International Association for the Scientific Study of Intellectual Disabilities

Challenging Behaviour & Mental Health SIRG Newsletter

Issue No 3 – February 2010

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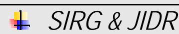
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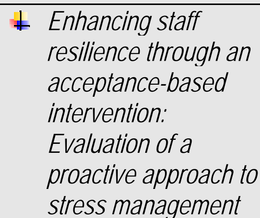
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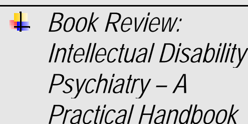
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INTRODUCTION

Edwin Jones - Secretary

The CB and MH SIRG committee hope you enjoy this third issue of the newsletter. It contains reports of interesting developments regarding supporting people with intellectual disabilities and challenging behaviour from Australasia, Malaysia and the UK. The feedback received regarding the two earlier issues has been very positive indeed and we welcome contributions of around 500 words for future editions. We are particularly keen to report on any developments in Africa, Asia and the Americas as well as continental Europe in future editions.

We are also pleased to review any books or other materials relevant to people with intellectual disabilities and challenging behaviour or mental health issues. Please send any comments or contributions either directly to the co chairs David Allen and Angela Hassiotis or to me. The e mail addresses of all committee members are on page 10. Finally, when renewing your membership to IASSID, don't forget to check that you've ticked the CB and MH SIRG box.

SIRG & JIDR

Many members of the Challenging Behaviour & Mental Health SIRG act a reviewers for manuscripts submitted to the special issues on mental health of the Journal of Intellectual Disability Research. To mark this contribution, and in reflection of the close links between the SIRG and the Journal, the cover of the special issues now bears the message 'The support of the Challenging Behaviour and Mental Health Special Interest Research Group of IASSID is gratefully acknowledged'. The SIRG thanks Professor Anna Cooper, Editor for the special issues, for her support and recognition; JIDR is published in association with IASSID.

INTERNATIONAL WORKSHOP FOR CARE GIVERS, SERVICE PROVIDERS AND PARENTS - MALAYSIA

Angela Hassiotis – Co-Chair

In June 2009, the International Association for the Scientific Study of Intellectual Disabilities (IASSID) held its 2nd Asia Pacific Congress in Singapore. As part of that, the IASSID Academy on Education, Teaching & Research had agreed to host accredited workshops prior to and following the congress. The workshops were planned for Singapore, Hong Kong, and the city of Ipoh in Malaysia. This article discusses the process of putting together the materials for the workshop and describes the local issues associated with the workshop in Ipoh, Malaysia.

The Ipoh application to the IASSID Academy for a workshop was submitted by the administrator of the Yayasan Sultan Idris Shah Community Based Rehabilitation (CBR) Centre, Regina Karrapaya. The applicants suggested what training might be helpful to the workers and the community. The topics put forward included: supporting families, supporting people with challenging behaviour, specific disabling conditions such as Down syndrome, programmes on habilitative therapies and inclusion programmes.

The resulting workshops were carried out under the aegis of the CBR Centre, the Perak Social Welfare Department and the IASSID Academy. They were designed and presented by Ivan Brown (Canada), Margaret Kyrkou (Australia), Nancy Jokinen (Canada) and Angela Hassiotis (UK) in collaboration with the IASSID Academy, CBR, and Mitchell Clark from Mount Royal College, Canada.

The setting - The Yayasan Sultan Idris Shah (YSIS) is a foundation dedicated to helping both children and adults with any disability, physical or intellectual. It was established 26 years ago, emphasising the involvement of the community in helping people with disabilities to lead fulfilling lives. It has an open door policy and has created additional outreach centres across the Malaysian state of Perak, which provide free rehabilitation services to those living in rural and less developed areas. It is estimated that 72,000 people need rehabilitation services in Ipoh, Perak's capital, alone. The YSIS model also provides training and certification as part of its Skills Training and Development Centre. Parents may also take such courses if interested.

The workshops - The format of the workshops combined didactic teaching, case discussion in small groups with emphasis on local problems and solutions, and evaluation of the students as several workers would be using it as part of their professional development portfolio. The size of the workshops ranged from 53 to 96 registered students, including professionals and paid or family carers.

The language of the workshop was English but several attendees spoke either both or solely Bahasa Malaysia. Most of the materials, such as handouts and tests, were translated in Bahasa and centre administrators were also available to interpret. Some of the bilingual attendees also mentored those with poorer English during the workshops.

Reflections - First, the combination of the internet and a highly committed professional group are great ways in which geographical separation can be overcome! Second, I found the participants receptive, enquiring and welcoming. Personally, I had to think about the cultural equivalence of the concepts I use in my day to day practice and how those might relate to the experience of the professionals in the room. It was reassuring to find out, for instance, that what may be considered as problem behaviour in the UK is also problem behaviour in Ipoh!

I am aware that inevitably, parts of my presentation had a UK-based flavour, particularly where assessment and multidisciplinary frameworks were mentioned. We found out that some employees at the centre had completed MSc. in the UK (UCL featured heavily!) or elsewhere, and others currently were applying for postgraduate courses abroad. There is acute lack of certain professions such as occupational or speech and language therapists and the Centre would like to hear from interested individuals who might be able to volunteer.

As probably is the case in most parts of the world, there were not any specific services for people with intellectual disabilities. The CRB centre facilities were used to support people with intellectual disabilities across the lifespan alongside people with other disabilities. We also discovered that many families face similar challenges in providing supports to their sons or daughters with disability as are faced in more developed countries; yet they take on the tasks wholeheartedly with limited social services.

Clearly service structures differ among the UK, Canada, Australia and Malaysia but I was impressed by what is being achieved. Despite the lack of or limited resources, communities and professionals learn to create alliances with other organisations such as religious groups, charities, international agencies, and NGOs (Dogra & Omigbodun, 2004). The YSIS foundation is such an example.

The workshops were labour intensive, but the experience overall was very stimulating and of great interest. I am aware that the Royal College of Psychiatrists has a significant international programme that fosters educational links with low income countries (although Malaysia has now moved up the ladder in this respect!). The risk always is that professionals and specialists from such countries as the UK, Canada and Australia are seen as "the experts." However, the most difficult task is to ensure that those receiving the teaching and education are empowered and trained to carry on and apply their skills to their home circumstances. We must also not be blind to successful examples abroad that can lead to innovation and opportunities in our own practice.

Acknowledgments: I would like to extend my thanks to Regina, Alfonso and Katrina who provided significant support and great food during the workshops. Also to my colleagues Roy, Mitch, Ivan, Nancy and Margaret who all provided expertise and assistance during the preparation of the training event and this article.

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DEVELOPMENT AND ROLL-OUT OF A PROGRAM FOR PARENTING CHILDREN WITH CHALLENGING BEHAVIOUR IN AUSTRALIA

Jan Matthews & Christine Cameron

The development, trial and wide-scale dissemination of the Signposts for Building Better Behaviour parenting program (Signposts) is an example of a successful collaboration between government, a university, an independent research centre with a focus on parenting, and regional family support services. The State Government in Victoria, Australia, funded the creation of Signposts for families of children aged 3-15 years who have challenging behaviour and developmental delay or intellectual disability.

Authored by staff of the RMIT University and the Parenting Research Centre (PRC), the program consists of eight written parent modules, a parent workbook, a DVD with both positive and negative examples of typical parent–child interactions, and a facilitator's manual (see www.signposts.net.au). It was designed to be made available in a variety of ways ranging from self-administration to facilitated group delivery and individual face to face or telephone support formats. The program aims to build positive behaviours to replace challenging behaviours and employs strategies based on functional assessment to decrease unwanted behaviours. Parents are equipped to devise their own action plan targeting selected behaviours and a generalisation plan for other behaviours or settings. The program also acknowledges how contextual factors can affect the success of interventions by providing resources for managing stressful circumstances, obtaining social support and working as a team.

Following a development phase which included a literature review, parent and practitioner focus groups, a parent survey, and the production of draft materials, program efficacy was evaluated in a controlled trial of three modes of delivery compared to a control condition (Hudson et al., 2003). Parents in the intervention groups reported less stress, greater parenting efficacy, fewer parenting hassles, improvements in child behaviour, and high levels of satisfaction with program content and delivery. There were minimal differences in outcomes between the three modes of delivery, except for drop out, with families in the self-administered condition less likely to complete the program.

After the trial, a state-wide dissemination phase was funded by a combination of state and national government funding and was managed centrally by the PRC. A 'hub and spoke' model was adopted which involved the establishment of a network of trained practitioners across all human services regions in the state. All regions had Signposts program coordinators, managed by the PRC, who were responsible for recruiting agencies and practitioners to be Signposts providers, arranging training by the PRC, providing post-training support and collecting data. A total of 524 practitioners were trained initially with 203 actively engaged in program delivery six months after training. Trainees were from all rural and metropolitan areas of the state and worked in a variety of government and non-government services, including schools, local councils, and community and disability services. Training included workshops and co-facilitation followed by telephone and web-based post training support.

Over 18 months of program delivery, 2119 parents or carers, representing 1790 families, received Signposts in one of the four formats. Child and parent outcomes achieved were similar to those of the trial with effect sizes ranging from small to large, depending on the measure and mode of delivery (Hudson, Cameron & Matthews, 2008). These results are considered promising given that Signposts was designed as a preventative program and participants were not experiencing high baseline levels of distress or serious challenging behaviour.

Since the state-wide roll-out, there have been a number of developments. Additional government funding has produced supplementary materials on acquired brain injury, autism, continence issues and working with families from indigenous and culturally diverse backgrounds. Materials are now available to trained practitioners on-line, and an on-line interactive version of the program is in development. Practitioner training has been extended to other states and countries, and research with a focus on fathers has commenced.

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ENHANCING STAFF RESILIENCE THROUGH AN ACCEPTANCE-BASED INTERVENTION: EVALUATION OF A PROACTIVE APPROACH TO STRESS MANAGEMENT

Mark Smith

Introduction

It is recognised that staff can experience significant levels of stress when supporting service users with intellectual disabilities and challenging behaviour. Resources therefore need to be invested in proactive interventions to reduce the risk of stress affecting staff in the first place. The Directorate of Learning Disability Services, ABM University Health Board, South Wales, UK has collaborated with colleagues from Bangor University (North Wales) and the Tizard Centre (University of Kent) to deliver an intervention tailored specifically to the challenges faced by staff working in this field, based on a therapeutic model known as Acceptance and Commitment Therapy (ACT), and to evaluate the results of this initiative.

Background to ACT

ACT takes as its starting point the view that stress (along with other negative emotions and experiences) is not "abnormal" but a part of everyday life. The focus is, therefore, not on how we can *get rid* of these experiences, but how we can live the life we want *in spite* of them.

ACT is based on relational frame theory (RFT) and views much of human suffering as a result of the way humans are able to use language. Language enables humans to problem solve- when we experience something we don't like, we have the ability to figure out how to solve it. However, the mind will also try to problem solve our private events - the thoughts, feelings, sensations, memories that we all have, and find difficult. Unfortunately, our attempts to avoid, control and escape these experiences often lead to more problems. ACT suggests that it is when we live in our thoughts, trying to avoid and control negative emotions, that we are unable to get on with living our lives (Hayes, 2005).

ACT differs from traditional cognitive behavioral therapy (CBT) in that, rather than trying to teach people to better control their private events, ACT teaches them to observe, accept, and embrace these events, especially previously unwanted ones. ACT helps the individual see themselves as more than just their thoughts, and to treat thoughts as just thoughts, which are not equivalent to life itself. ACT also aims to help the individual clarify their personal values and to take action that is consistent with these values, rather than being sidetracked by unpleasant thoughts and feelings (Hayes & Smith, 2005).

ACT commonly employs six core principles to help clients develop psychological flexibility:

1. **Cognitive defusion**: Learning to perceive thoughts, images, emotions, and memories as what they are, not what they appear to be.
2. **Acceptance**: Allowing them to come and go without struggling with them.
3. **Contact with the present moment**: Awareness of the here and now, experienced with openness, interest, and receptiveness.
4. **Observing the self**: Accessing a transcendent sense of self, a continuity of consciousness which is changing.
5. **Values**: Discovering what is most important to one's true self.
6. **Committed action**: Setting goals according to values and carrying them out responsibly.

Noone & Hastings (2009) tailored a workshop format, based on these core principles, to address the specific needs of staff who support service users with intellectual disabilities and challenging behaviours.

This was based on earlier work by Bond & Bunce (2000, 2003) who had developed similar interventions for staff working in the service sector.

Noone & Hastings' intervention consisted of a range of exercises, metaphors and discussions to draw out the key ACT principles, delivered over a whole day with a half day follow up (this took place 2-3 months later). Results of a small scale pilot showed a significant positive change in scores on the General Health Questionnaire (GHQ) when comparing pre-intervention to follow up, but no change in staff perception of stress per se. Furthermore, there was no change in the absence of an intervention amongst a small control group. This is consistent with the aims of the ACT approach, which would predict that positive changes in the ability to *cope* with stress, rather than the experience of stress per se should occur (Noone & Hastings, 2009).

Aims of the present study

The aims of the study are to replicate Noone & Hastings intervention with a larger sample of staff working in specialists services for adults with learning disabilities and challenging behaviour. A further aim is to examine the effectiveness of a 'train the trainers' approach, by intensively training a small group of staff to deliver the workshops with supervision and support from a qualified clinical psychologist. The rationale for this is two fold- (1) to maximise the availability of the workshops (rather than relying on a small number of clinical psychologists), and (2) to move away from a traditional approach of 'bringing in the experts' by increasing knowledge and skills *within* the workforce.

Methodology

The first phase of the study consisted of training the trainers- and was completed successfully, a total of 6 staff received 4 intensive training days, delivered by an experienced ACT therapist and were assessed as competent to deliver the workshops. The second phase consists of the trainers training approx 70 staff in a series of 6 workshops staggered over a 6 month period and scheduled to be completed in March 2010.

The workshops are being robustly evaluated through a set of questionnaire measures which participants will be asked to complete: pre 1 (prior to any workshops commencing); pre 2 (at the start of the actual workshop attended by participants); post 1 (3 months) and post 2 (6 months). The questionnaires include a wider set of measures than used by Noone & Hastings and comprise the following:-

1. Demographic information sheet
2. General Health Questionnaire (12 item version- Goldberg, 1978)
3. Staff Stressor Questionnaire (Hatton et al, 1999)
4. Values Questionnaire (Noone, 2006)
5. Dysfunctional Attitude Scale (Weissman, 1980)
6. Acceptance and Action Questionnaire (Hayes et al, 2004)
7. Maslach Burnout Inventory (Maslach et al, 1996)

Progress to date

At the time of writing this report, 3 of the 6 workshops have already taken place. Initial feedback from participants has been extremely positive, with participants reporting that the groups were extremely helpful and brought a new perspective on their perception of 'stress'.

The aim is to complete and fully write up the project by the summer of 2010 and disseminate the results. For more information contact Dr Mark Smith via e mail on MarkL.Smith@abm-tr.wales.nhs.uk

References & further reading

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FINDING ALTERNATIVES TO THE USE OF RESTRICTIVE PRACTICES IN AUSTRALIA AND NEW ZEALAND

Keith R. McVilly

The use and misuse of restrictive practices (e.g., restraint and seclusion) is the subject of great concern and much debate in Australia and New Zealand. The debate has been advanced by a series of legislative and policy reforms across the states of Australia and in New Zealand, fuelled by the adoption of the United Nations Convention on the Rights of Persons with Disability (2006).

The Australasian Society for the Study of Intellectual Disability (ASSID), in conjunction with the Victorian Office of the Senior Practitioner, hosted a discussion during their 2008 conference at Melbourne. Subsequently, an Australasian-wide committee was formed with representation from researchers, policy makers, services providers and, importantly, self-advocates.

The Australasian-wide committee formulated a number of proposals which have since been presented to the Australian Parliamentary Secretary for Disability Issues, the Hon. Bill Shorten, and the New Zealand Minister for Disability Issues, the Hon. Tariana Turia. The proposals that were drafted are:

- To promote the human rights and dignity of both people with disability and those who support them (i.e., family members and paid staff) by reducing (or where ever possible eliminating) the use of restrictive practices when supporting people with disability.

- To develop an Australasian-wide strategy to promote consistency in policy and practices, including clear inter-jurisdictional definitions of various forms of restrictive practice.

- To instigate Australasian-wide research to accurately define the extent of the use of various restrictive practices and to enable long-term monitoring of such practices, together with evaluation of the effectiveness of policy and other strategies to decrease or, where possible, eliminate their use. This would include the establishment and maintenance of an inter-jurisdictional database.

- To establish Australasian-wide best practice standards to inform policy and procedural developments across jurisdictions and to inform educational activities in both vocational and higher education sectors.

- To seek funding for an inter-jurisdictional strategy in the disability sector across Australasia, similar to that already established in the mental health sector, designed to reduce the use of restraint and seclusion in disability services.

The proposals were further debated during the recent 2009 conference of ASSID, conducted at Hobart in November. Support for advancing the committee's proposals has been signalled by the Australian Guardianship & Administration Council and the Australian Psychological Society.

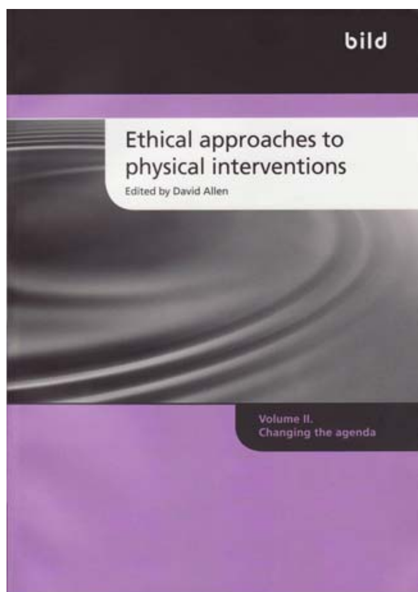
The Australian Psychological Society has taken action to formally enact a special interest group on "Intellectual & Other Developmental Disabilities", with a sub-committee currently working on a set of guidelines to promote evidence-based psychological interventions as alternatives to restrictive interventions. These guidelines will be used in the education of practitioners and in collaborative actions with other health and allied-health professional associations across Australia and New Zealand.

ASSID is currently preparing a formal position statement on the use of restrictive practices. It is expected that the policy statement will assert that restrictive practices are: unethical & inconsistent with internationally accepted human rights; ineffective in bringing about positive, long-term behaviour change; cause both physical and psychological harm for persons being restricted; and cause both physical and psychological harm to those applying the restriction.

The position to be advanced by ASSID is expected to be that it will promote and support: policies & procedures which establish positive alternatives to restrictive practices; education and skill development for staff and caregivers in the use of evidence-based alternatives to restrictive practices; the commissioning, conduct & dissemination of research to strengthen the evidence-base for positive alternatives to restrictive practices; and the development of policy and legislation to strengthen the rights of people with disabilities, especially for those whose behaviours make them vulnerable to the use of restrictive practices.

BOOK REVIEW: ETHICAL APPROACHES TO PHYSICAL INTERVENTIONS VOLUME II – CHANGING THE AGENDA

Kathy Lowe



Edited by David Allen. BILD Publications 2009.
ISBN 978-1-905218-11-0

This timely volume brings the thorny issues of physical intervention up to date and heralds the way forward to best practice for the future. Coming in the wake of a series of national scandals concerning tragic consequences from continued use of inappropriate restraint, the first two sections of the book contains several chapters reviewing the effectiveness of training in physical intervention, associated risks and ethical concerns with various practices. These make for sombre reading whilst also highlighting good practice. The issue of training for the all too often forgotten family carer is also faced.

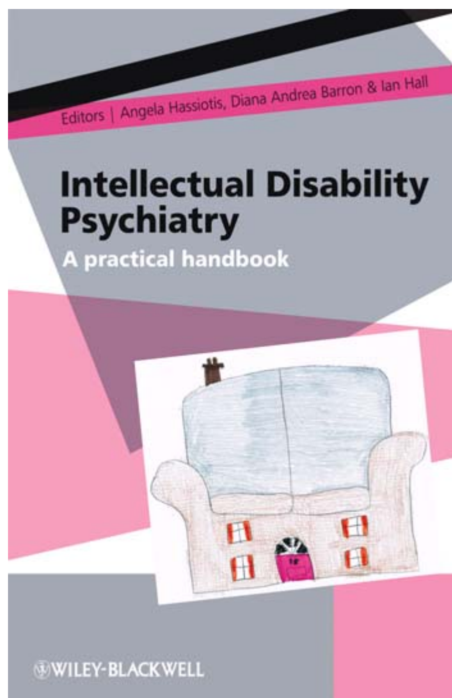
The third and final section of the book takes a different approach, with a shift in focus from reaction to prevention. Positive behaviour support is championed as the strongest evidence-based therapeutic contemporary approach to challenging behaviour, embracing, as it does, both proactive and reactive strategies but having a clear emphasis on the former.

Antecedent change and skill teaching are then explored as key primary prevention strategies. The final chapter draws all these themes together in a novel way by examining restraint, concluding that successful reduction strategies are dependent on the adoption of proactive approaches.

The book addresses its topic in a frank and refreshing manner and presents a clear overview of the current situation with insightful direction from many of the clinical leaders in our field.

BOOK REVIEW: INTELLECTUAL DISABILITY PSYCHIATRY – A PRACTICAL HANDBOOK

Gillian Nethell



Editors: Angela Hassiotis, Diana Andrea Barron & Ian Hall
Publisher: Wiley-Blackwell, 2009
ISBN: 978-0-47074-251-8

This book is an introductory handbook to working with people with intellectual disabilities who present with mental health problems and additional difficulties such as challenging behaviour, substance misuse, dementia and offending behaviour. There are also useful chapters on capacity and consent and on community care and the history of services for people with intellectual disabilities. Most contain key, up-to-date references and helpful suggestions for further reading.

This book 'does what it says on the tin'. It provides an introductory overview of a range of mental health problems and other salient issues that affect people with intellectual disabilities. As it stated on the cover, it is written predominately by psychiatrists for psychiatrists. It would be best suited for psychiatrists in training or newly qualified psychiatrists, but it could also be a useful reference guide for other professionals in training. To a lesser extent, it may also provide a useful refresher for more experienced professionals.

There are a number of very good chapters. For example, the chapter on 'effective communication' is written in a holistic and person-centred way and is practically based. 'Assessing mental capacity' is easy to read and an informative guide for a range of professionals. The chapters on 'psychotic illness' and 'pharmacological interventions' are very useful. They are very considered and broad in their focus (e.g. emphasising the biopsychosocial model and the importance of the context when assessing and treating people with intellectual disabilities). 'Pharmacological intervention' carefully describes when to use medication for problem behaviours and is sensible in its view that medication should not be used in the first instance and that a thorough contextual assessment is required - what a pleasant surprise this chapter is. The chapter on 'psychological interventions' provides a brief overview of a range of psychological approaches to mental health problems such as anxiety and depression. Although it feels like it stands alone and doesn't really make links with any of the other chapters, it provides a good overview of psychological approaches to mental health problems in people with intellectual disabilities.

The chapters on 'substance misuse' and 'offending' in people with intellectual disabilities are useful overviews of these difficulties in people with intellectual disabilities, and provide a realistic description of the literature (e.g. prevalence, treatment evidence base). The contribution on offending also provides a good list of risk assessment tools validated on people with intellectual disabilities. The chapter on 'challenging behaviour' stands out from the rest as an excellent chapter that goes beyond an overview and is thoroughly recommended.

Some of the chapters are perhaps too brief and could be better structured; the chapter on autistic spectrum disorders and mental health also contains some puzzling statements and worrying generalisations (for example, 'It is now recognised that most people with ASD are of normal or high intelligence' and 'Many people with ASD, especially the milder forms, are highly successful in business').

Although the book is a little variable in its quality, it provides a good introduction to working with people with intellectual disabilities and mental health problems overall. As an introductory text, it is not designed to meet the needs of those seeking in depth information. However, it is highly appropriate for its target audience, psychiatrists in training and has been endorsed by IAASID.

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FORTHCOMING CONFERENCES

BILD International Conference, Positive Behaviour Support -Leading the way and Reducing Restrictive Practice.	5th - 7th May 2010 - Dublin
For more information: http://www.bild.org.uk/behavioursupport.htm	
3rd IASSID European Congress	20th – 22nd October 2010 - Rome, Italy
2012 IASSID World Congress	9th – 14th July 2012 - Halifax, Nova Scotia, Canada
NADD 2010 International Congress & Exhibit Show	14th – 16th April 2010 - Ontario, Canada
NADD Ohio State 8th Annual MH/MR Conference	28th – 29th September 2010
NADD 27th Annual Conference and Exhibit Show	3rd – 5th November 2010 - Seattle, Washington
For more information: http://www.thenadd.org/pages/conferences/calendar.shtml	
Disability Policy Seminar	12th – 14th April 2010 - Washington, DC
AAIDD Annual Conference	8th – 11th June 2010 - Providence, RI
For more information: http://www.aaidd.org	
45th ASSID Australasian Conference	29th September - 1st October 2010, Hilton, Brisbane, Queensland
10th ASSID Disability Support Worker Conference	17th – 18th November 2010 – University of Melbourne

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