

SIRG-PIMD Newsletter

Newsletter of the IASSID Special Interest Research Group on Persons with Profound Intellectual and Multiple Disabilities
 July 2009 Volume 1, Issue 1

The purpose of a SIRG is to provide opportunities for international and multidisciplinary networking between researchers and members of IASSID 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.

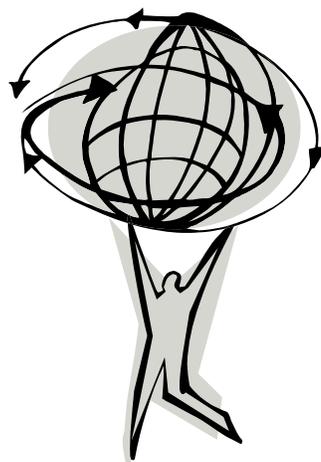
Membership

In May we have received an overview of the paying IASSID-members that are registered as a member of our SIRG-PIMD. This number totals up to 56 members. We were very surprised and pleased by that number. The SIRG-PIMD includes 11% of all IASSID-members that join one or more SIRGs. But this number could be larger, since at this moment 148 persons (!!)

are listed on our SIRG-mailing list. First of all, we want to thank all those who join the SIRGPIMD. You may be aware of the new policy of IASSID. In summary, this is, IASSID-members are free to choose any SIRG they want to join, without paying an extra fee. Each SIRG now receives an initial set amount of funding which is then topped up according to the number of members registered for each SIRG. This is very important for us, because it gives us the possibility to organize roundtables, young researchers meetings, newsletters etc. If you

are not yet an official IASSID-member, you may still start or renew your membership fee (see www.iassid.org). Please speak to your colleagues and contacts and encourage them to join our SIRG. They will find information about our mission, our activities and the members of the SIRG on www.sirgpmid.be. Members are key to the continued success and development of our activities. If people are interested, please ask them to send a mail to the SIRG-PIMD-secretary

(erik.lenaerts@ped.kuleuven.be)



News of Members:

Jean Ware (previously Director of Special Education, St Patrick's College Dublin) is now Reader in Education (Special Education Needs) at Bangor University, Wales. Her new email address is j.ware@bangor.ac.uk

PhDs:

Many congratulations to members or students of members who have been awarded doctorates in the past year:

Jenny Wilder (Malardalen and Stockholm Universities, Sweden) Proximal processes of children with profound multiple disabilities

Jill Bradshaw (Manchester Metropolitan University, UK) Staff Attributions of Challenging Behaviour and Perceptions of Communication in Adults with Learning Disabilities.



In this issue:

Memberships	1	Recent Conference Report	2	Resources	3
Membership Renewal	1	Upcoming Conferences	2	Articles	3
News of Members & PhDs	1	Collaborations Wanted	3		
2009 PhD Studentships	2	Research at KU Leuven	3		



International Association
for the Scientific Study
of Intellectual Disabilities

We're on the Web!
www.sirgpimd.be

2009 PhD

Studentships

To celebrate it's 125th Anniversary, Bangor offered PhD Studentships in 2009. Two of these studentships were awarded, and one candidate was funded who worked in the area of PIMD and bilingual education. There will be an additional college-funded studentship some time this year or next year for student education needs (preferably Profound Intellectual and Multiple disability). For more information visit www.bangor.ac.uk/scholarships



**Visit the website
for more upcoming
conference dates**

The editors of this newsletter, Krysti DeZonia and Juliet Goldbart, would welcome any feedback on this new style of newsletter and content for the next edition. Please email krystid@teriinc.org or J.Goldbart@mmu.ac.uk. Many thanks to Brooke Trayer for excellent work on its presentation.

Recent Conference Report

On June 11, 2009 PAMIS held a conference at the University of Dundee in Scotland to discuss the development of planned expert consensus guidelines on invasive procedures. A wide range of invasive medical procedures are required for persons with profound and multiple learning disabilities. Execution of these procedures by social care staff remains a contested area, with some staff refusing or not being allowed to carry out one or more procedures, leading to people with profound intellectual and multiple disabilities being denied service. Speakers addressed the changing needs of people with profound and multiple learning disabilities and the ethical issues underpinning invasive procedures. Family experiences and the training needs of parents and care staff were also discussed. Workshops were also conducted in order to develop a consensus on good practice in the area.



Conferences

September 8-10, 2009—Health Issue SIRG's Roundtable—Kingston, Canada

This Roundtable will foster collaboration in the conduct of research and knowledge translation/mobilization around the world. The premise of the roundtable is that we have much to learn from each other through collaborative and comparative endeavors. Five workshops will be conducted which include *Epilepsy, *Obesity, nutrition, and lifestyle, *Sensory impairments, *Health promotion, and *Healthcare delivery with the goal of generating international collaboration and opportunities to apply knowledge. To register visit <http://www.iassid.org/pdf/health.pdf>

September 23-25, 2009—Aging SIRG's Roundtable—Edinburgh, Scotland

September 23-25, 2009—PMID SIRG's Roundtable—Cologne, Germany

This meeting is an ideal opportunity to network. The themes are: Behavioral problems and interventions for persons with PIMD, Learning of and education for persons with PIMD, and Social participation of persons with PIMD. For details of how to attend, contact Brigitte.paffenholz@UNI-KOELN.DE

September 25, 2009—Colloquium for Young Researchers —Cologne, Germany

In Maastricht, for the first time, a separate meeting for young researchers was organized resulting in a very positive experience for all participants. Therefore, we are pleased to announce the Round Table in September will again be coupled to a Colloquium for young

Researchers at the University of Cologne. The aim of this colloquium is to meet fellow young researchers, to get an overview of current research on persons with PIMD, and to help others in the research process. For more information or to subscribe to this meeting, please email Ine.Hostyn@ped.kuleuven.be

September 30-October 2, 2009—International Seminar on Greening Education—Karlsruhe, Germany

This event will take education and environmental policy makers, head of education institutions, school managers, teachers and representatives of government organizations and international agencies through the need for greening education and then discuss effective initiatives that governments, education institutions, and developmental organizations need to take and can take to provide sustainable knowledge, skills, values and practices in the classrooms and the communities. For further information, please visit <http://www.etechgermany.com/GreeningEducationEvent.pdf>

October 20-22, 2010—IASSID-Europe Regional Congress—Rome, Italy

Call for papers will be available on November 1, 2009



Collaborations Wanted

As part of the newly agreed work plan between IASSID and the World Health Organization we have been commissioned to undertake three rapid systematic reviews as background to their mhGAP program. This is a six year program to scale up the delivery of mental health service, especially in low and low-middle income countries. One of the eight priority areas is "mental disorders" in children. One of the two evidence-based interventions in this area is the prevention of developmental disorders. The three reviews will address 1) the effectiveness of community-based rehabilitation (CBR) for children with intellectual disabilities in low/middle income countries (lead: Eric Emerson, UK), 2) the approaches available to enable primary health care workers in low/middle income countries to identify children with intellectual disabilities and manage support for them (and their families) (lead: Chris Hatton, UK), 3) the effectiveness of parent education programs in low/middle income countries (for parents of children with or at risk of intellectual disabilities) (lead: Stewart Einfeld, Australia). We will be undertaking literature searches using the traditional databases. We are only too aware, however, of the fallibility of such approaches (especially in identifying relevant reports and papers in well indexed journals). **So if you are aware of or have undertaken relevant research in low or low-middle income countries, please let us know!!** If possible send PDF copies of papers/reports or web links to eric.emerson@lancaster.ac.uk

Resources:

*Thanks to Nancy Schumacher for her recommendation about Talkaboutit website in Epilepsy: <http://www.talkaboutit.org>

Narrated by stars from the popular TV show Heroes, this is a really well produced source of information and support. It would be particularly useful for siblings and school friends of young people with epilepsy.

*A listserv for PhD students studying in the Learning Difficulties/Learning Disabilities/Intellectual Disabilities field has been established. It is aimed at PhD students within social science or arts (non clinical) disciplines.

If you are a PhD student and are interested in joining please email neil.morris@radishonline.net



Current Research Projects

PALLIATIVE CARE FOR PEOPLE WITH PIMD

Researcher: Jakob De Maeyer

Supervisor: Prof. Dr. Bea Maes

In this exploratory research we gather the experiences of different health carers and families of recently deceased persons with PIMD (between 2005 and 2008) who required palliative care prior to their deaths. We selected 15 cases of persons with PIMD, aged between 4 months and 62 years, all living in different residential or day care institutions in Flanders. In each case we interviewed their parents or a family member, the doctor, the psychologist and an educator of the institution where the person lived or spent most of his days. Using NVIVO we aim to analyze different key aspects in organizing qualitative palliative care for persons with PIMD, to be able to guide health carers and families through this intense period of care.

Contact: jakob.demaeyer@ped.kuleuven.be

THE INTERACTION BETWEEN PEOPLE WITH PIMD AND THEIR CAREGIVERS

Researcher: Kristien Hermans

Supervisor: Prof. Dr. Katja Petry

We make video-observations of 1-1 interactions in four conditions (without an object, with two preferred objects, with two non-preferred objects and with new objects) and all of these conditions are once with caregiver A and once with caregiver B.

During the interactions, we look at the way how the caregiver interacts. Also, we look at the effect on the happiness and the engagement of the client. We will compare the interaction between the two caregivers and between the four conditions. So, we want to know what influences the interaction and how we can improve these interactions.

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EVALUATING THE QUALITY OF INTERACTIONS BETWEEN PERSONS WITH PIMD AND THEIR DIRECT SUPPORT STAFF

Phd Researcher: Ine Hostyn

Supervisor: Prof. Dr. Bea Maes

The aim of this doctoral research project is, on the one hand, to provide an overview of the key components in the interaction with persons with PIMD and, on the other hand, to find observational methods to examine and measure these components. Our final goal is to develop an observation protocol that can be used to evaluate the quality of interactions between persons with PIMD and their partners.

Contact: ine.hostyn@ped.kuleuven.be

SNOEZELLEN AND ALERTNESS IN INDIVIDUALS WITH PIMD

Phd Researcher: Vera Munde

Supervisor: Prof. Dr. Carla Vlaskamp

Snoezelen (or multisensory stimulation) is one of the most frequently used treatment activities for individuals with PIMD. However, empirical studies investigating the activating effect of Snoezelen revealed conflicting results. The present study aims to clarify the relationship between Snoezelen en alertness in individuals with PIMD. Thereby, the central research question is: How can Snoezelen contribute to increase or maintain alertness levels in individuals with PIMD?

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MEASURING POSITIVE AND NEGATIVE EMOTIONS OF PERSONS WITH PIMD.

Phd Researcher: Pieter Vos

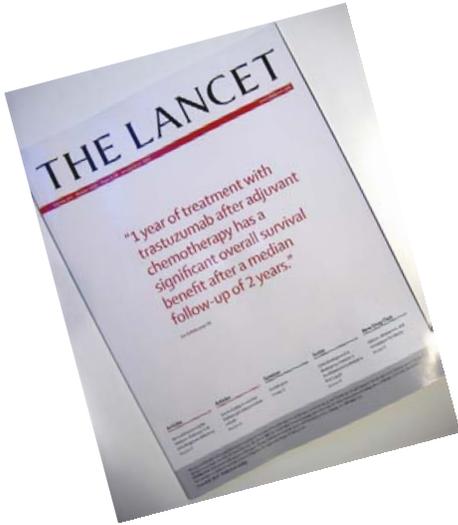
Supervisor: Prof. Dr. Bea Maes

The focus of this research is on finding physiological variables (such as breathing, skin conductance, heart rate,...) which can tell if a person with PIMD is experiencing negative or positive emotions. If we find such variables, these could be used to assess the level of subjective well-being of people with PIMD.

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ARTICLES

Bringing disability off the sidelines: a call for papers



Ask anyone what seam runs through the many layers of health care, affecting how we think about everything from disaster relief and national programmes for disease prevention to primary-care provision and clinical teaching, and they might say gender, or poverty, or perhaps ethnicity. They would be unlikely to say disability.

Why not? Although there is no agreement on definitions and little internationally comparable data on disability, commonly used estimates suggest that 10% of the world's population has some form of disability,¹ and that figure does not include the families of those affected. Part of the problem may be that disability is complex and multifactorial, and, certainly, stigma and lack of understanding have placed millions of people who live with a disability at distinct disadvantage. The fact that disability has not been addressed by, or included in, the Millennium Development Goals reinforces the impression that disability has little relevance to development efforts. Responses are further hampered by the lack of evidence about the scale of the problem, and about what works to improve participation

for people with disabilities.

We seek to kick-start a change by encouraging health academics to take on a strong agenda for research in disability. Lack of information and evidence is a serious barrier to developing effective policy and practice options. We need aggregation and dissemination of high quality research, but also need to identify clear directions for future research. We hope to contribute to the disability revolution by encouraging health scientists to generate a strong knowledge base in disability. We therefore invite original contributions to a special issue later in the year that focuses on people with disabilities.

But what do we mean by disability? The International Classification of Functioning, Disability and Health (ICF)² shifts the focus from the cause of disability to its effect, and emphasises the environment (physical, cultural, social, political) in which a person with a health condition lives rather than simply focusing on disability solely as a “medical” or “biological” dysfunction. The new UN Convention on the Rights of Persons with Disabilities³ also sets out a framework to ensure that people with disabilities can fully participate in all aspects of society. Yet in this (most welcome) move to embrace disability as a social issue, the health needs of people with disabilities, including access to health services, must not be overlooked.

In our special issue, which will complement WHO's World Report on Disability and Rehabilitation due to be published in 2010, we want to include work on all types of disability and take a global approach. So contributions could cover high-tech innovative research but other contributions could provide evidence on how the needs of people with disabilities in poorer countries can be better met in a more effective way. Additionally, in the spirit of the motto behind the UN Convention “nothing about us without us”, our special issue will also include narratives from people with all types of disability from around the world.

Rhona MacDonald, Zoë Mullan, Richard Horton, Nora Groce, Tom Shakespeare, Alana Officer, Shekhar Saxena *The Lancet*, London NW1 7BY, UK (RM, ZM, RH); Leonard Cheshire Disability and Inclusive Development Centre, Department of Epidemiology and Public Health, University College London, London, UK (NG) and WHO, Geneva, Switzerland (TS, AO, SS)

1 Mont D. Measuring Disability Prevalence, SP Discussion Paper No. 0706. Washington, DC, USA: The World Bank, 2007.

2 WHO. International classification of functioning, disability and health. 2001. <http://www.who.int/classifications/icf/en/> (accessed March 18, 2009).

3 UN. Convention on the rights of persons with disabilities. 2006. <http://www.un.org/disabilities/convention/conventionfull.shtml> (accessed March 18, 2009).