Challenging Behaviour & Mental Health SIRG Newsletter

SIRG BUSINESS MEETING – SINGAPORE CONFERENCE

David Allen

The SIRG held a business meeting at the recent 2nd IASSID Asia-Pacific Regional Conference. Twenty-two delegates from twelve different countries attended. The meeting commenced with an account of the creation of the SIRG and its activities since its formation in Cape Town in 2008. Some really useful suggestions were made about how the SIRG page on the website could be developed, and with the IASSID Council making a decision to invest in website development at its meeting later in the week, it should be possible to achieve many of the changes proposed. An open discussion then followed on potential future activities, during which important contributions were made from members of the Ethics Affinity Group and the Comparative Policy & Practice SIRG. Initially this focussed on the idea of producing a joint position paper between these groups on reducing restrictive practices (that is, restraint, seclusion and the use of emergency medication). Eventually, a decision was made to produce a broader 'gold standard' statement on effective intervention for people with intellectual disability and additional emotional or behavioural disorders, and work on this will commence shortly.

The full minutes of the meeting can be accessed via the SIRG page on the website.

SIRG Membership

The SIRG currently has 134 members. Individuals wishing to join should indicate their interest in doing so by ticking the relevant box on the application form for membership of IASSID. It is also important that people do so on *renewing* their membership as, at present, the website is unable to retain information about past SIRG options.

PRESIDENT'S KEYNOTE ADDRESS ON "CHALLENGING BEHAVIOUR: A BARRIER TO INCLUSION"

Glynis Murphy

Glynis Murphy, President of IASSID, gave a keynote on the final day of the Singapore conference on the above title. The abstract of Glyn's talk is given below and a copy of her presentation is accessible via the SIRG webpage:

Arguably, the most important outcome measure for services to people with intellectual disabilities is quality of life. Quality of life has been defined in numerous ways and may consist of many aspects, including physical, material, and emotional well-being, as well as interpersonal relationships, personal development, self-determination, social inclusion, and civic rights. However, the most important aspect is social inclusion. People with intellectual disabilities who show challenging behaviour, however, often make other people uncomfortable so that social inclusion is more difficult, and evidence suggests that both children and adults with intellectual disabilities and challenging behaviour (and their families) have poorer quality of life and more restrictions in their lives than others with intellectual disabilities. Examination of the psychosocial aspects of quality of life indicates that modern services are still not good at providing people with challenging behaviour with opportunities for making relationships, employment, and social inclusion. We need to improve our ability to target these areas of quality of life, particularly social inclusion for people with challenging behaviour.

DIAGNOSING MENTAL DISORDERS IN PERSONS WITH INTELLECTUAL DISABILITY: A NEW DIAGNOSTIC MANUAL

Robert J Fletcher

To facilitate a more accurate psychiatric diagnosis of people with intellectual disability (ID), the National Association for the Dually Diagnosed (NADD), an organisation for persons with developmental disabilities and mental health needs, in association with the American Psychiatric Association (APA), has developed the *Diagnostic Manual – Intellectual Disability (DM-ID): A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* This book is an adaptation of the *DSM-IV-TR* for use with individuals who have intellectual disability. Chapters in the *DM-ID* cover specific issues (e.g., assessment and diagnostic procedures and presentations of behavioural phenotypes of genetic disorders) as well as the full range of psychiatric disorders. Grounded in evidence-based methods and supported by the expert-consensus model, the *DM-ID* offers a comprehensive approach to each diagnostic category.
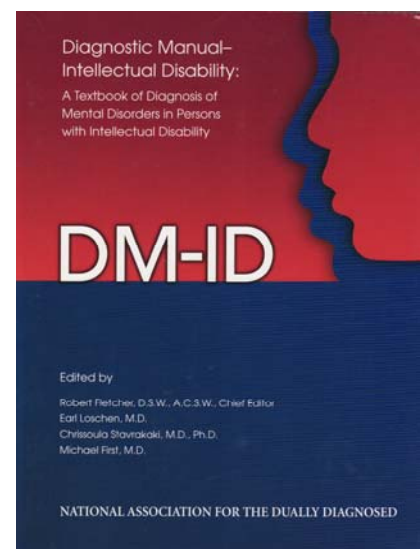
For each disorder, descriptive text and details of how to apply diagnostic criteria, as well as tables of adapted diagnostic criteria, are included.

Each diagnostic chapter has a comprehensive review of the research literature, a standard rating of the quality and rigor of the research is applied, and a section on etiology and pathogenesis covering risk factors, biological factors, psychosocial factors, and genetic syndromes.

In addition to adapting the *DSM-IV-TR* diagnostic criteria where appropriate, the *DM-ID* provides advice about and considerations for assessing and diagnosing individuals with ID and coexisting mental health needs. In some cases, it is not so much that the criteria need to be adapted, but that a different method of eliciting the necessary information must be used. Information is provided on recognising common behaviours of individuals with intellectual disabilities and on how to differentiate these behaviours from psychiatric disorders.

The *DM-ID* is designed to help clinicians better understand complex behaviours and guides the clinicians to better comprehend the difference between problem behaviours as compared to the expression of specific psychiatric disorders. Furthermore, the *DM-ID* provides a wealth of information on the presentation of psychiatric disorders manifested in adults as compared to children and adolescents. Additionally, the criteria subsets are differentiated between mild-moderate ID as compared to severe-profound ID.

Field study research on 848 patients using 63 clinicians from 11 different countries showed that the *DM-ID* is a useful adaptation of the *DSM-IV-TR* for persons with ID. Research participants indicated that the *DM-ID* was easy to use, resulted in accurate diagnoses, and can reduce the use of the Not Otherwise Specified (NOS) category. A shorter volume, *Diagnostic Manual – Intellectual Disability (DM-ID): A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disability*, has been abridged for clinical usefulness. The *DM-ID Clinical Guide* is analogous to the *Quick Reference* for the *DSM*.

Additional information about the *DM-ID* is available at the *DM-ID* website (www.dmid.org) including: sample excerpts, table of contents, book reviews, and information on ordering.
For further information, contact the author at:

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A NEW CENTRE FOR RESEARCH AND TRAINING IN CHALLENGING BEHAVIOUR FOR AUSTRAILIA

Robert Heron and Monica Cuskelly

In response to a government sponsored inquiry into the services provided to adults with an intellectual or cognitive disability and severely challenging behaviour, an integrated set of initiatives has been introduced by the Queensland Government. One element of the government's response was to establish the Centre of Excellence for Behaviour Support which was created as a partnership between the Queensland Government and the Social and Behavioural Sciences Faculty of The University of Queensland.

The Centre has been established to conduct research relevant to practice and policy development, and to provide learning and development programs to government and non government service providers, all with a particular emphasis on positive behaviour support. The Centre has a remit to develop national and international research collaborations around issues relevant to the work of the Centre and is currently advertising several postdoctoral positions. Interested readers should go to: http://www.seek.com.au/ or contact Fiona Flint (f.flint@uq.edu.au) for details.

In addition to its research focus, the Centre has responsibility for developing and delivering state wide training for government and non-government service providers as well as contributing to the development and delivery of tertiary education and workforce training.

THE DEVELOPMENT OF A COMBINED DATABASE TO EVALUATE THE IMPLEMENTATION AND IMPACT OF POSITIVE BEHAVIOUR SUPPORT

Kathy Lowe

Positive Behaviour Support (PBS) is being increasingly recognised as best practice in delivering effective, ethically stringent interventions for challenging behaviour (Carr et al.,1999). PBS is based on understanding of why, when and how behaviours happen and what purposes they serve, through a systematic functional analysis of individuals' behaviour. Intervention is multi-component with a main focus on proactive strategies for changing behaviour, which includes ecological approaches and altering triggers for behaviour in order to reduce the likelihood of the behaviour occurring and the use of skill teaching to address adaptive skill deficiencies. It involves the implementation both of preventative strategies and of reactive strategies for managing behaviour when it occurs, and reduces or eliminates the use of restrictive or punishment procedures.

However, although research on PBS outcomes is generally positive, there are several deficiencies in the information available. The number of participants reported across the studies is still very small and their cultural context is in North America. Intervention settings are biased towards specialist provisions delivered by specialist personnel rather than by carers within the participants' regular day-to-day environments. Also, less positive data tend not to be reported and there is no clear information about which components of a PBS package may be most effective in producing positive behavioural change. Critically, despite the emphasis that advocates of PBS place on demonstrating improved quality of life as an outcome, few research studies (as Glynis Murphy's keynote in Singapore pointed out) have tracked this in practice.

The three partner organisations involved in this study (ABMU NHS Trust, Wales; Sussex Partnership Trust, England; The Callan Institute, Republic of Ireland) have adopted PBS as the treatment approach for all persons with intellectual disabilities and challenging behaviour referred to their services. This has provided a unique opportunity to develop a shared database in order to amass substantial practice-based and longitudinal evidence of PBS implementation in the UK.

The purpose of the study is to develop a viable database to track the processes and outcomes of PBS services for people with intellectual disabilities and challenging behaviour. The database is designed to capture all combinations of intervention design, the personal characteristics of the individuals served and the impact of intervention on behaviour and quality of life and on carer response. Each agency is responsible for maintaining their own database on an ongoing basis, requiring a change in the routine recording of clinical practice for each agency.

All participants in the study are adults with intellectual disabilities, referred between October 2008 and September 2009. All participants are prescribed an intervention by their relevant organisation. Therefore there are no control groups or randomised allocation of treatment. Longitudinal data are collected at referral, discharge and follow-up (12 months after discharge). In addition to the clinical tools used, standardised assessment scales are also being administered to assess each individual's level of adaptive skills, the severity of their challenging behaviour across a range of behaviour types and the extent of their participation in community life. This will allow multivariate analysis of the results, examining any relationships between intervention types, personal characteristics and outcomes.

The results of the study will facilitate a detailed description of what PBS is in practice in terms of the combination of components implemented and what long-term impact such interventions have, not just on challenging behaviour, but on individuals' quality of life and how carers respond to them. The database and all processes involved will also be made widely available to promote the further implementation of PBS in the UK.

The Project Team is:

Professor Kathy Lowe - (ABMU NHS Trust)   Dr Edwin Jones - (ABMU NHS Trust)

Professor David Allen - (ABMU NHS Trust)   Dee Davies - (ABMU NHS Trust)

Wendy James - (ABMU NHS Trust)   Dr Sarah Hawkins - (ABMU NHS Trust)

Peter Baker - (Sussex Partnership Trust)   Dr Caroline Dench - (Callan Institute, Dublin)

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CHALLENGING BEHAVIOUR – NATIONAL STRATEGY GROUP

Vivien Cooper & Gemma Honeyman

November 7th 2008 saw the launch of the Challenging Behaviour National Strategy Group (CB-NSG); a new key UK wide group to address the needs of children, young people and adults with learning disabilities whose behaviour is perceived as challenging. The long-term objective of the CB-NSG is to develop a co-ordinated and strategic approach that will offer lasting solutions for individuals whose behaviour challenges our present services.

The Challenging Behaviour Foundation is aware of many important initiatives and policy opportunities around individuals who challenge. We know that much better support and services could be provided – including evidence from the individual families who contact the Challenging Behaviour Foundation, research and policy reports. However, the current situation is that organisations/ stakeholders initiate work, commission research or reports or carry out pilots around specific themes or groups. What is missing is a group which has an overview of this work, its impact and the policy opportunities available in order to develop a co-ordinated and coherent strategy across child and adult provision to ensure that every individual benefits. The formation of this group, bringing together key stakeholders will address this.

The Challenging Behaviour Foundation has instigated this action-focused group as we are uniquely positioned, building on our work of the last eleven years with children, adults, families, professionals and with a wide range of organisations and groups.

Utilising the skills and experience of a wide range of stakeholders a charter has been developed which sets out the human rights based aims and principles of the group as well as identifying what action needs to be taken. The group is developing a comprehensive work plan and identifying priorities.

For more information visit our website: www.challengingbehaviour.org.uk

A SELF-AUDIT CHECKLIST FOR MONITORING THE QUALITY OF SERVICES FOR PEOPLE WITH CHALLENGING BEHAVIOUR

Dee Davies

The Welsh Assembly Government's (2007) Statement on Policy and Practice for Adults with a Learning Disability made significant reference to those people whose behaviour poses challenges to services. In order to support agencies to monitor and further develop services for this group, the Learning Disability Implementation Advisory Group (LDIAG) has produced a Self-Assessment Checklist (2008). As its name indicates, the Checklist is a tool intended for use by commissioners and providers from health and social services to establish what is in place and working well for people with learning disabilities and challenging behaviour in local areas.

The Self-Assessment Checklist for Monitoring Services for People with Learning Disability and Challenging Behaviour

Ideally, the self-assessment should be based on a process that involves key stakeholder services, users and carers. The Checklist can be used as a first step towards service improvement and development and afterwards at regular intervals to track developments, celebrate achievements and keep moving forward towards even better services and support for people with learning disabilities whose behaviours challenge.

The checklist will be formally launched for use in Wales later this year. Its wider application within the field is very much welcomed and interested parties who wish to learn more about the tool can contact Dee Davies, Service Development Consultant, Special Projects Team, Abertawe Bro Morgannwg University NHS Trust, via email:
dee.davies@abm-tr.wales.nhs.uk

References

Learning Disability Implementation Advisory Group (2008) **The Self-Assessment Checklist for Monitoring Services for People with Learning Disability and Challenging Behaviour.** Welsh Assembly Government: Cardiff.

Welsh Assembly Government (2007) **Statement on Policy and Practice for Adults with a Learning Disability**. Welsh Assembly Government: Cardiff.

FORTHCOMING CONFERENCES

7th European Conference of Mental Health in Intellectual Disability, Sept 3-5th, 2009, Amsterdam, The Netherlands (www.amsterdamcongress2009.org)

NADD 26th Annual Conference, October 21st-23rd, 2009, New Orleans, USA.
(www.thenadd.org)

Association for Behavioural Phenotypes, 14-16th October, Corpus Christi College, Cambridge, England (www.ssbp.co.uk)

Bild International Conference, Positive Behaviour Support-Leading the way and Reducing Restrictive Practice. 5-7th May, 2010 Dublin
(http://www.bild.org.uk/behavioursupport.htm)

EXECUTIVE COMMITTEE

The current officers of the SIRG/CBMH committee are:

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CB/MH SIRG MEETINGS & ROUNDTABLES

Rome 2010	Roundtable on a 'Unified Approach to Challenging Behaviour'
	Business & Executive Committee Meeting
University College London 2011	Roundtable
	Business & Executive Committee Meeting
Halifax, Canada 2012	Roundtable
	Business & Executive Committee Meeting