework which can form a basis for further research and the development of interventions that aim at stimulating communicative abilities.

Juliane Dind

Institution: Université de Fribourg, Département de Pédagogie Spécialisée

Contact: juliane.dind@unifr.ch

Website: <http://www.unifr.ch/spedu/index.php?page=fr>

Research topic: Identifying the expressions of ecological self-awareness in children with PIMD

The aim of this exploratory study is to verify and to validate empirically with children with PIMD two theoretical models about ESA. **Method:** A situation-based list with 60 items about manifestations of ESA has been created. This list of eliciting and natural situations is inspired by those used in developmental psychology studies. The developmentalists have highlighted indicators of ecological self, which arises from the infants' embodied experience and their interaction with the environment. The ecological S-A results from the perception and is the first step toward the development of the conceptual S-A, which results from the cognition. 20 children with PIMD (aged from 4 to 12 years) will be observed in each situation of the list. Each observation session will be videotaped and coded on the basis of minimal/maximal performance definition. **Results:** the data analysis will allow to hypothesize heterogeneous profiles of S-A in children with PIMD and to describe some indicators of ecological S-A.

Rano Zakirova Engstrand

Institution: Stockholm University, Department of Special Education

Website: <http://www.specped.su.se/english/>

Contact: rano.engstrand@specped.su.se

Research topic: Impact of environmental factors on development of children with autism spectrum disorders in Sweden: Learning environments, teacher knowledge, and the role of culture.

Sanne Everaarts

Institution: University of Groningen, the Netherlands

Contact: s.everaarts@rug.nl

Research topic: Together to school classes

Introduction: The attention paid to the inclusion of children with Profound Intellectual and Multiple Disabilities (PIMD) in regular school settings has increased over the last few years. An example of this is 'Samen Naar School Klas' (SNSK), a Dutch project in which children with PIMD who were supported by professionals of a day care center are integrated into a regular school. Although practitioners are positive about the project, it is unclear what factors contribute to the success of such projects.

Objective: The aim of this study is to promote the inclusion of children with PIMD in the Netherlands, by determining which factors contribute to the success of this project, what motives parents of children with PIMD have to choose for such projects and what the effects of the project are.

The aim of this presentation is to inform the members of the SIRG-PIMD about the study, so you can bring up any new ideas to improve the study.

Method: To identify the factors that contribute to the success of the project, and to identify what motives parents have to choose for such projects, interviews will be used. To find out to what extent parents of children with PIMD are satisfied about SNSK, surveys will be used. The effects of the project on the development of children with PIMD will be determined by assessing the extent of alertness, sleeping problems, challenging behaviour, social interaction of the child with the environment and adaptive functioning of the child. To assess the effects regarding

the attitude of teachers, pupils without disabilities and their parents towards children with PIMD, surveys will be used.

Results: The study has not been started, so there are no results yet.

Discussion/Conclusion: We invite you to bring up new ideas to improve this study.

Gineke Hanzen

Institution: Royal Visio de Brink (Vries)

Contact: ginekehanzen@visio.org

Research topic: I'm a physical therapist and researcher at Royal Visio de Brink. The objective of my study is to improve participation of adults with visual and severe or profound intellectual disabilities.

The first step is to define and operationalize the concept Participation of these adults. Method: we asked parents/relatives, professionals, and experts of adults with visual and severe or profound intellectual disabilities for perspectives and statements about the concept Participation. Subsequently, we asked them to sort and rank these statements. Online concept mapping was used to obtain this information.

Results of this study can be used to develop a method to improve participation of these adults.

Laura Jones

Institution: Bangor University, North Wales

Contact: edp2d2@bangor.ac.uk

Research Topic: Language of Instruction, Access to the Curriculum and Inclusion.

The research aims to study how the language of instruction influences access to the curriculum and inclusion, when learning through a second language, for children from Welsh and English home backgrounds who have Special Educational Needs (SEN). The research will adopt a multiple case study design, which will include 3-5 primary schools within Wales. It will provide functional recommendations to support pupils with SEN in bilingual settings by identifying

strategies used to support curriculum access and how they fit within evidence based good practice along with providing information to support parents' choices about their child's education.

Ines van Keer

Institution: KULeuven (Belgium)

Contact: ines.vankeer@ppw.kuleuven.be

Personal website: <http://www.kuleuven.be/wieiswie/nl/person/00099810>

Project website: www.ojko.be

Research topic: The influence of family resources and family patterns of interaction on the development of children with a severe cognitive and motor delay.

In my doctoral research project, I will focus on the influence of contextual factors, more specific family influences, on the development of young children (between 6 months and 4 years at the start of their participation) with a severe cognitive and motor developmental delay. This study is part of a broader research project on the development of these children. In this project information on various developmental domains (cognitive, motor, communicative and social-emotional domain) and influencing child and context factors is collected by six monthly administrations. The study's results will permit us to characterize the patterns of interaction and resources within families with young children with severe cognitive and motor developmental delay and to evaluate the relationships between family patterns of interaction, family resources and child developmental outcomes both cross-sectionally as longitudinally. With regard to optimally stimulating the development of these children, our study aims to inform future research as well as practical guidelines.

Katherine McKenzie

Institution: Queen's University (Canada)

Website: www.hcardd.ca

Contact: k.mckenzie@queensu.ca

Research topic: Frailty and aging with intellectual and developmental disabilities (IDD), home care and long-term care
In my Master's thesis, I analyzed the use of an IDD-specific frailty measure in a population of adults with intellectual and developmental disabilities accessing home care services in the Ontario, Canada's most populous province. This thesis is part of a larger research project investigating the aging process and use of aging-related health care services in this population.

Heleen Neerinckx

Institution: KULeuven (Belgium)

Contact: heleen.neerinckx@ppw.kuleuven.be

Sara Nijs

Institution: KULeuven (Belgium)

Contact: sara.nijs@ppw.kuleuven.be

Website: <http://www.kuleuven.be/wieiswie/en/person/u0076423>

Research topic: Peer interactions of persons with PIMD
Peer interactions positively influence various quality of life and developmental outcomes. Interactions between two persons with PIMD with and without the presence of the direct support worker are investigated. An intervention for the direct support worker is designed to increase the interactions among persons with PIMD. Also the interactions between persons with PIMD and siblings is investigated.

Anna Rensfeldt Flink

Institution: University of Gothenburg

Contact: anna.rensfeldt.flink@vgregion.se

Research topic: Communicative support for children with profound intellectual and multiple disabilities. The aim of the study is to evaluate the effect of a parental communication training programme (the ComeAlong course).

The ComeAlong Course is a well established communication intervention in the Scandinavian countries. It is a parental education programme that addresses communication, communication development, play, responsive communication strategies and AAC (augmentative and alternative communication). It is offered to families with children with a wide range of disabilities, including children with multiple disabilities. The evaluations of the effect of the ComeAlong Course up to this point have included very few children with multiple disabilities and we don't know how this intervention works for this group specifically. My aim is to evaluate the effect of the ComeAlong Course specifically on the PMID group regarding the children's communication development and the parents' communicative style (parental responsiveness and use of AAC).

Gertruud Schalen

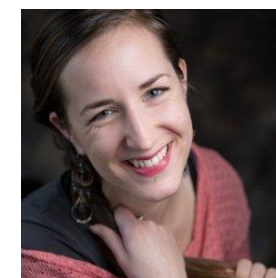
Institution: University of Groningen (The Netherlands)

Contact: g.h.schalen@rug.nl

Personal

website: <http://www.rug.nl/staff/g.h.schalen/>

Project website: www.ojko.be



Research topic: Longitudinal study into the motor development of young children with high risk of persistent and profound intellectual and multiple disabilities.

This longitudinal project is aimed at analyzing the motor development of young children (0;6 – 7;6 years) with profound intellectual and multiple disabilities (PIMD). This study is part of a broader research project (OJKO) in collaboration with KU Leuven. Stimulation of the motor system is important for the reduction of motor delays (Guralnick & Conlon, 2007; Shonkoff & Phillips, 2000; Van der Putten, 2010) and might lead to improved opportunities for exploring the environment. For the child, enhanced opportunities to explore can be beneficial to the development in other areas (Ulrich, Ulrich, Collier, & Cole, 1995). The purpose of this research is to expand knowledge about the motor development of children with PIMD, possible patterns and potential critical periods therein, and the influence of factors such as aetiology and comorbidity. This knowledge can help to better inform parents and healthcare providers about the development and on how to support children with PIMD.

Lena Talman



Institution: Mälardalen University (Sweden)

Contact: lena.talman@mdh.se

Research topic: Participation in everyday life for persons with profound disabilities.

Adults with profound disabilities are in need of society's support. Such support should facilitate the disability policy vision of "a good life", which

means full participation in society and equality in living conditions as well as conditions for independence and self-determination. The aim is to highlight and problematize conceptions of participation and how participation manifests itself in everyday life and in implementation plans for people with profound disabilities living in group homes or in private homes with personal assistance.

Dinette van Timmeren

Institution: Hanze University of Applied Sciences. Research group Healthy Ageing Allied Health Care and Nursing

Contact: e.a.van.timmeren@pl.hanze.nl

Research topic: Physical health issues in persons with severe or profound intellectual and motor disabilities (SPIMD).

People with SPIMD encounter numerous physical health problems. There is a risk for these problems to go unrecognized, which can lead to discomfort and pain. There are several studies reporting the need for health screening for people within the ID population. Given the interrelatedness of the disabilities in people with SPIMD and the different prevalence of physical health problems compared to people with less severe ID, the need for an adjusted health screening for people with SPIMD, is evident. The aim of this research is developing a screening instrument for physical health problems in people with SPIMD.

