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**International Association
for the Scientific Study
of Intellectual Disabilities**

Special Interest Research Group Profound Intellectual and Multiple Disabilities

Newsletter - January 2019

The purpose of a SIRG is to provide opportunities for international and multidisciplinary networking between researchers and members of IASSIDD within the same area of interest. In this way, they may create opportunities for sharing information, developing initiatives, identifying new colleagues and being visible to newcomers in the field. Through the SIRGs, groups of researchers in the field may easily collaborate on common themes of interest.

Introducing the Board

- Bea Maes, Belgium, *Chair*
- Juliet Goldbart, UK, *Treasurer / secretary and IASSIDD council representative*
- Annette van der Putten, The Netherlands, *Member*
- Nan-Chieh Chen, Taiwan, *Member*
- Krysti De Zonia, US, *Member*
- Gare Fablila, Mexico, *Member*

New projects

PIMD children and adolescents: neuropsycholinguistic approach and care perspectives

PhD student, Sam Aristide Niamké, enrolled in language Science with specialization in psycholinguistic, at the University Felix Houphouet Boigny (Abidjan-Ivory Coast), our work revolving around the issue of communication in complex disabilities situations. Our sample is composed with children and adolescents with PIMD. In the stigma context of the disability people, we decided to conduct a scientific study to order to understand and analyzes thanks to the neuropsycholinguistics perspective the communication mechanism of people with high cognitive impairment. For this

News from the SIRG

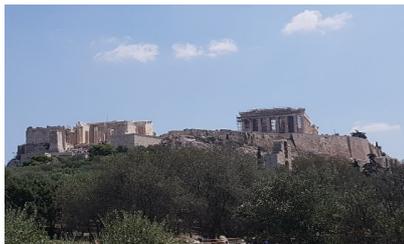
Last year IASSIDD created a Facebook and Twitter account. These platforms are used to inform members on a regular

basis. We from the SIRG PIMD get the opportunity to post new projects, news, research output,... starting from the 14th of January till the 20th of January. Jorien Luijkx will coordinate our social-media-week. If you have something you want to share please do not hesitate to contact her: j.luijkx@rug.nl And don't forget to follow IASSIDD on Facebook and Twitter!

Past events

8th Early Career Researchers Meeting SIRG PIMD

July 17, 2018 | Athens



Before the start of the 5th IASSIDD Europe Congress in Athens, the SIRG PIMD early career researchers and senior researchers gathered during the ECR meeting. We started the day in the conference hotel and walked together to the venue of the ECRM: the Athens Conservatoire. There, we had an introduction round and we divided the participants in two groups: the seniors prepared an observation workshop with tips & tricks for the afternoon and the early career researchers had time to get to know each other and each other's research projects using posters. They all drew a picture representing their research project to talk about their research in an informal way.

population this is a first approach, for the time being all study focused on language and learning impairment. The motivations related to our study unveil that people with PIMD are little-know and do not have access to any specific cognitive care. Very often, after medical care, paramedical care is limited to motor rehabilitation. Knowing that despite their intellectual disability, people with PIMD are able to develop an atypical and multimodal mode of communication. So we decided to do scientific research to characterize, appreciate and analysis this communication, in general difficult to identify. On the other hand, if they are able to interact this supposes the preservation of certain cognitive abilities. So our study firstly target the exploration of those specific cognitive abilities and secondly the developement of PIMD evaluation strategies, but also perspectives of cognitive care. The study is underway and we have already a sample on we have realized observations. For more information, we remain fully available. Our email

address: samaristide1987@gmail.com.

This thesis project has started since 2015 and is still ongoing. I am therefore in my third year of thesis. My work takes place in Ivory Coast, precisely at the University Felix Houphouet Boigny of Cocody - Abidjan. Through this research, I want to show the cognitive abilities of children with multiple disabilities. In our context, it is a handicap still unknown. Because of their complex handicap, here people with multiple disabilities do not benefit from management of cognitive functions. With my work, I want to study and present the communicative abilities of these people, then consider rehabilitation prospects.



The early career researchers explaining their research projects.

Next, we had an inspiring and interesting workshop about publication, by Prof. dr. Juliet Goldbart: "What's the story, Morning Glory?" Getting qualitative research in learning/communication disability published. This workshop contained tips and tricks to keep in mind when submitting research for publication.



The observation workshop of Prof. dr. Juliet Goldbart.

In the afternoon, we focused on the topic 'observation', and discussed questions such as: "How to achieve a high inter-rater reliability, given the idiosyncratic and subtle behaviors of persons with PIMD?", "What are standards for evaluating inter-rater reliability?", "How to discern intentional behavior from non-intentional behavior?". Good practices and ideas concerning these issues were shared with each other and examples of observation research to illustrate this were discussed.

In addition, some early career research got the chance to present about their research and to raise questions they were still struggling with or to introduce studies they needed input on. We ended the ECRM with a workshop about

Upcoming events

Polyhandicap et processus d'apprentissage" (PIMD and learning process)

March 2019 | Paris, France

Nowadays, there is a consensus on the need to integrate the learning dimension into the individualized projects of children or teenagers identified with "polyhandicap" (in French) or "profound intellectual and multiple disabilities" (PIMD). Access to learning for people with PIMD is only now starting to be discussed. This puts emphasis on cognition, pedagogy and learning places, including school. What do we mean by learning for young people with PIMD? What are the characteristics of a student with PIMD? What socio-emotional and sociocognitive processes are mobilized? How could we support their learning?"

The conference will take place in Nanterre University (close to Paris) in March 2019. It will bring together researchers, but also professional and families in order to meet three objectives: developing scientific knowledge, supporting innovative methodology and approaches, and promoting the dissemination of knowledge and practices on society. Call for papers will be open in September on the website of INSHEA (<http://www.inshea.fr/>), and communications may be in French or English.

IASSIDD World Congress

August, 2019 | Glasgow

The next World Congress will take place in Glasgow, Scotland in August, 2019.

<http://www.iassidd2019.com/>

For the upcoming World Congress of the IASSIDD in Glasgow, we start preparing several SIRG PIMD symposia as well as

participation of parents in research, including a video in which two parents talked about their motives and reasons to participate or not to participate in research. This gave us food for thought and inspired us to pay considerate attention to parent participation in future research.

To conclude the ECRM, there was a social dinner on the 18th of July to get to know each other in an informal way.



Social dinner of the Early Career Researcher.

We had an inspiring meeting. We were pleased to see many familiar faces and to welcome some new researchers. For more information about the SIRG-PIMD and ECRM, including newsletters, we refer to the following websites: <https://www.iassidd.org/content/profound-multiple-disabilities> and <https://ecrmpimd.weebly.com/>. See you on the next ECRM meeting?

New projects

Profound multiple connections

About me: I'm a psychomotor therapist specialize one PIMD. Since September 2018, I'm doing a Master degree in public Health in the Catholic University of Louvain (UCLouvain). I developed in 2017 the project named Profound and Multiple connection.

Project objectives: The main objective of

symposia across the PIMD track and for example the SIRGs of ethics, mental health, Health, Families etc.

Can you please inform us about:

- Are you planning to submit an abstract, or did you already submitted one? If so, can you please give us the title so we can cluster the submissions into different symposia?
- Would you like to be part of a (specific) symposium on the PIMD track or one across one of the others mentioned?
- Are you willing to be a moderator of one of the SIRG-PIMD symposia?

Please note the following:

- Early career researchers can apply for the Carla Vlaskamp Award scholarship. Please encourage people within your networks to apply. Applicants must be members of the SIRG- PIMD. See: <https://www.iassidd.org/uploads/article/about/gene...>
- At August the 5th, there will be an early career research meeting (ECRM).
- There will be also a SIRG- PIMD round table meeting during the conference. We will keep you updated about the exact date, time and location.
- Please let us know if you have a suggestion for a specific discussion/ topic for this round table meeting. Special formats (e.g. a film) are especially welcome.
- Please select the SIRG- PIMD when you renew your IASSIDD membership

Please contact:

Annette van der Putten

this project is to spotlight the life of people concerned with PIMD at a worldwide scale by providing specific data and information on their daily life and their condition of life thanks to a website. The Project have two specific objectives:

(1) bring together data, information about PIMD one several countries and share it thanks to a data map available in several language. To realize this objective we work on a database by collecting specific data on PIMD on several region of the world. We are collecting data and information about:

- Specific PIMD term use in different country
- Specific data on PIMD (Number of case reported)
- Information about disabilities rights.
- Useful like (Local association)
- Local correspondent contact

For the time being we are collecting information and data in 5 countries (Belgium, Switzerland, Madagascar, France, Ivory-Coast). We have the ambition to collect valid and reliable data in 20 countries before publishing the map. We hope to publish a fist version of the map in the end of 2019.

(2) Promote the life of people concerned with PIMD thanks to photography project and a documentary video. For this objectif we aim to bring together photographer and filmmaker of different regions of the world to realize portraits of personnes with PIMD, and thus expose their daily life. Through this project we want to give the opportunity to anyone to discover the daily-life reality of person concerned with PIMD thanks to a series of photography and short video bring-together on a website. We would like to start this photography project in 2019.

Website of the project

:<https://www.profound-multiple->

a.a.j.van.der.putten@rug.nl

AND

Jorien Luijkx j.luijkx@rug.nl

Early Career Research Meeting SIRG PIMD in Glasgow

August, 2019 | Glasgow

We are pleased to announce that we will organize the ECRM PIMD on Monday the 5th of August in Glasgow (before the IASSIDD World Congress). Information on the location and the program will follow later on. We hope to see you all in Glasgow this summer!

Sien, Marleen & Jacqueline

Symposium of international exchange of the researches on PIMD

September, 2019 | Japan

Dr. Suemitsu and Sui Sone are organizing a symposium of international exchange of the researches on PIMD on september 20th to the 21st. We hope especially early carrier researchers to visit Japan. If you want to participate to this program, or if you want more information, just mail me. If you are concerned about visiting Japan (including economical one), please do not hesitate to ask me. We heartedly welcome you. Sui Sone (e-mail: med.sui-sone@hmc-smid.jp)

Announcement

Han Nakken Price 2018

The Han Nakken Price 2018 is awarded to Dr. Sara Nijs (KU Leuven, University of Tilburg) for her article 'Promoting Social Scaffolding Behaviors in Staff Members and Peer-Directed Behaviors Among Persons With Profound Intellectual and Multiple Disabilities: An Intervention Study' published in the Journal of Policy and

connections.org/

E-mail : pierrick.ferjani@ntymail.com

Health supporting environment for people with moderate to profound ID

Hanze university of applied sciences Groningen, Research group Healthy Ageing, Allied Health Care and Nursing and Radboud university medical center Nijmegen, Department of Primary and Community Care, The Netherlands. In collaboration with the Department of General Practice, Intellectual Disability Medicine, University Medical Center Rotterdam, and the Department of Special Needs Education and Youth Care, University of Groningen, The Netherlands.

DESCRIPTION: Health promotion research among people with moderate to profound intellectual disabilities (ID) has limited attention for environmental support for healthy living. To achieve long-term healthy behavior, sustainable ways of health promotion are needed. Creating supportive settings for healthy living can sustainably stimulate healthy behavior, proven in studies among the general population. Application of this approach, such as training support persons to use behavior change techniques (BCT's) and making health supportive changes in the physical environment, is limited in research and practice on health promotion for people with ID.

CONTRIBUTION: This research contains two projects which are closely connected. In the first project 28 direct support professionals expressed their support needs in order to help people with ID to achieve a healthier lifestyle. In addition, direct support professionals were observed to identify BCTs they use in daily support of people with ID. In the second project 41 researchers specialized in either 'healthcare for people with ID' or

Practice in Intellectual disabilities.



Sara Nijs en Annette van der Putten

Book announcement: "Belonging for Individuals with Profound and Multiple Learning Difficulties: Pushing the Boundaries of Inclusion"

In February/March 2020 a new book edited by Melanie Nind and Iva Strnadová will be published (Routledge). Book summary: People with profound and multiple learning difficulties (PMLD) are among the most marginalised and vulnerable populations. With a minority status, even within a population of people with disabilities, they remain on the margins of interest of policy makers, practitioners, service providers and researchers. They are often yet to realise their right to be included in communities, and more importantly, to belong. This book aims to push boundaries in the way we approach people with profound and multiple learning difficulties, and in how we work with them in education and research. While it is grounded in diverse theoretical frameworks from disciplines, the book coheres around a commitment to seeing people with PMLD as equal citizens who belong in our classrooms, research projects and community lives and shows this in action.

Next newsletter

'healthy settings' participated in a concept mapping study about healthy settings for people with ID. They identified 13 clusters encompassing the social environment, the physical environment, and societal preconditions. In an additional study people with moderate ID and proxy respondents of people with severe/profound ID identified and prioritized support needs from their living environment.

The knowledge from both projects will be used in the development of (1) an intervention for direct support professionals with the following determinants: Environmental Context and Resources, Social/Professional Role and Identity, Social influences, Skills and Knowledge, and (2) an environmental assessment tool which can be used to identify health supporting factors and factors for improvements in locations where people with ID live, work and engage.

In 2019 the intervention and environmental assessment tool will be implemented and evaluated. This research project contributes to the improvement of supportive environments for people with ID in which making healthy choices are easy. For more information or questions, contact person project 1: a.overwijk@pl.hanze.nl, and contact person project 2: Kristel.vananrooij@radboudumc.nl.

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 June of 2019.

To compose an interesting newsletter we need your input. Please send us (sara.nijs@kuleuven.be) before the 1th of May your information on:

- Past events
- Upcoming events
- Finished doctoral theses
- New projects
- Interesting books, articles,... with regard to the group of persons with PIMD (published after December 2018)
- Miscellaneous

Kind regards,
Sara Nijs and Leentje van Alphen

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

Hanzen, G., Waninge, A., Vlaskamp, C., van Nispen, R. M., & van der Putten, A. A. (2018). Participation of adults with visual and severe or profound intellectual disabilities: Analysis of individual support plans. *Research in developmental disabilities*, 83, 132-141.

Malbrán, M.D.C (2017). Tito's privacy and rights. A personal story from Argentina about setting

boundaries. *Everybody matters. Dutch Coalition on Disability and Development (DCDD)*, 54, 55 - 57 <https://indd.adobe.com/view/a81cb023-742c-4de2-8f44-650d1d16dcf2>

Kadastik, J. & Artla, T. (2018). Creating Together! The Creation of Learning Tools for Students with Severe and Profound Intellectual and/or Multiple Disabilities. *International scientific conference "Rural Environment. Education. Personality" at Latvia University of Agriculture*, 269-280. <https://doi.org/DOI:10.22616/REEP.2018.033>

Kadastik, J., Artla, T. & Schrepp, M. (2018). Your Experience is Important! The User Experience Questionnaire (UEQ) - Estonian Version. *International scientific conference "Rural Environment. Education. Personality" at the Latvia University of Agriculture*, 281-287. <https://doi.org/DOI:10.22616/REEP.2018.034>

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