

SIRG-PIMD Newsletter

Newsletter of the IASSID Special Interest Research
 Group on Persons with Profound Intellectual and Multiple Disabilities

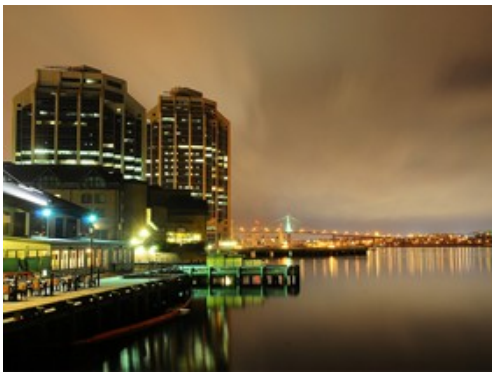
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The purpose of a SIRG is to provide opportunities for international and multidisciplinary networking between researchers and members of IASSID within the same area of interest. In this way, they may create opportunities for sharing information, developing 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.

Upcoming Events:

- **Communicate, Participate, Enjoy! Solutions to Inclusion - 21 - 22 March 2011.** Scope Victoria (Australia) invites you to the 2010 conference to be held in Preston, Melbourne on the theme 'Communicate, Participate, Enjoy! Solutions to Inclusion'. The conference will provide participants with practical strategies to facilitate the active inclusion and participation of people with profound intellectual and multiple disabilities in every day activities and life choices. There will be two concurrent streams of papers/workshops which have a focus on communication, behaviours of concern, sensory focused practice and active participation. The conference will be of interest to support workers, health professionals, educators, disability service providers and families.
<http://www.scopevic.org.au/index.php/site/whatweoffer/communicationresourcecentre/educationtraining/trainingworkshops/communication>
- **2010 IASSID World Congress July 9-14, 2012.** Halifax is an historic port city that is home to friendly people, spectacular summer weather, and countless attractions. Museums, galleries, parks, historic sites, restaurants, pubs – Halifax has it all. To get an idea of everything the city has to offer, please visit the Halifax tourism website at www.halifaxinfo.com. But don't stop there! In the coming months, remember to visit www.iassid.org to get updates on things such as registration dates, plenary speakers, conference themes, hotel listings and the call for abstracts. This will be only the second time the World Congress has been held in Canada, and the organizing committee is already working hard to make it a success. A venue has been chosen in the heart of the city and it will soon be possible to book rooms at conference rates.
- Visit www.iassid.org for more information



Membership:

If you are not yet an official IASSID-member, you may still start or renew your membership fee (see www.iassid.org).

Remember to click the box under the section SIRG for the SIRG Profound and Multiple Intellectual Disabilities. As you know part of the membership fee is given to the SIRG's to organize meetings and roundtables !

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, Bea Maes

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News on People:

◆ Juliet Goldbart will be giving her inaugural professorial address in Manchester on 24th February. The title is "Strategy or Serendipity: In Praise of Collaboration." All members of the PIMD SIRG are warmly welcomed to attend. For details of the event, email Jo on j.e.ashton@mmu.ac.uk

RESEARCH

TO PRACTICE



Applying mentor-modeling approaches in professional development for staff supporting students and young children with profound and multiple disability in various educational contexts:

An update from Australia (Foreman, Arthur-Kelly, Bennett and Neilands)

In 2010 we completed an extensive project that investigated the impact of mentor-modeling on the uptake of communication strategies for teaching staff in several school and early childhood settings. Following work in special schools (2008), regular schools (2009), we extended our work with two related initiatives.

In the first phase, we conducted two intensive case studies with staff engaging with young children in an early childhood intervention program. Without doubt the most significant finding here was the importance of genuinely working alongside all involved in interacting with young children with PMID, especially family members and related service personnel such as speech pathologists.

In our final phase, we introduced a modest school level program of support for staff in a local special school. The goal here was to explore, through consultant assessment and advice, the meaningful use of AAC supports and ways of checking the reliability of behaviour state coding amongst research observers and teachers and aides working daily in classrooms. Our findings here set the scene for a follow up project we hope to commence in the next few years involving a wider range of delivery modes for professional development of staff working in this important area.

For further information contact
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What do parents find important in the support for their child with profound intellectual and multiple disabilities (PIMD)?

To find this out, we asked 600 parents – all members of a Dutch parent organization for disabled persons – to fill out a questionnaire, named the Dutch Measure of Processes of Care PIMD (Dutch MPOC-PIMD). This questionnaire has been developed in the field of pediatric rehabilitation and has become a widely used measure to assess parents' experiences and perceptions of the provided care by health professionals, more specific, the behavioural and interactional aspects of professional activities (e.g. providing specific information about the child, giving respectful and supportive care).

Conclusions of this pilot are that according to parents, behaviour of professionals that can be described as family-centered is important and occurred often in the residential facilities, schools or day service setting that were included in this pilot. Overall, parents deemed the provided services important for their child with PIMD. On the other hand, almost a fifth of the parents pointed out that their child did not receive the support they find important.

In further research the opinions of service providers about what they find important in the support they give to persons with PIMD will be gathered. In this way differences and similarities between parents and service providers in what they find important in the support for the child with PIMD will become manifest. This in turn can be a starting-point to establish cooperation between parents and service providers in the support for persons with PIMD. If you want more detailed information, please contact drs. Suzanne Jansen at S.L.G.Jansen@rug.nl.

Meaning Making in Dialogue between Persons with PIMD and Direct Support Staff

Recently, the dialogical theory on human meaning has been applied to interactions with persons with profound intellectual and multiple disabilities (PIMD) (Hostyn, Daelman, Janssen, & Maes, 2010). Eighteen videotaped observations were described with the Scale for Dialogical Meaning Making. The results demonstrate that the dialogical approach invites us to see how persons with PIMD can and must have a valuable contribution in the search for shared meaning. Even their most simple utterances such as vocalisations or hand movements can be used as a starting point in developing dialogue, by for example imitating them. The interaction partners have a responsible role in stimulating the contribution of the person with PIMD and in creating the conditions for dialogue to occur. To develop true dialogue with persons with PIMD is: supporting the development and well-being of persons with PIMD, through sharing nice experiences together, through mutual consultation, by building on their strengths and initiatives, and by taking into account their interests and (dis)abilities.

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Attuning: A Theory of Interaction of People with Severe and Profound Intellectual and Multiple Disability and their Carers.

The ability of people with profound intellectual and multiple disability to communicate effectively is limited because they appear to understand little and cannot speak. This presentation reported on a study that aimed to develop a theory that would explain how people with PIMD and staff communicate.

Video recordings of three pairs of a staff and an adolescent with profound intellectual and multiple disability were made in a school in Ireland. Key episodes from these tapes were transcribed and coded. The data was analysed using classic grounded theory methodology.

The most important thing for the participants was identified as being how they communicate and regulate their communicative relationship. The theory of attuning that emerged from the data states that the participants communicate by attuning to each other to a greater or lesser extent. Seven categories were identified as comprising the theory—namely attuning (the core category), attention, being, setting, stimulus, action and engagement. The theory makes clear how each category is important. The presentation concluded that:

Attuning [putting oneself in the mindset of the other] is the key process in communication.

People with PIMD have the innate capacity to attune to others consistently and across multiple settings.

People with and without profound intellectual disability communicate in the same way but the manifestations of their communications differ.

Colin Griffiths



RESEARCH TO PRACTICE

Frequency and severity of challenging behaviour in people with profound intellectual and multiple disabilities. P. Poppes, A.A.J. van der Putten, C. Vlaskamp

Does challenging behaviour occur in persons with profound intellectual and multiple disabilities (PIMD), and if so, how often does it occur and how severe is it? We also wanted to look at the relationship between the existence of additional disabilities (such as poor hearing), general health problems (such as epilepsy) and the occurrence of challenging behaviour. To find this out we collected data about 181 people with PIMD using a questionnaire: the Behaviour Problem Inventory (BPI). With the BPI we could determine the prevalence, frequency and severity of self-injurious (SIB), stereotypical and aggressive/destructive behaviour. We administered an additional questionnaire to find out whether sensory impairments and health problems were present among the participants.

We found out that challenging behaviour within the target group of people with PIMD is very common. Results show a prevalence of 82% for SIB and stereotypical behaviour in the sample. Aggressive/destructive behaviour was seen in 45% of the participants. All three types of challenging behaviour occur on a weekly, daily and hourly basis. Participants with visual impairments, tactile impairments or psychiatric problems showed more challenging behaviour than people without these additional problems.

Although challenging behaviours occur frequently in people with PIMD, we found that direct support professionals are not inclined to rate this behaviour as of serious consequence. This might be the case because direct support professionals don't know about

the effects of challenging behaviour. For example: are they aware of the consequences of a child hitting itself against the head constantly? This might lead to loss of sight, loss of hearing but also leads to less opportunities to play and therefore develop. That is why it is very important to make staff aware not only of the manifestation of challenging behaviour but also of the possible impacts of this behaviour through training.

If you want more detailed information, please contact Petra Poppes at p.poppes@rug.nl

Sharing experiences of everyday life

My research is about supporting people with profound disabilities to remember and share their experiences of everyday life - in just the same way that you and I tell little anecdotes to our friends and families, remembering together things that happened to us.

My interest started when I was working as a speech therapist in day centres and schools. I noticed that the conversations between staff and children and adults with PIMDs tended to be about wants and needs, behaviour and social chitchat (hallo, jokes, compliments). When staff were together, they told each other stories all the time about what had happened to the users of the service. But they never told these stories with the service users themselves. I did some research to find out why - and it was only partly because of the communication problems of the individuals. It was much more to do with attitudes, and a focus on routine (which is the death of story). So I then looked for some ways of changing this. I found that if we think of a story that is just a sequence of events, told correctly by one person, with all the characters, time and place elements there - it's not possible. But actually the stories we tell each other everyday about ourselves are not like this. We tell them together, finishing off each other's sentences. We don't worry too much about the order (sometimes we start at the end). And what is most important is the music in our voices, and the feelings we convey - this is what builds empathy and friendship. And of course we tell these stories over and over again. Once we adopt this framework (associated with the work of William Labov, Alyssa McCabe and Neal Norrick) we have a way in for people with PIMDs - because the focus is on joining in however you can (a sound, a gesture, a message on a communication aid, showing a picture or prop) not on trying to remember and tell on your own.

The approach I developed is called StorysharersTM and has proved successful in increasing participation, broadening relationships, and developing staff skills. You can find out more on our website www.openstorytellers.org.uk. If you want to read about it, try these:- Grove, N., Harwood, N., Ross, V. (2010). Sharing stories of everyday life with adults and children who have severe/profound intellectual disabilities. In V. Prasher (ed) *Contemporary Issues in Intellectual Disabilities*.

Multisensory storytelling as an aid to assisting people with profound intellectual disabilities to cope with sensitive issues

Hannah Young, Maggi Fenwick, Loretto Lambe and James Hogg

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A range of methods have been employed to enhance social engagement and assist the understanding in individuals with profound learning difficulties. Little is known about the effectiveness of multi-sensory storytelling to facilitate interaction in these ways. Our research was conducted in Scotland, UK in order to explore the outcomes of using multi-sensory stories that were personalised to the individuals with profound intellectual and multiple disabilities (PIMD).

Stories depicted topics of sexual development, social interaction and health. Each individual's behaviours were observed across the storytelling sessions while interviews from parents and professionals provided observations within and out-with the sessions. Increases in story engagement and social behaviour were found while some exhibited understanding of the sensitive topics. This research indicated that multi-sensory stories positively engage people with PIMD and highlight the educational value of their use.



International Association
for the Scientific Study
of Intellectual Disabilities

We're on the Web!
www.IASSID.org

Highlights:

- Juliet Goldbart and Sue Caton (both Manchester Metropolitan University, UK) have completed their report "Communication and People with the most Complex Needs - What works and why this is essential," which was commissioned by Mencap and the Office of the National Directors, Valuing People Now team at the Department of Health, UK.

The report was launched on 16th December at the PMLD Network Conference at Nottingham Contemporary.

Copies of the report, both full and an easy-read summary, are available at <http://www.mencap.org.uk/page.asp?id=1539>

Many thanks to PIMD SIRG members for their contributions. "

*Visit the website
for more
upcoming
conferences*

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.

OTHER NEWS!

- <http://pimda.blogspot.com/> This blog by Sheridan Forster features news of events, new publications, and personal opinions. It targets Australia, however, given the low profile of PIMD in Australia, international happenings are also incorporated and welcomed.

- Following the publication of the article "Age-appropriateness: Enabler or barrier to a good life for people with profound intellectual and multiple disabilities?", Sheridan spoke about this issue at a conference for Disability Support Workers in Australia. The topic certainly gets people thinking. In the presentation she used the video of Victoria from Mansell's Raising Our Sights (http://www.dh.gov.uk/en/MediaCentre/Media/DH_117967) to promote discussion about what is age appropriateness, what is not, what are necessary accommodations to compensate for physical impairments and what are necessary accommodations for cognitive impairment, what might Victoria's story look like if all of the "age inappropriate" engagements and objects were removed? Have a look at the clip yourself and see how you might answer these questions. Sheridan used this discussion to promote an individualised approach to determining what should happen in a person's life, rather than a rigid pre-determined concept of what someone should be doing at a certain age.

- A new MA degree majoring track: "Intellectual Disability", in the Special Education Department, School of Education, Bar-Ilan University, Israel A new MA Program in Intellectual Disability (ID) is offered by the School of Education, at Bar-Ilan University, Ramat-Gan, Israel. This program was opened at the beginning of the 2010-2011 academic year. The head of this program is Dr. Hefziba Lifshitz.

- The presentations that have been given at the Rome-conference and that have been sent by the SIRG-members are available on the website. See: <http://www.sirgpmid.be/reports.php>

New Projects

◆ A new Quality of Life certification Protocol: introduction and practical training on main issues

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Abstract:

Aim: Can we outline a “best practice comprehensive System” in the field of service provision for people with Intellectual Disabilities? Such a challenge may become a real opportunity when a coherent, empirically and scientifically founded Certification system is available for agencies and organizations delivering supports to people with IDD.

AIRIM, the Italian Association on Intellectual and Developmental Disabilities, has a committee panel of experts in this field who wanted to offer an up-to-date protocol in order to facilitate service providers which wish to deliver supports to people with ID and their families, specifically oriented to Quality of Life improvement and based on the 11th edition of “Definition, Classification and Systems of Support” and the Supports Intensity Scale proposed by the American Association on Intellectual and developmental Disabilities (AAIDD).

Results and Conclusions: Data from multidimensional assessment show a series of contrast in different areas of functioning, which become particularly relevant when compared to support needs (Supports Intensity Scale). Critical questions consequently emerged on the development of the multidisciplinary treatment, useful to align data and orient intervention.

◆ Sheridan Forster, in Australia, has been using Video Interaction Guidance in her work with adults with PIMD. She has found this to be very successful for opening new perspectives of disability support workers about the possibilities for engagement. In a recent case, a disability support worker went from thinking that he could not capture the interest of the person with whom he worked without the aid of objects, to finding out that indeed he could capture her interest through clapping, touch, and close contact. Sheridan hopes to engage in some formal evaluation of the work in the future, and would be happy to speak to anyone interested in this work.

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Recent Research Projects



ATTENTIONAL PROCESSES IN INTERACTIONS BETWEEN PEOPLE WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES AND DIRECT SUPPORT STAFF

Hostyn Ine, NeerInckx Heleen and Maes Bea

• K.U. Leuven, Parenting and Special Education Research Group, Vesallusstraat 2, P.O. Box 3765, 3000 Leuven, Belgium

Abstract

Few studies have examined joint attention in interactions with persons with profound intellectual and multiple disabilities (PIMD), despite its important role in high-quality interaction. The purpose of this study is to describe the attention-directing behaviours of persons with PIMD and their direct support staff and the attention episodes resulting from their interactions, and to understand how these variables relate to each other. Video observations of 17 staff–client dyads were coded using partial interval recording. The results showed considerable variation across individuals and dyads. In general, persons with PIMD directed the attention of staff members infrequently. The staff members frequently directed their clients’ attention towards a topic of interest but did not often use the tactile modality. Within the staff–client dyad, there was not much joint attention; however, shared attention episodes occurred frequently. Shared attention and joint attention are strongly correlated. A negative correlation was found between clients not using attention-directing behaviours and staff members using tactile methods to direct the attention, and joint attention episodes. This study presents both directions for future research and practical implications.

THE EXPRESSION AND ASSESSMENT OF EMOTIONS AND INTERNAL STATES IN INDIVIDUALS WITH SEVERE OR PROFOUND INTELLECTUAL DISABILITIES

Dawn Adams and Chris Oliver

Abstract

The expression of emotions and internal states by individuals with severe or profound intellectual disabilities is a comparatively under-researched area. Comprehensive or standardized methods of assessing or understanding the emotions and internal states within this population, whose ability to communicate is significantly compromised, do not exist. The literature base will be discussed and compared to that applicable to the general population. Methods of assessing broader internal states, notably depression, anxiety, and pain within severe or profound intellectual disabilities are also addressed. Finally, this review will examine methods of assessing internal states within genetic syndromes, including hunger, social anxiety, and happiness within Prader-Willi, Fragile-X and Angelman syndrome. This will allow for identification of robust methodologies used in assessing the expression of these internal states, some of which may be useful when considering how to assess emotions within individuals with intellectual disabilities.

Collaborations Wanted

Multisensory Interventions

The research that I presented at IASSID in Rome, and am still working on with other professionals in Spain, is related to multisensory interventions in general and in particular those that are conducted in Snoezelen rooms. This topic has generated several scientific studies in recent years. It is clearly an issue that contributes to improving the quality of life of people with intellectual disabilities and their families. It is important that we continue to conduct serious research about this subject and that we make this type of intervention information easily available to others. In Spain, there is a group of professionals from different Centres and cities who are studying multisensory interventions, to include the work done in Snoezelen rooms. We would be interested in collaborating with other IASSID members so we can take advantage of synergies, enrich our efforts, and help spread information about these interventions to make day to day life easier for people with disabilities and their families. Please let me know if you are interested in collaborating.

Regards— Maria J. Cid, Dr. Psychology

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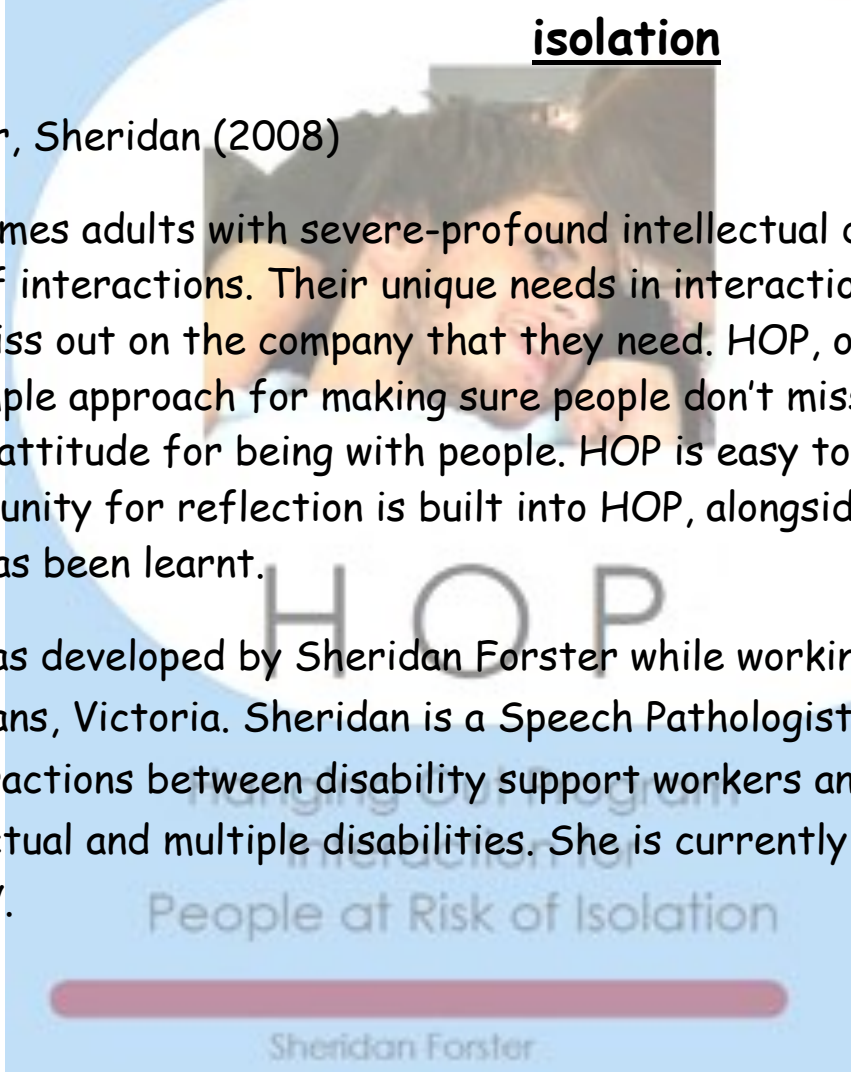
PUBLISHED BOOKS & ARTICLES

HOP: Hanging Our Program: Interaction for people at risk of isolation

Forster, Sheridan (2008)

Sometimes adults with severe-profound intellectual disabilities end up on the edge of interactions. Their unique needs in interactions mean that sometimes they miss out on the company that they need. HOP, or the Hanging Out Program, is a simple approach for making sure people don't miss out. It is both an approach and an attitude for being with people. HOP is easy to use and implement. Opportunity for reflection is built into HOP, alongside a way of documenting what has been learnt.

HOP was developed by Sheridan Forster while working at Yooralla First Base, in St Albans, Victoria. Sheridan is a Speech Pathologist and researcher interested in interactions between disability support workers and adults with profound intellectual and multiple disabilities. She is currently working on her PhD at the CDDHV.



Behavioural and emotional problems in people with severe and profound intellectual disability

S. Forster^{1,*}, K. M. Gray¹, J. Taffe¹, S. L. Einfeld^{2,3}, B. J. Tonge¹ Article first published online: 4 JAN 2011

DOI: 10.1111/j.1365-2788.2010.01373.x

Abstract

Background People with severe and profound levels of intellectual disability (ID) are frequently examined as a single group in research. However, these two groups may be significantly different, particularly in the area of emotional and behavioural difficulties.

Method The Developmental Behaviour Checklist (DBC) was completed by parents and caregivers of 107 people with severe ID and 22 people with profound ID at four time periods across 12 years. Regression analyses were used to examine trends in sub-scale scores across time and groups.

Results Significant differences between the groups of people with severe and profound ID were found. People with profound ID had significantly lower scores across all sub-scales except *Social Relating*. This was usually related to fewer items being selected as present for people with profound ID, as opposed to the scores being attributable to lower item severity scores.

Conclusions There are significant differences between groups of people with severe and profound ID in scores on the DBC, indicating differences in behavioural and emotional problems. Caution should be exercised by researchers treating these two disparate groups as a single group, and by practitioners translating such findings into practice.