



# mental health and intellectual disability...

*Link*

## coordinator's message...

Welcome to the third issue of the CHW School-Link Newsletter. The CHW School-Link team has been charging ahead despite the absence of Hebah and I, while on maternity leave. Many thanks to David and Alison for working so hard while we were busy rearing our little ones in their all-important first few months of life. Parenthood is no easy feat and I now have a new found respect for all the mums and dads out there and an appreciation for all the community services and parenting manuals at my fingertips. Having questions about my babies' development easily answered from a textbook (so far at least) makes me even more motivated and determined to continue creating resources through this School-Link Health/DET/ADHC partnership to improve the mental health support available for children and adolescents who skew from the standard textbook path of development.

The CHW School-Link Supervision Pilot with Western DET was implemented in terms three and four 2010 and preliminary data suggests that these interagency case discussions of students with an intellectual disability and a mental health problem or disorder resulted in increased levels of school counsellor confidence and competence in the management of these cases. A more detailed report will be available next year.

We hope you enjoy this third newsletter issue. A/Professor David Dossetor once again delivers a thought provoking article in homage to Professor Trevor Parmenter where measures of IQ, quality of life and even spirituality are debated (pg14). Having a brother and cousin with ASD, I was particularly interested in reading about the conference review from the 3<sup>rd</sup> IASSID conference that research now suggests a lower risk of heritability of autism than previously thought (pg 4). A practical insight into the role culture can play in clinical practice is highlighted by the CHW Cultural Clinical Consultant (pg 6), a snapshot of Indigenous youth with an intellectual disability and a mental health disorder or problem is outlined on pg 3 and the drug ritalin is demystified in our regular medicine cabinet feature (pg 11).

Please send your comments about this issue and suggestions for future articles to: [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au). We look forward to your feedback.

Jodie Caruana, School-Link Coordinator, The Children's Hospital at Westmead ●

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Learn more about School-Link and the Children's Hospital at Westmead project on page 16 or visit [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)

# feature article: Positive Behaviour for Learning

*Across NSW, some special schools are implementing Positive Behaviour for Learning (PBL) both in the general management of the school, and within teaching learning programs. Some of our readers have asked for more information about this topic. The following is an excerpt from one of the earliest Australian pieces about PBL. Look out for follow-up articles in 2011:*

## **Why Positive Behaviour for Learning: The How's and Why's of Translating a US Model for Local Sustainable Education.**

*Mooney, M., Dobia, B., Power, A., Watson, K., Barker, K., Yeung, S., Denham, A., McCloughan, G., and Schofield, J. (2008).*

### **Abstract**

Positive Behaviour for Learning (PBL) is an initiative of the New South Wales Department of Education and Training Western Sydney Region (NSW DET WSR) that has been progressively introduced into schools. In adapting the US model of Positive Behaviour Interventions and Support (PBIS) program, DET WSR changed more than the name of the Australian model of the intervention. The original model was extended beyond behaviour management to emphasise the facilitation of learning outcomes. As a result of local adaptations, various changes occurred at both the school level and regional level. From fieldwork data comprising focus group discussions and individual interviews with stakeholders, the reasons for these changes and their effects, expected or unexpected, provided rich information that may facilitate further improvement of the intervention. Distinctive features of the WSR schools' adaptation of PBL were observed in terms of cultural and contextual factors.

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The implications of student behaviour for learning are becoming an increasingly major concern of teachers, parents and policy makers in Australia. Disruptive student behaviour not only impedes learning outcomes for students but also impacts negatively on teacher efficacy and wellbeing (Tschannen-Moran & Woolfolk Hoy, 2001; Lewis, 1999). Poor student behaviour, low student engagement and motivation can overwhelm teachers who often become less effective in the classroom, experience less satisfaction and are more likely to resign their positions, leading to an exacerbation of poor educational outcomes and associated behavioural problems and contributing to the problem of 'hard-to-staff' schools (Howard & Johnson, 2002). A recent study of primary teachers in Western Sydney found that even teachers who felt confident about their teaching abilities expressed concern about student disobedience, distractibility and disruption of others, as well as less frequent but more challenging behaviours such as physical aggression and bullying (Stephenson, Linfoot & Martin,

2000). In the New South Wales Department of Education and Training Western Sydney Region (NSW DET WSR) there had been dissatisfaction with the ways that behaviour problems in schools were being managed.

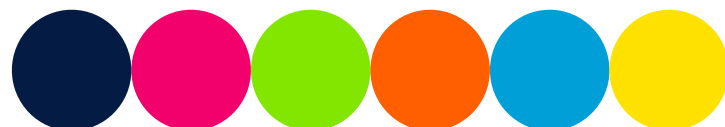
The NSW DET recently revised its discipline policy guidelines to emphasise that 'quality learning environments' should provide 'an environment free from disruption, intimidation, harassment and discrimination. To achieve this, all schools are expected to maintain high standards of discipline' (NSW DET, 2006a). In some cases, managing problems at the school level frequently led to an escalation of conflict. This is consistent with research findings that show that coercive discipline aggravates problem behaviour (Lewis, 2001). As well, the DET WSR noted disparities across the Region in the capacities of different schools to deal effectively with student behaviours. As a result, DET WSR emphasised that schools and teachers should employ more effective behaviour management programs by adopting a consistent region-wide initiative for managing student behaviour (NSW DET, 2006b).

This initiative is derived from the Positive Behaviour Interventions and Supports (PBIS) process that was developed in the United States and renamed as Positive Behaviour for Learning (PBL). This strategic initiative of DET WSR has been progressively introduced into schools across the region since November 2005. Despite the apparent success of PBL in improving student behaviour and school-wide behaviour management practices in the short period of PBL implementation, it was unclear how the implementation of this initiative, adapted from another culture, could accommodate features that are specific to the local Australian school environment. Consequently, research was conducted by the University of Western Sydney during 2007 with a cross-section of WSR schools that had implemented the PBL process. The purpose of the research was to examine the reasons for changes and their effects, whether expected or unexpected when adapting PBIS from the USA to suit specific school needs in Western Sydney.

### **From PBIS to PBL**

Impressed by the adaptability and whole school focus of the PBIS initiative in the USA, DET WSR introduce the USA model to local principals from primary and secondary schools across the region. The program was renamed from PBIS to PBL after the first group of 13 schools met in the first PBL

training conference. WSR's uptake as PBL reflects the regional priority on improving not only students' behaviour but also their learning outcomes in particular. Since then, the model has been progressively adopted for government schools across the region. Targeting positive behaviour in the USA, the PBIS approach is consistent with established, evidence-based methods of behaviour management that aim to identify, explicitly teach and reinforce identified target behaviours and minimise the use of punishment (Sulzer-Azaroff & Mayer, 1994). "Teaching behavioural expectations and rewarding students for following them is a much more positive approach than waiting for misbehaviour to occur before responding. The purpose of school-wide PBIS is to establish a climate in which appropriate behaviour is the norm" (OSEP Centre on PBIS, 2006). Thus, the PBIS model encourages schools to use data to inform the adoption of systems and practices that apply sound behavioural principles in their approach to managing student behaviour. It aims to equip schools to identify and teach behaviours that they have determined are appropriate for their students. A key feature of the PBIS model, which was attractive to WSR, is its systemic focus. The central emphasis of the PBL process is on establishing strong systems that support



both staff and students and to implement evidenced-based practices that support student behaviour and learning. Critical to this process is the gathering of observational data to inform decision-making around systems and practices and on evaluating specific outcomes on the basis of the data collected (Newcomer, 2005). An advantage of an evidence-based approach is its capacity to challenge perceptions based on prior assumptions a school may have that are often inaccurate or unhelpful. Teacher (mis)judgments and false assumptions are more easily debunked when behaviours are analysed in terms of what, actually, has occurred, in what circumstances and to what effect. The efficacy of the PBIS (and hence PBL) model is evident in the longitudinal research on how the use of behavioural data based on observing patterns of behaviour in a range of school settings, for example, school-wide (school expectations for all), non-classroom (routines, procedures, playground, hallway assemblies, cafeteria), classroom (classroom management systems and learning environment and pedagogy) and individuals (small proportion of the student population whose behaviours have a disproportionately high impact on school-wide, non-classroom and classroom systems) (Lewis

& Sugai, 1999). These data are analysed by a team of school staff and are used to inform decisions about making changes to systems and/or practices so that the smallest change has the biggest impact on behaviour and learning. Furthermore, the PBIS model promotes an explicit, structured, team based, problem solving process for developing schools' capacities to assess and address behaviour issues (OSEP Centre on PBIS, 2004). The PBIS process is conceptualised in terms of four key interrelated elements within the circle that will impact on features external to the circle. These are:

- Research-based practices for supporting positive student behaviours
- Collecting and analysing data as the basis for decision-making
- Systemic change in staff behaviour
- Academic and social outcomes (OSEP Centre on PBIS, 2004).

Research on classroom management across Australia has found that teachers frequently revert to coercive and ineffective forms of discipline when they are challenged with difficult behaviour (Lewis, 1997). Consequently, the establishment of workable, positive and sustainable processes for dealing productively with student behaviour issues remains an edu-

cational challenge for this Region and across the state.

### Summary

Though an admirable emphasis on fidelity to the PBIS model has been central in DET WSR's implementation of PBL, it is apparent that the change of name to PBL has entailed a strategic emphasis on the connections between behavioural support and learning outcomes. While it is clear that the PBIS systems model, underpinned by databased decision making has had a significant impact on teaching and cultural practices within WSR, it is also evident that the emphasis in WSR on supporting learning has influenced implementation of the PBL model. Further work to articulate and incorporate this conceptual underpinning and to consider the interface between PBL and other related school initiatives will enhance the process of contextualising the PBL initiative to meet the needs of schools in this region and support students' positive behaviour and learning.

For references and results of this research please see the full article available at <http://www.aare.edu.au/08pap/moo08423.pdf> ●

Are you implementing PBL in your workplace? Contribute to our newsletter or Tell us more by emailing [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)

## Indigenous Young People with Intellectual Disability and Mental Health Issues.

Very little data is available in relation to MH&ID within the Aboriginal and Torres Strait Islander (ATSI) community; this is in spite of the fact that ATSI peoples, it has been noted, are the most over researched group in the country. Given the data we do have available though, it does appear that young people with an ATSI background with mental health and/or intellectual disabilities are over represented in the juvenile justice system within Australia.

According to the report 'Preventing Crime and Promoting Rights for Indigenous Young People with Cognitive Disabilities and Mental Health Issues' Social Justice Commissioner, 2008, Indigenous young people in the criminal justice system are some of the most disadvantaged young people in Australia, but Indigenous young people with cognitive disabilities and mental health issues face an even greater burden of disadvantage. They are faced with institutions that fail to pick up on their disabilities, services that do not cater to their needs and a culture where they are simply forgotten or put in the 'too hard' basket.

The 2008 report by the Social Justice Commissioner (excerpt below) is both extensive and interesting. On page 16 in the report a

connection is made in relation to Indigenous young people with cognitive disabilities and/or mental health issues and the juvenile justice system.

"There is a long standing contention in the literature that cognitive disabilities and/or mental health issues are connected to offending behaviour and delinquency. There is evidence that these groups of young people are over represented in the juvenile justice system. However, there is no real consensus on how or why this is the case. In particular, there is even less known about how this affects groups such as Indigenous young people.

*Incidence of cognitive disabilities/mental health issues in the criminal justice system.* Establishing the incidence of cognitive disability and/or mental health issues amongst young people in contact with the criminal justice system is not a simple task. Unlike other personal and social characteristics that are routinely measured in statistical studies, cognitive disability and/or mental health issues are not always observable or stable. They require specialist assessment to confirm a diagnosis. Few criminal justice agencies formally collect disability data on a regular basis and even fewer research studies have been undertaken in this area.

The only comprehensive health status study of a juvenile offending population conducted in Australia has been a collaborative project between the University of Sydney, NSW Department of Juvenile Justice and Justice Health.

Based on a culture fair estimate, 10% of the Indigenous sample in custody could be diagnosed with an intellectual disability.

Indigenous young people are already at a much greater risk of contact with the criminal justice system. Nationally, Indigenous young people are 23 times more likely to be placed in detention than non-Indigenous young people. Adding cognitive disabilities and/or mental health issues into the mix increases a young person's disadvantage, and therefore, risk of contact with the criminal justice system.

Progression into the criminal justice system is not a fait accompli. Not all young people with cognitive disabilities or mental health problems go on to become offenders. However, they do appear to be over represented in the offending population." ●

The full report is available on the link provided below

[http://www.hreoc.gov.au/social\\_justice/publications/preventing\\_crime/cog\\_disr.doc](http://www.hreoc.gov.au/social_justice/publications/preventing_crime/cog_disr.doc)

# conference review: training curriculum project (TCP) goes to Rome..

Lesley Watson is a Team Coordinator at the Statewide Behaviour Intervention Service with the Office of the Senior Practitioner, Ageing, Disability and Home Care, Department of Human Services.



Presentation of the Training Curriculum Project & Evaluation Data- David Dossetor, Donna White, Jane McCarthy & Lesley Watson

The theme of the 3<sup>rd</sup> IASSID (International Association for the Scientific Study of Intellectual Disabilities) Europe Conference was *Integrating Biomedical and Psycho-Social-Educational Perspectives*. The Clinical Framework and its evaluation data were presented to delegates on October, 21<sup>st</sup> and were very well received. A lively discussion followed the presentation of the three papers and there was significant audience encouragement to publish both the curriculum and evaluation outcomes.

The conference provided a wonderful opportunity to connect with colleagues with similar areas of interest; primarily the growth of services for children and adolescents with intellectual disability and emotional/behavioural disturbance. A key attendee of our symposium was Dr Jane McCarthy, a Child Psychiatrist working at the Institute of Psychiatry at The Maudsley, King's College London. Jane was keen to discuss differences in our service systems and the allocation of resources to this area. Jane, like us, noted the relatively small number of presentations specific to child and adolescent mental health/challenging behaviour.

There were many inspiring presentations over the week, amongst these the plenary session given by Dr Ted Brown, which focussed on recent progress in understanding the genetics of intellectual disability. This presentation highlighted the genetics of autism as one area of new and additional discovery and talked to the number of specific gene mutations and copy number variations within individual cases. Dr Brown outlined recent studies on autism that suggest that there is a lower risk of heritability than previously thought. These same studies point to the prenatal environment and epigenetic factors, in genetically susceptible children, as poten-

tial contributors to autism phenotypes. This work is continuing.

Included in the many fascinating presentations were several Australian research projects and practice papers that offered new insights into our work. Keith McVilly (School of Psychology, Deakin University, Burwood, Australia) spoke to the models of effective services for people with challenging behaviour and highlighted the current focus on ecological manipulations and environmental engineering within behaviour support plans. There was discussion in this session about the tendency to minimise the importance of systematic skills building, including a drop off of adaptive behaviour skills assessment for planning and intervention, rather than diagnosis only. This session highlighted the complexity of the service system required to meet the needs of this population and affirmed that bringing together critical elements of this system is achievable where a set of practitioners and the agencies they represent are committed to a sector-wide longitudinal plan.

Of great interest was the symposium presented by Karen Nankervis (University of Queensland, Ipswich, Australia), titled *Relinquishing Care*, which was seated within the Families and Parenting stream. This presentation focussed on the many reasons a family might relinquish care of their family member with a disability and considered the age of the person and the scale of their support needs as contributors to this decision. Several take-home messages stood out – the need for respite models to incorporate intervention alongside respite, as a means of addressing some of the causal factors that lead to relinquishment, and that challenging behaviour is often a key factor in cases of relinquishment (more than half of the cases considered as part of this research identified challenging behaviour as causal). Factors examined by the study included individual characteristics, family characteristics and the support context.

Also home-grown was Kylie Gray's presentation on the behaviour and emotional problems in pre-school children with developmental delay (Centre for Developmental Psychiatry & Psychology, Monash University, Clayton, Victoria, Australia). In this study, the Developmental Behaviour Checklist – Under 4, had been used to examine the behaviour problems of children in a community setting aged between 18-48 months, with or suspected of developmental delay. The study also considered associations with maternal and paternal psychosocial distress. This presentation underlined that greater understanding of the emergence of behaviour and emotional problems during early childhood is critical in developing specific early interventions. Kylie suggested that this may also provide insight into the origins of severe behaviour difficulties observed in later childhood and adolescence.

Following Kylie's presentation in the Mental Health and Behaviour stream, Eric Emerson spoke about the predictors of persistent conduct difficulties. An Australian sample had been used and the research done in collaboration with Stuart Einfeld and Roger Stancliffe. The bottom line was that there were strong and independent associations between persistent conduct disorder and child gender, socio-economic context, family composition and parenting styles at aged 4-5 years. The implication here is that there is a need for preventative preschool interventions for children at risk of persistent conduct difficulties.

Other presentations of note included a series of three regarding parental stress, moderated by Chris Oliver, a systematic appraisal of the evidence for behavioural intervention presented by Kathy Lowe and a presentation delivered by Richard Hastings titled, *Continuities of engagement: towards a revised analysis of staff working with people who challenge*. This last presentation provided an updated model for considering staff behaviour and support needs. This research suggests a move away from staff training and staff beliefs about challenging behaviour to a model of support that includes acknowledgment of staff emotional responses. Mindfulness and acceptance-based training were flagged as potential means of addressing staff avoidance and escape processes.



**Poster Session: A special school based initiative for improving mental health outcomes of children and adolescents with ID**

Thankfully David thrives under pressure, because as well as the TCP symposium during the afternoon of the 21<sup>st</sup>, he also managed the poster presentation of the School Link project. David had a steady stream of delegates interested in speaking to him about the details of this initiative. Many educators in particular wanted to talk about the connection of mental health services and educational settings and were very pleased to be able to take copies of the School-Link newsletter away.

All in all, an exhausting but enriching few days. ●

Visit [www.iassid.org](http://www.iassid.org) for more information

# upcoming training...

## Intellectual Disability:

The **Centre for Disability Studies** at the University of Sydney, and **Australasian Society for Intellectual Disability** (ASID NSW) is presenting a series of workshops in which people with intellectual disabilities and their supporters can learn how to *Plan and Direct Inclusive Research*. 6 Dec 2010, 28th Jan 2011 and 18th March 2011. participants will then get the chance to share at a mini conference towards the end of 2011. For a brochure in Easy English, contact 02 8878 0500 or email: [mcarrick@med.usyd.edu.au](mailto:mcarrick@med.usyd.edu.au)

**Stopping the abuse and neglect of people with intellectual disability.** Griffith University and Endeavour Foundation. Griffith University Nathan Campus. 13th and 14th of December. RSVP to Debby Johnson by email [d.johnson@endeavour.com.au](mailto:d.johnson@endeavour.com.au) or fax 07 3908 7278. More info <http://www.qldalliance.org.au/international-symposium>

## Mental Health:

**2010 Central Coast Mental Health and Schools Conference.** Caring, Connecting and Collaborating. 16th December 2010, Kariong Mountains High School. \$65, 8.30am-3.15pm. DET contact Daniel Hayes 0409 839 092, NSW Health contact Helen Astolfi 4304 7878, Catholic Schools Office contact Elizabeth Douglas 0418 403 668.

**Robert Mezzina Seminar and 'It can be done'** Film showing. Addresses the lessons learned moving from clinical services to community based mental health in Italy. 15th December 2010, NSW institute of Psychiatry, 5 Fleet St, Parramatta. 3.30-8.00pm. Register by contacting [joanne.morgan@nswiop.nsw.edu.au](mailto:joanne.morgan@nswiop.nsw.edu.au), p: 9840 3833. For more information contact [michelle.everett@nswiop.nsw.edu.au](mailto:michelle.everett@nswiop.nsw.edu.au)

**International Mental Health Conference,** Gold Coast. 24-26th of August 2011. Personality Disorders; Out of the Darkness. Visit <http://anzmh.asn.au/conference2011/> for more information and a list of speakers or email [conference@anzmh.asn.au](mailto:conference@anzmh.asn.au).

**Rock and Water Workshop.** 16-18th May 2011. Campbelltown. \$989. Family Action Centre 4921 6403 or [FAC-events@newcastle.edu.au](mailto:FAC-events@newcastle.edu.au)

## Disability:

**People with Disability** training calendar includes *Disability Awareness* 10th December 2010 Sydney, 23rd February 2011 Queanbeyan, 10th March Newcastle 9.00am-4.30pm \$300. *Responding to Abuse and Neglect* 22nd February 2011 Queanbeyan, 9th March 2011 Newcastle, 15th March 2011 Sydney 9.00am-4.30pm \$300. *Responding to Sexual Assault* 7-8 December 2010 Queanbeyan, 1-2 March 2011 Sutherland, 29-30 March 2011 Newcastle, 9.00am-4.30pm \$650. [www.pwd.org.au/archive/10/July2010-June2011.pdf](http://www.pwd.org.au/archive/10/July2010-June2011.pdf)

**Resourcing Families** is providing a free information session for family members and friends of young people with developmental disability. *Circles of Support* is run near your location at a time convenient to you. Contact 9869 7753 or 1800 774 764 (non metro) or email for more information at [info@resourcingfamilies.org.au](mailto:info@resourcingfamilies.org.au) You can also visit [www.resourcingfamilies.org.au](http://www.resourcingfamilies.org.au)

*Physical Disability Council of NSW* presents **Word Matters;** A workshop dedicated to exploring the language of disability in media. Friday 10th December, 10.30am-12.00pm. The Sargents Centre, 9-13 First Avenue, Blacktown, Must book, contact Amy Lawton on 9839 6067 or [amy.lawton@blacktown.nsw.gov.au](mailto:amy.lawton@blacktown.nsw.gov.au)

ADHC is providing **Acquired Brain Injury Awareness training** commencing February 2011. E-learning training modules and a series of facilitated training workshops will be provided across NSW. A summary of the content is now available at: <http://www.abistafftraining.info/>. To register your interest for the facilitated training workshops in 2011, please contact arbias Ltd at email: [training@rbias.com.au](mailto:training@rbias.com.au)

## Challenging Behaviour:

**Challenging Behaviours Collaboratively Workshops.** These workshops are aimed at parents with children with ADHD, Oppositional Defiant Disorder, Conduct Disorder or Challenging Behaviour. Thursday 10th Feb and every Thursday until the 31st March 2011. 6.30-8.30pm. Buzy Bee Kindy 102 Merlin St, The Oaks. Free of Charge. Registration essential Community Links Wollondilly 4683 2776

**Karitane** offers a one day interactive workshop for professionals. Toddler clinic workshop designed as an introduction to *Parent Child Interaction Therapy Model* to gain an understanding of challenging behaviour. Carrahar, Friday 4th March 2011, Friday 3rd June 2011 and Friday 2nd September 2011 or organise your own workshop. 9.00am-4.30pm. \$175. Contact 9794 2300 to register or 9794 2348 to organise your own.

## Autism Spectrum Disorder:

**Getting Ready for 2011;** Orientation and Beyond. Includes information about teaching strategies and positive behaviour support. Monday 6th December Penrith and Tuesday 7th December Cammeray. \$125. Phone or SMS 0433 660 379, [dearne@suelarkey.com](mailto:dearne@suelarkey.com) or Fax 1300 656 408

**Free workshop** for family and carers of someone with Autism by Tony Atwood. Dubbo. 10th March 2011, 8.3am-3.00pm. Contact 1800 052 222 by 25th February

**Asia Pacific Autism Conference (APAC).** International and national speakers. 8-10 September 2011. Perth. Visit [www.apac11.org](http://www.apac11.org). Contact 08 9389 1488

## Save the Date!!

School-Link Conference 2011

*From little things, BIG things grow...*

Mental Health and Intellectual Disability-  
From Theory to Practice  
27th May 2011

Register your interest; Contact Vivian Benjamin at [vivian.benjamin@sswahs.nsw.gov.au](mailto:vivian.benjamin@sswahs.nsw.gov.au) or phone 9616 4251

# a day in the life of Hadia Baassiri with case study...



*Hadia Baassiri  
Cultural Clinical  
Consultant  
Department of  
Psychological  
Medicine*

*The Children's  
Hospital at  
Westmead*

*Hadia Baassiri has been the Cultural Clinical Consultant at the Department of Psychological Medicine at Children's Hospital at Westmead for 6 years. This position has been a partnership project position with the Centre of Transcultural Mental Health. This article is based on a presentation by Hadia, David Dossetor and Lesley Whatson at the TheMHS Conference (The Mental Health Services) in Sydney in September 2010 describing her role working with families with a child with intellectual disability. Visit [www.themhs.org](http://www.themhs.org)*

The developmental psychiatry clinic is a cross agency multidisciplinary conjoint

clinic which runs in partnership between the Developmental Psychiatry team at the Children's Hospital at Westmead, the Statewide Behaviour Intervention Service of ADHC and more recently the Principal Psychologist of DET. This clinic consists of a child psychiatrist/s, clinical psychologist/s, OT, Speech therapist, pharmacist, Principle Psychologist (DET), Special educator, paediatric registrar and Cultural clinical consultant. The clinic consults to the referring paediatrician, the involved Disability team, representatives from the school and other involved services as well as to the child and family. Cases referred to this clinic have complex behaviour, developmental and mental health problems in their context. During the last five years, 45% of cases were from culturally and linguistically diverse backgrounds (CALDB). This over representation of CALDB in this tertiary clinic suggests that as a group they may have greater difficulty accessing services for their children with intellectual disability and mental health problems. This view was also expressed by school counsellors in the CHW School-link needs analysis.

Review of these cases suggest that the problems encountered by CALDB are sometimes directly related to cultural diversity issues such as: language barriers, cultural perspective about intellectual disability or mental health, lack of advocacy within schools and other services and lack of knowledge of existing services. Parenting style is not specific to any culture, but cultural differences often

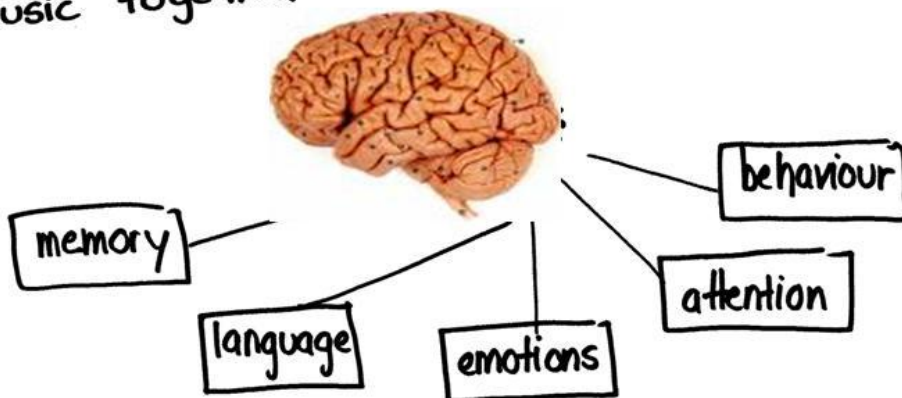
lead to greater inflexibility in understanding the influence of parenting style on childhood development and behaviour such as autocratic/harsh parenting or excessively permissive/enmeshed, indulgent parenting. A regular problem is unrealistic expectations, for example parents wanting children to achieve in maths/reading when they lack basic independence and self care skills as might be expected from a child of a developmental age of 2-3 years old. Sometimes there is a failure to implement strategies recommended or problems with limit setting. Sometimes there is excessive expectation that medication will cure problems. Other factors can add to the burden on families managing their children with intellectual disability and challenging clinicians' expertise. For example, the roles and expectations within the family system in some cultures, cultural experiences of those families prior and after settlement need to be understood to reach CALDB families and help them to understand, implement and comply with treatment. Sometimes this can contribute to relationship stress or mental health problems in other family members.

My role as a cultural clinical consultant is to provide cultural consultancy and reflective clinical practice around culturally based issues prior and during the assessment and intervention process. This includes culturally appropriate assessment, formulation, referral to culturally appropriate services if necessary, educating clinicians about the influence of culture, language and ethnic heritage on symptom presentation and the impact of immigration and adjustment as well as cultural beliefs about illness and treatment. Sometimes my role becomes one of mediating between a clinician and a family over different conceptual frameworks for understanding a clinical predicament, and helping find common ground to progress the treatment of the child or young person.

## Case example

A 15 year old boy was referred to the clinic due to problems with outbursts of anger and aggression and other antisocial behaviours that had brought him to the attention of the police. He attended a special class in a mainstream school. He had a mild to moderate level of intellectual disability, history of speech and language impairment, short term memory deficits,

Front part of the brain is like a conductor in an orchestra. It controls and coordinates all the other parts of the brain, like the conductor tells the strings, woodwinds and other parts of the orchestra how to play music together.



# *My role is to provide cultural consultancy and reflective clinical practice around culturally based issues prior and during the assessment and intervention process*

ADHD and a frontal lobe syndrome. His early history included health complications around his birth, and a history of possible head injuries in early childhood. He was only one of a large family to experience significant learning and behavioural difficulties. The family social history was complex, with repeated experience of war related violence in Afghanistan. The family came to Australia as refugees.

## **Assessment and intervention**

The first intervention occurred prior to the initial appointment with the family, while preparing for the assessment. An interpreter was arranged (Dari language). I consulted the treating team regarding the social and political circumstances of the family in Afghanistan. The family experience as refugees pre and post migration experiences were likely to include: loss & grief, trauma, being cut off from families and other sources of social support and settlement issues; experience of health services in the country of origin where many people during wars do not have any access to health services. Political issues affect people differently even within the same culture. This family came from a minority group in Afghanistan (Hazaras). Given the psychosocial circumstances of this family and that literacy problems are common within many CALDB communities, I recommended that verbal information would be more beneficial than written. The traditional family structure in Afghanistan would have respect of the hierarchy and the influence of the extended family.

Assessment confirmed that the family did not have any access to medical services in Afghanistan. All children were born at home. The family had witnessed a lot of violence, trauma and torture. The patient's father was on a disability pension, the older sons look after the siblings, including the patient. Mother was a full time housewife who tried to give the patient anything he asked for and cov-

ered for him when he was in trouble to keep the peace at home and to avoid her in-laws blaming her for his behaviour. The grandparents had a big role in parenting and treatment decisions. Cultural factors that impacted upon this family's engagement and follow through with the service. Importantly language barriers, particularly in the context of literacy difficulties, are likely to limit understanding information and awareness of existing services and resources.

There were issues with the use of an interpreter. In the initial assessment, despite the presence of a Dari interpreter, the family persisted with using his younger sister to interpret for them. The family had concerns about confidentiality with mental health and disability issues within this community. Accordingly I recommended a Dari speaking interpreter from Iranian background. Stigma and embarrassment also contributed to the family reluctance to use an interpreter and they were embarrassed to discuss the son's criminal activities. It was explained to the family through their daughter that our job was to treat their son's mental problems and not to talk about his criminal activities. This helped the family become more comfortable and engaged.

Their understanding and beliefs about disability needed consideration. For example, the family was very focussed on medication, with limited understanding of the nature of their son's problems, and presuming and hoping for a medical cure. They also focused on his problems of memory deficits rather than broader intellectual disability (ID). The family refused the option of a special school and could not understand why their son was not achieving like his siblings. They had difficulty accepting and understanding the diagnosis of intellectual disability in the context of a normal physical appearance and the value of special education.

The team had difficulty explaining their son's conditions, especially medical terminology such as: executive functioning. It was important to avoid jargon and to use clear descriptions in ordinary language to improve the communication with the family. I suggested the use of analogy and visual supports as a strategy to address some of the communication difficulties. Since the father had an interest in music, the concept of an orchestra conductor was a useful analogy for explaining the concept of executive functioning in the brain. This format made the complex concept accessible for the family. Such psycho educational approaches helped their access to services: translated information and visual support strategies, educating all family members about the child's disability, including the extended family, educating family members on services available and encouraging them to use them. We emphasised the rights of family members to request an interpreter and a cultural consultant for clarification and involvement in the treatment plan.

Over a number of sessions, these approaches contributed to a successful engagement with everyone in the family. Respect of the family beliefs, understanding and culture enabled their empowerment and self determination. Interventions reduced jargon and made information more accessible for the family. These approaches contributed to improved outcome. The Multicultural Disability Advocacy Service was involved to advocate for the family and a bilingual Dari speaking clinician from the Transcultural Mental Health Centre was used during a school visit. Such additional culturally appropriate services continued to help the family with their further journey through the specialist service systems for young people with intellectual disability and mental health problems. ●

*Interesting Reading*  
**My Name is Jack-  
Australian Story about  
Ian Rogerson and his wife Nicole**

<http://www.abc.net.au/austory/content/2007/s2652214.htm>

## resources...

- **Free online Advice Sessions** about Down Syndrome available. These online advice sessions provide interactive discussions between participants and an expert panellist on a range of different topics. They are provided free of charge and are suitable for parents, teachers, teaching assistants, educational/school psychologists, speech and language therapists/pathologists, other health and education professionals and representatives of support groups. The online advice sessions are convenient and easy to join, and are available anywhere in the world with a computer, telephone line and Internet connection: Visit <http://www.downsided.org/en/gb/> and select Events for details of upcoming seminars. This is a great resource with opportunities for free training
- **Learning Difficulties Coalition** is a coalition of individuals and parent support groups which provides support and information about children (5-18yrs) with learning difficulties and related conditions. Their recent newsletter for term four is filled with interesting resources and ideas to help in the school setting. There is also a helpline for parents open during the school term 02 9806 9960, for more details visit [www ldc.org.au](http://www ldc.org.au)
- **Resourcing Families** is an initiative of family advocacy (a state-wide not for profit disability advocacy organisation that works with families to promote and defend the rights and interests of people with developmental disability). Resourcing families offers information and advice via the phone and email; workshops about a range of topics and a mentoring system to support networking and the sharing of information. Their website [www.resourcingfamilies.org.au](http://www.resourcingfamilies.org.au) has useful resources and information for families. Contact on 9869 7753 or 1800 774 764 for NSW callers outside Sydney.
- **Respite Camps for teens with an intellectual disability** provided by *Sport and Recreation and Aging, Disability and Home Care*. Have a look at the flier on our website [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au) or contact the respite camps coordinator/intake officer from Aging, Disability and Home Care in your region. Western 1300 134 450, Southern 1300 841 566, Northern 6659 1331, Hunter 1300 205 268, Metro North 9841 9438 and Metro South 9334 3827.
- **Healing Thresholds Newsletter**. Connecting Community and Science to Heal Autism. Healing Thresholds is a free website dedicated to healing the lives of families touched by autism. Provides comprehensive therapy fact sheets, daily updates of autism therapy research and news, and a global directory of autism-related therapists and services. <http://autism.healingthresholds.com/>
- **CHERI** is pleased to announce that the presentations from this year's conference 'Moving to Succeed: Supporting Motor Difficulties and Utilising new Technologies' are now available and have been uploaded to the CHERI website. Visit the link below. <http://www.cheri.com.au/presentations.html>
- **Aspect Autism Information Line** is a free service staffed by professionals and has a wide range of information about autism spectrum disorders, services and resources. Call 1800 069 978 or email [infoline@autismspectrum.org.au](mailto:infoline@autismspectrum.org.au)

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# the medicine cabinet: Ritalin...

This column addresses the use of medications in children and adolescents with an intellectual disability. It will attempt to cover the type of information helpful for non-medical people working with these children.

George Liangas  
Child Psychiatry Fellow with special interest in intellectual disability

## Ritalin

**Generic Name:** methylphenidate (METHYLPHENIDATE) Brand Names: *Concerta, Ritalin, Ritalin LA*

Ritalin belongs to the stimulant class of medication. The other medication in this class is dexamphetamine. The stimulants are the first-line medications for the treatment of Attention-Deficit/Hyperactivity Disorder (ADHD). Attention Deficit Disorder (ADD) is a subtype of ADHD, formally known as 'ADHD, inattentive type'. ADHD can be a very disabling illness because affected children find it much harder to be settled and focused, and this problem affects their ability to progress at school. It also affects other aspects of their lives as they grow up, such as following instructions at home, participating in sports, learning to drive, and focusing on their tasks when they get a job. In many cases, children with ADHD will 'grow out of it' as they progress through adolescence and early adulthood, but often by that stage, they are affected by 'second order changes' that are more enduring, such as self-esteem, scholastic abilities, and the quality of the relationships at home, school and the wider community.

ADHD is found in up to 7% of children in the general population, but in 15-30% of children with intellectual disability. One reason for why these two disorders coexist so commonly is that they both, along with the autistic spectrum disorders, are believed to be derived from problems in the brain's development.

Ritalin and related medications help to target the core symptoms of ADHD; namely inattention, hyperactivity and impulsivity. In other words, the medications help these children to be more focused and settled. They literally are performance enhancing in terms of learning capacities and emotional regulation. However long term effects are mediated by the second order changes mentioned above.

Unlike most other medication, the effect of Ritalin is immediate; i.e. on the same day of administration. These effects are especially noticeable in the classroom, and hence it is often helpful for teachers to note these parameters before and after the medication is started, and feed this back to the parents, carers and/or clinicians. In saying this, many children's behaviour problems are more complex than simply attributable to ADHD. Thus, often a comprehensive management plan including behavioural interventions and is usually also required to manage behavioural problems.

## Children's behaviour problems are more complex than simply attributable to ADHD

The stimulants are generally safe medications when used correctly. The main side-effects include loss of appetite and poor sleep. Prescribing Ritalin earlier in the day is a common way to manage the potential sleep problems. If there are decreases in appetite, there tends to be a rebound increase in appetite when the medication wears off in the afternoon or evening. Other potential side effects include nervousness, irritability, drowsiness and dizziness. For those suffering from tic disorders, stimulant medication can make them worse, and just as likely to make them better. Sometimes, these side effects can be tolerated, but if they cannot, the medication would need to be ceased or changed. Sometimes, one child may not tolerate one stimulant but may tolerate another. When no stimulant medication can be tolerated, a non-stimulant medication for ADHD may be considered. These medications include Strattera (atomoxetine), Catapres (clonidine) and Endep (amitriptyline). Sometimes combinations of these medications may be needed.

Stimulants work in approximately 80% of children with ADHD. However, in children with intellectual disability the rates of success in lower and rates of side effects are

higher. This is a truism of psychotropic usage in children and adolescents with intellectual disability. Unfortunately their need for medication is often greater, as other psychological approaches used in the mainstream population are often unsuitable or ineffective.

The effect of Ritalin is very short, generally lasting 3-4 hours. Hence, they are often given 2 or 3 times per day. Ritalin LA and Concerta have been formulated to be released slowly once inside the body and hence have a longer-lasting effect, requiring once-daily dosing. Typically the initial dose is determined using the shorter-acting form, and then there may be a switch to the longer-acting forms.

Stimulant medications can be misused by those who abuse substances. For this reason stimulants are regulated by the NSW Pharmaceutical Board. This is not a problem for the children that really need them for symptom management, and research has shown that responsible medical management of ADHD reduces the risk of a young person becoming a substance abuser. Potential for substance misuse is even less of a problem for children and adolescents with intellectual disability. However, there have been cases where people have taken these medications from the children to whom they have been prescribed, and taken by others inappropriately. In those cases, the prescriber and the authorities need to be informed.

By and large, however, the stimulants are very beneficial medications that can help manage a potentially very impairing condition. The teachers' role in the prescription of Ritalin is important as they are in an ideal position to monitor the effects of these medications in the classroom. ●

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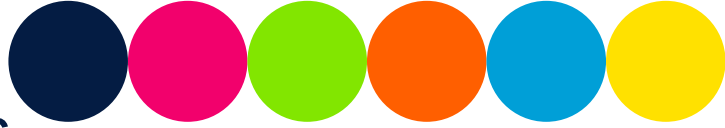
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## in the news...

### Autism Register

*AIHW Online News Issue 28, October 2010*

THE Functioning and Disability Unit at the Australian Institute of Health and Welfare are working with the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to explore the feasibility of developing an Autism Spectrum Disorders (ASD) Register. This register would record the diagnosis of people with ASD, and would include sufficient diagnostic and treatment detail to inform policy and to support the development of future research.

Dr Uebel-Yan of the Functioning and Disability Unit said there are fluctuating rates of ASD reported across the world. 'Rates have been reported as low as 2 to 5 per 10,000 or as prevalent as 100 in 10,000'. Australian rates are suggested as averaging 46 in 10,000 among 0 to 6 year olds and 77 in 10,000 for children aged 3 to 5 years. The Autism Spectrum Disorders Register would cover Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Delay-Not Otherwise Specified, Childhood Disintegrative Disorder and Rett's Syndrome. Primary Contact Sean Ackland Functioning and Disability Unit, Australian Institute of Health and Welfare [info@aihw.com.au](mailto:info@aihw.com.au)

### Significant health gap between Australians with and without disabilities

*Menzies Health Policy - visit [www.menzieshealthpolicy.edu.au](http://www.menzieshealthpolicy.edu.au) Accessed 30th November 2010*

Almost half of Australians with severe or profound disability are not in good health, according to a report released today by the AIHW. The report, *Health of Australians with disability: health status and risk factors*, found that 46% of Australians aged 15-64 years with a severe or profound disability reported poor or fair health, compared to only 5% of those without disability. People in this group had higher rates of all types of long-term health conditions than those without a disability. People with severe or profound disability were more likely to have acquired a long-term health condition earlier in life.

### Disability groups call for Labor to honour its funding promise

*Adele Horin, SMH, October 27, 2010*

DISABILITY groups are rallying to demand the state government commit \$2.5 billion over five years to new services and housing it has promised. The services were outlined in a 10-year strategy announced in 2006 by the former disabilities minister John Della Bosca. The government provided \$1.3 billion for the first five years. But with the funding to run out next year and no money for the next five-year stage allocated in the forward estimates of the budget in June, disability groups are keen to hold the government to its promise.

In the first five years, the government had funded 1400 new accommodation places, 600 extra attendant care packages, an extra 2800 therapy places, and nearly 500 more intensive support packages.

### Mental Health Hospital to Open in Kellyville

*Jade Wittman, Hills News, November 02, 2010*

THE Hills Clinic will open a purpose-built private mental health hospital in Kellyville to meet growing demand for mental health treatment in the Hills — the first of its kind in NSW. The clinic will accommodate 32 patients and extend to a 60-bed unit within three years, set among 8000 square metres of therapeutic gardens and next to another 8000 square metres of public space. The plan was announced at a Mental Health Month seminar on Saturday attended by mental health professionals, community members and keynote speaker John Brogden.

### There's an App for that!

*Bridget Borgabello, November 16, 2010*

iPad and iPod Touch application developers have recently created several programs which help aid the learning and development for children with autism. Proloquo2Go is a new application that is designed to offer an easy communication platform for people who may have difficulty speaking. The app features natural sounding text-to-speech voices, language symbols and a default vocabulary of over 7,000 words. The app allows the user to tap a series of symbols that are then placed into the message box, and the sentence is spoken by the chosen voice. Users can even create and store regular sentences to their library for fast and easy access to commonly used phrases. Typed paragraphs can be automatically converted into symbols. Read More about the programs many features at <http://www.gizmag.com/ipad-offers-autism-breakthroughs/16866/>. Tell us what you think of this! Email us [schoolink@chw.edu.au](mailto:schoolink@chw.edu.au)



facts and figures...

## Interesting Facts to Know!

The Hon Ian West MLC, has tabled the final report of the Inquiry into services provided or funded by ADHC. Some of the key recommendations contained in the report include: the creation of an independent agency to monitor service quality and compliance, handle complaints and manage third party accreditation of disability service providers; the provision of at least \$2.5b for phase 2 of Stronger Together; the provision of free interpreter services for people with disability who are from NESB and an increase in the number of supported accommodation placements available. You can download the report from [parliament.nsw.gov.au](http://parliament.nsw.gov.au)

The 3rd of December is International Day of People with Disability. This day recognises the contribution of people with a disability and brings together people with a disability and the general community. There are many events held throughout December. Check out [www.idpwd.com.au](http://www.idpwd.com.au)

NSW Health is seeking proposals for a Specialised Clinical Service Pilot for people with Intellectual Disability whilst the Australian Government is commissioning early advice on assistance for students with Disabilities and Special Needs. We are on the right track! Reference: NSW Health RFP/HAC 10/51 and DEEWR Minister for School Education 5th Nov 2010

The Intellectual Disability Rights Service is a community legal centre in NSW who work with people with an intellectual disability to exercise and advance their rights. They also support people with an intellectual disability in police custody. [www.idrs.org.au](http://www.idrs.org.au) or 1800 666 611

Over 6,500 young people with a disability are living in aged care facilities throughout Australia with no alternatives. SMH, Dec 3, 2009. [www.smh.com.au](http://www.smh.com.au)

## reviews...



### Journal/Book Review:

#### **The Curious Incident of the Dog in the Night Time**– Mark Haddon.

This funny and heartfelt book is the story of Christopher, a young boy with Aspergers as he investigates the murder of his neighbours dog. As he finds out more about the dogs murder, other things about his world also come together. This fiction novel is written from an interesting perspective of this young boy who loves puzzles and maths. Some light summer reading.



### Website Review:

#### **www.downsed.org**

Downsed International is a great resource for anyone working with clients with Down syndrome. Have a roam through their website that includes research, information, assessments and outreach. This is a UK-based charity that works around the world to improve education for young people with Down Syndrome. Check-out our upcoming training on page 5 to get in contact with their free online training sessions.



### Organisation Review:

#### **Centre for Disability Studies (CDS)**

The CDS is a non profit organisation that designs and develops research and disseminates information to improve the lives of people with disabilities. The centre also has a focus on teaching and clinical practice as part of the Sydney Medical School. Head to their website for conferences, recent presentations, clinical services, current research, and many articles to read through.

[www.cds.med.usyd.edu.au](http://www.cds.med.usyd.edu.au)

Have you been to a conference, read a book or visited a website that you loved?  
Send us an overview to: [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)

**Peckys Limited Peer Support** is a recreational program for adolescents with intellectual disabilities aged between 13–18 years who reside in the Prospect/Cumberland Local Government area.

The Peer Support program offers a variety of community and centre based activities for service users and provides a supported environment to meet new friends, develop skills and see new sights.

Activities & programs offered may include: Bowling, Taronga Zoo, Sports, Craft, BBQ's & Lunches out, Aquarium, Public Transport, Movies, National Parks, Bushwalks, Fairs & Shows, Beach visits, Weekends away, Museum's, Concerts and Live Shows, Cooking, Luna Park, Sydney Tower experience, Fishing, Disco's, Wood work, Competition days, Motor cycle rides on modified bikes (wheel chair accessible), and Night Activities.

Peer Support programs are planned in-cooperation with: skill building, educational activities, sensory activities, light exercise, leisure and familiar activities to facilitate overall general improve-

ment, self independence and empowerment.

Hours of operation are Saturday's 10.00am- 4.00pm. The Peer Support program meets and greets client's at Seven Hills station car park on days of operation (a convenient location easily accessible by public transport).

Through recreation, Peer Support aims to create opportunities which encourage members to interact with peers, build new friendships and increase social experiences in a FUN environment.

The Peer Support program currently has vacancies within our program. So whether you are looking at developing some new skills, experiencing new places and activities, forming new friendships or just want to have fun, we are the program for you.

#### **Contact**

Peer Support Coordinator-  
Jodie Caruana  
email- [peersupport@peckys.org.au](mailto:peersupport@peckys.org.au)  
phone- 96883268 or  
mailing address- PO Box 889 Seven Hills NSW 1730



# training in mental health and intellectual disability for Paediatricians ...

*Dr. Pankaj Garg, Advanced Paediatric Registrar with the Paediatrics and Child Health division of the Royal Australasian College of Physician currently on a 6 month term with the Developmental Psychiatry Team, Department of Psychological Medicine, Children's Hospital at Westmead.*



I chose to do a training term in Child and Adolescent Psychiatry with the developmental psychiatry team within the Department of Psychological Medicine at the Children's Hospital at Westmead. I felt my confidence was shaky in a few prior experiences in dealing with families, and in handling children with complex problems involving behavioural and mental health issues in the context of intellectual disability, pervasive developmental disorders, and children with complex tics with associated co-morbidities - the term was both a challenging and fun experience, vastly different to problems in acute paediatrics.

Learning to manage children with complex issues in the context of challenging family dynamics was an indispensable life experience. The impact of these children with high needs on families was self evident. I witnessed the positive impact of parent training programs such as Triple P on these families which highlighted a significant need for broader or even universal intervention. I learned to appreciate the role and importance of various support services like disability services (ADHC), and welfare services (DOCS) and local community mental health teams.

It was surprising and sobering to witness the wide spectrum of medical conditions and problems associated with intellectual disability. It was an eye opener to witness the wide range of possible reasons for

challenging and often disruptive behaviours these children displayed. On one end of the spectrum are the physical triggers such as pain, dental problems and constipation etc, while on the other, there were co-existing mental disorders such as ADHD, mood dys-regulation, anxiety and depression. Also it was interesting to experience behavioural phenotypes associated with rare specific medical conditions such as ADHD with Sanfilippo syndrome (Mucopolysaccharidosis Tye III).

A critical skill is appreciating the principles and roles of psychopharmacology in the management of children with complex needs. More specifically the beneficial role of drugs was gained such as: SSRI'S for depression and anxiety; atypical antipsychotics and mood stabilizers for mood dys-regulation; stimulants, clonidine and tricyclic antidepressants for ADHD and Risperidone for self injurious behaviour and aggression. One also has to appreciate the limitations and need for close surveillance of side effects of medications in these children.

I learned about the impact of complex trauma (including emotional abuse and neglect, sexual and physical abuse, witnessing domestic violence, etc) on children's development of secure attachment. I noted with anguish the consequences of complex trauma on core capacities for self-regulation and interpersonal relatedness in children. I found that trauma has evident far reaching effects on domains of attachment, biology, affect regulation, dissociation, behavioural control, cognition and self concept.

I learned about the theory of attachment models and the various causes, course and prognosis of children presenting with conversion problems. I found the recent research relating to neurobiology to explain the link between physical symptoms of conversion disorders and psychology interesting. The role of multi-disciplinary teams and involvement of families in a positive way was indispensable.

The interface between neurology, child

**The role of multi-disciplinary teams and involvement of families in a positive way was indispensable.**

psychology, psychiatry, developmental paediatrics, adolescent medicine and principles of family and social systems was intriguing. It left me with more questions than answers. The value of the roles of allied health professions such as child clinical psychologists, neuro-psychologists, social workers, family therapists could nowhere be better seen. The diagnostic dilemmas and uncertainties even with validated tools were observed. The role of school staff including counsellors and teachers in supporting these children in a learning environment is an important contribution.

The term also gave familiarity with the principles of psychosocial interventions such as Cognitive and Dialectical Behavioural Therapy. It was interesting to understand Becks cognitive theory of how an individual's view of themselves and



# early days project on autism spectrum disorders...

their world determines behaviour and the basis of cognitive behaviour therapy (CBT) on cognitive triad, errors and beliefs. The wide reaching role CBT was new to me, often as an adjunctive therapy, in a range of conditions such as anxiety disorders (including phobias, obsessive compulsive disorder, generalised anxiety disorder), depression, bulimia nervosa, binge eating, insomnia, post traumatic stress disorder, bipolar disorder, schizophrenia, chronic illness, personality disorders and pain and somatoform disorders.

I was also introduced to the principles of family therapy, to family communication and emotional processes and the need for the family therapist to stay out of the emotional pull to act effectively as a neutral therapist. I appreciated the structured assessment of families based on four basic elements of: family functioning viz: family structure (adaptability, cohesion, boundaries and subsystems); family communication (clarity, emotional expression, problem solving); family beliefs (recurring themes in life, puzzling patterns); and family regulation of behaviour and child development.

Being first on call for child and adolescent psychiatry was a challenging prospect especially for the first few weeks. However, nothing could provide a more enriching learning opportunity than taking up this challenge. This scenario gave opportunity to see a variety of cases including: the impact of minor noxious events disrupting and overwhelming children with complex trauma, acutely suicidal young adolescents often presenting with self harm (often from poorly organised families), unmanageable disruptive behaviours exhibited by children with pervasive developmental disorders, acute drug and alcohol overdoses, substance abuse related mood disorders, children presenting with acute on chronic psychosis and the occasional child with mania/hypomania. This experience increased my competence in mental state examinations, managing one's own anxiety in helping children presenting with acute mental health issues, comprehensive suicide risk assessment and engaging challenging adolescents.

Training in mental health issues and intellectual disability in children and their families would form an indispensable experience for any Paediatrician. The opportunities for learning were immense and would help Paediatricians to function more effectively in contemporary Australian society. ●

*The following is an excerpt from the Higgins, J. and Beecher, S. (2010). Early Days project on Autism Spectrum Disorders August 2010. SNAICC and the Parenting research Centre*

Early Days is a national program that provides free workshops for mothers, fathers and other family carers of children aged six years and under who have an Autism Spectrum Disorder (ASD). Early Days approached SNAICC in mid 2009 to invite SNAICC to partner with them to help ensure Early Days is inclusive of Aboriginal and Torres Strait Islander families and meeting the needs of Aboriginal and Torres Strait Islander families parenting a child with an Autism Spectrum Disorder.

Three objectives were identified for the SNAICC / Early Days Project on Autism Spectrum Disorders

- 1.To ensure Early Days workshops are inclusive and welcoming of Aboriginal and Torres Strait Islander families and communities.
- 2.To help services and organisations working with Aboriginal and Torres Strait Islander (ATSI) families to adapt and deliver Early Days workshops directly to their families.
- 3.To develop other strategies for ensuring Early Days is inclusive of Aboriginal and Torres Strait Islander families and aiming to meet the needs of Aboriginal and Torres Strait Islander families parenting a child with Autism.

The project included workshops, interviews with families and service providers, SNAICC website focus, SNAICC conference presentation and general feedback. The recommendations found from the research included the following;

## **A. Recommendations for the Parenting Research Centre**

- 1.That the PRC develop a culturally appropriate Aboriginal and Torres Strait Islander specific section of the Early Days web site.
- 2.That facilitators of Early Days workshops be Aboriginal or Torres Strait Islander or be required to demonstrate that they have had Aboriginal and Torres Strait Islander specific cultural competence training or otherwise achieved competence in this area.
- 3.That the PRC offer Early Days workshops for individual Aboriginal and Torres Strait Islander families, inviting extended family and using a culturally competent facilitator. A local co-facilitator should also be used to liaise

between the facilitator and the family.

- 4.That the content of the Early Days workshops for individual Aboriginal and Torres Strait Islander families be tailored to meet the needs and circumstances of families and should reflect the issues identified in this project.

## **B. Recommendations for SNAICC**

- 1.That SNAICC maintain information about autism, the outcomes of this project and the Early Days workshops on its web site.

## **C. Recommendations for the Commonwealth Government**

- 1.That the Commonwealth Government fund Aboriginal and Torres Strait Islander specific cultural competence training for all Autism Advisors
- 2.That the Commonwealth Government make funding available to enable all Aboriginal and Torres Strait Islander child care services to be offered *Understanding Autism* workshops.
- 3.That the *Understanding Autism* workshops at Aboriginal and Torres Strait Islander child care services include local Autism Advisors as a way of linking the Autism Advisors in with Aboriginal and Torres Strait Islander communities.
- 4.That the content of further *Understanding Autism* workshops be modified in consultations with SNAICC to ensure they better meet the needs of all participants.
- 5.That the Commonwealth Government fund research into the barriers which may prevent Aboriginal and Torres Strait Islander families seeking a diagnosis and accessing early intervention services.
- 6.That the Commonwealth Government fund a range of initiatives to increase awareness of Autism in Aboriginal and Torres Strait Islander communities including culturally appropriate pamphlets and story books for children.

To read more about the Early Days project, its implementation and findings visit <http://srs.snaicc.asn.au/projects/default.cfm?loadref=203> <http://www.earlydays.net.au/>

There is also a great case study about Murri-Jak who was diagnosed with Autism Spectrum Disorder at two and a half years. His mother Jacqueline French gives great insight about Autism in her community. ●



## a note from David Dossetor...



### Appreciating the more important things of life: Professor Trevor Parmenter's Festschrift

Associate Professor David Dossetor, Child Psychiatrist with a special interest in intellectual disability and autism, Area Director of Mental Health, Children's Hospital at Westmead.

*Epistemology* is the study of "why we are the way we are". This is the motif that Vivien Riches hung on her wall while she was Trevor's PhD Student, one of his earliest from some 30 years ago. A questioning of the theory and origin of knowledge is a measure of most significant academics. A festschrift is a book or academic meeting honouring a respected person, as was presented to honour Trevor Parmenter on 14/8/10 on his retirement as the Foundation Professor of Developmental Disability at the Centre for Disability Studies, Sydney Medical School, at University of Sydney, and indeed the first such professor in Australia. Trevor, who was born to a country life, started his teaching career in a single teacher school in regional Australia. 1970-73 he was a principal at Rowland Hassall School, Parramatta for those with learning difficulties, where he inspired both students and teachers alike in appreciating that you can't measure someone by their IQ, as he valued all other traits of human valour. He first became a university academic in 1972 first as a Lecturer at Kuringai College of Advanced Education and then at Macquarie University where he became a Senior Lecturer in 1980, associate professor in 1988 and Professorial Fellow in 1990. He took up the Director of the Centre Disability Studies in 1997 and has certainly has been at the

head of the development of academia in intellectual disability studies in Australia. He was Editor-in-Chief of the *Australia and New Zealand Journal of Developmental Disabilities*, now known as the *Journal of Intellectual & Developmental Disabilities*. He was on the executive of the International Association for the Scientific Study of Intellectual Disability (IASSID) for 13 years and served as its president. This gave him an international network of colleagues for mutual influence.

The focus of the day was concepts of intelligence and concepts of intellectual disability. The development of the intelligence test in the 1900s has led to an excessive reliance on the result of a simple test to identify certain people. It is one thing to identify the need for additional support, services or funding for which identification can be helpful, but such identification can also lead to a loss of status, access to certain environments, such as employment, or entitlement to choice in society. The threat of doing harm has led to changes in the definition of intellectual disability over time, to include "having problems of independent functioning in at least two areas" in DSM-IV (Diagnostic and Statistical Manual of Diseases) (1994) at a time that no such reliable measure had been developed. The next (Vth) version of DSM is moving away from the measurement of intelligence to a measure of "need for support", with further problems of reliability and validity of measures. Undoubtedly these concepts are mathematically correlated, but also make important and meaningful distinctions.

Professor Roy Brown, Trevor's visiting international friend and peer from Calgary, Canada, previously of Adelaide, described how much our concepts of intelligence have changed. 20 years ago we believed that brain cells couldn't reproduce or adapt, and aging was a constant decline and loss of neuronal activity from birth. This is no longer

a valid belief, with the discovery of ways of retraining brain activities and promoting repair and regeneration of neuronal activity. Roy argued that we are too preoccupied with science, which approaches understanding from the top down, with an assumption of knowing which deconstructs function, as opposed to the study of biology, which looks at natural function and adaptability and thereby teaches us about potential and change in different environments.

Further, intelligence is not a fixed human attribute but is an interaction of genetic faults and a lack of appropriate environment. Every decade the population becomes more intelligent as based on standardised testing (an average improvement of 34 points since 1950). The resilience model of understanding humans described by Alan and Anne Clarke (2003) is a combination of biological resources and social support. For example one additional attribute such as motivation can change IQ testing by 20 points! Accordingly we may be better to talk of competencies rather than a measure of generic potential, as implicitly measured by IQ.

Trevor helped set up the international working group on Quality of Life in IASSID in 1996. In an article he describes quality of life as: beliefs, goals, aspirations, knowledge of self and of how the world works. Nowhere is IQ mentioned. One can see how much of quality of life is dependent on an environment that gives choice. Social inclusion also provides stimulation and maximises choice. Accordingly intellectual ability is dependent on cognitive, social and quality of life components. Intellectual ability is therefore dominated by environmental factors, but also has major influences on that same environment. That is to say the broader qualities of ability have



a large impact in shaping the environment that you are faced with. Roy Brown quoted "if I hadn't believed it I wouldn't have seen it" to illustrate how important our concepts of the human predicament in influencing how we perceive our fellows. In this context, Normalisation is freedom and capacity to be yourself amongst others and therefore applicable to anyone. Indeed intelligence is more to do with awareness of self and consciousness. The core of a quality of life is a person understanding themselves. One may conclude that self concept is more important than intelligence. In the debate for greater achievement in schools, driven by the competition to im-

## One can see how much of quality of life is dependent on an environment that gives choice.

prove intelligence and materialism, we are at risk of creating a segregated group of elites who lack an understanding of the connection to others. In this age of the human genome, in the near future, these segregated elite may soon be derived from designer babies with genetically selected qualities. Such a spectre risks losing the natural variance we have as human beings which is our genetic resource for the future. This means that we all carry qualities of importance, it is just that we may not value them all. Conversely with rising complexity in our society, we may be increasing the number of people who cannot function in socially normed or accepted ways, thereby increasing the numbers who are intellectually disabled. I suspect this is a factor of not coping that is driving the rising numbers of emotional and behavioural disturbance in schools.

At a subsequent meeting Roy talked about his research with the Family Quality of Life Scale and the growth of international comparisons of quality of life in families with a member with intellectual disability. The dimensions are: health of the family, financial well-being, family relationships, support from other people, support from disability related services, spiritual and cultural beliefs, careers and preparing for careers, leisure and enjoyment of life, and community and civil involvement. This measure can draw comparisons between families with a member with intellectual disability to those without. There is plenty of research showing that in the current context these families are highly disadvantaged across most of these domains. International differences can be drawn according to cultural, policy and service differences for people with and intellec-

tual disability. Of additional concern is the difference between families with a child with autism compared with one with a child with intellectual disability. The quality of life for the former was worse in terms of lack of support from services (including a lack of respite), a lack of support from other people such as neighbours and community, and a lack of leisure and community involvement. Autism has a greater influence on poorer financial well-being and family relations, but this is related to the lack of services and community support above. This research provides epidemiological evidence that Autism remains an inadequately recognised and supported disability in our country, even more than intellectual disability!

Graeme Watts, retired Professor at the University of Sydney and current PhD student, talked on intellectual disability and spiritual development. As president of IAS-SID, Trevor had helped establish the Special Interest Research Group on intellectual disability and ethics. Within IASSID there is also a group with a special interest in spirituality and intellectual disability. Spirituality is to do with the dimension of growth in life that leads to finding meaning, transcendence, and recognition of the sacred. It has been suggested that intellectual disability in children impairs spiritual growth and church leaders have at times made mistakes in making prejudicial assumptions about people with an intellectual disability, limiting their social recognition and status as humans. It is clear that many with an intellectual disability have significant spirituality. Spirituality involves a developmental process which is aided by communication through symbols, and the influence of close personal relationships. Graeme drew analogy from Piaget's developmental stages that all humans follow, and to Winnicott's theory of object relations, from which one's sense of otherness derives from close relationships but becomes the 'transitional space', with that sense of connected with otherness which is explored through symbols. For those in whom it is hard to see much spiritual awareness, there is still the underlying extraordinary pattern of developmental processes that have a capacity to lead to such awareness. Hans Reinders, Professor of Ethics at the Free University in Amsterdam, who attended by video conference, suggested such patterns can be seen as indicative of a divine intelligence. Indeed, it is often said that you can access the spirit by clearing the mind of intellectual struggle, and experience life like a child. Intelligence can be seen as finding your place in the world, in the way a baby finds the nipple that feeds him or her. In contrast Wolfensberger warned: we must take heed against investing technology with God like

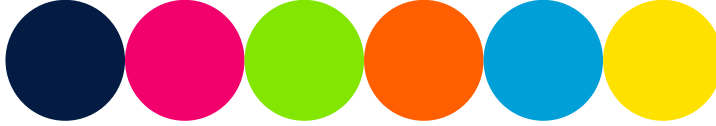
capacity.

In another of Trevor's articles: "Intellectual disability: quo vadis?" he addressed issues of ethics: stating that in an ethical community all are valued. Professor Stewart Einfield's quote in the analysis of Australian mental health services for people with intellectual disability was "this is science in the service of those in need".

Sam Arnold, analytical psychologist with Centre for Disability Studies, and a current PhD student, reviewed the reliability and validity of the psychometric testing of intelligence. Intellectual disability is diagnosed by a score on a test outside of 2 standard deviations from its mean. This necessarily means that measures around or below 70 will be unreliable, as it is at the extreme of its variance. Yet in the last century this measure was used to recommend individuals with an IQ below 70 for institutionalisation and/ or sterilisation. In some cohorts 80% of immigrants failed on this measure (failing to consider language and cultural issues). He summarised the issue IQ with Einstein's observation: "Only two things are infinite, the universe and human stupidity, and I am not sure of the first!" More recently the generic potential of IQ took a further loss of conceptual and mathematical validity in 1999, when Howard Gardner described and validated multiple intelligences. Those he included were: linguistic, logical-mathematical, musical, spatial, bodily kinesthetic, naturalist, interpersonal and intrapersonal. This has spawned a new approach to education. Trevor anticipated this broadening of concepts in the 70s by describing capacities for 'information processing', as distinct from intelligence, one of the themes of his PhD thesis.

Professor Patricia O'Brien has succeeded to Trevor's Chair at the Centre for Disability Studies. She developed the National Institute for Intellectual Disability at Trinity College in Dublin, where young people previously identified as intellectually disabled completed a university degree, completing 10 modules of learning which empowered them to fully participate as citizens and community leaders.

In the eyes of God, the differences between people are so minimal that we can but see ourselves as equal. The challenge of humanity and humanism is to find connectivity with others despite wars, poverty or disability. The day gave cause to acknowledge the conceptual, scientific and human limitations we are subject to. Such an acknowledgement and value system also unifies us as people and professionals in the challenge to help our fellows in the hardships they face. The breadth of this festschrift certainly honoured the man. ●



## What is School-Link?

The NSW School-Link Initiative is a collaboration with NSW Health and the NSW Department of Education and Training (DET) that has been addressing mental health in schools since 1999. The Children's Hospital at Westmead (CHW) has recognised the potential to further develop the existing School-Link Initiative by focusing on students with an intellectual disability.

In 2009, the CHW School-Link Project, in partnership with the DET, Ageing, Disability and Home Care - Department of Human Services NSW (ADHC) and MH-Kids, scoped the professional needs of school counsellors of students with an intellectual disability in Schools for Specific Purposes (SSPs) in the following three areas:

- 1) Assisting in the pathways to care for students with mental health problems and disorders.
- 2) Supporting the implementation of school based mental health promotion, prevention programs, and early intervention programs.
- 3) The training and education needs of school counsellors.

Over the next three years, The CHW School-Link Initiative has been funded to support the mental health needs of children and adolescents with an intellectual disability. Activities will focus on further building local partnerships, raising awareness with various stakeholders, increasing education and support to relevant staff and clinicians and supporting the development of mental health promotion, prevention and early intervention.

## Landmark declaration signed on the health of children with intellectual disabilities...

Health policy-makers from the 53 countries in the WHO European Region signed a declaration expressing their commitment to improving the lives of children and young people with intellectual disabilities by improving their access to high-quality health care. The declaration was signed at the WHO European Conference: Better Health, Better Lives: Children and Young People with Intellectual Disabilities and Their Families, held in Bucharest, Romania.

Intellectual disabilities affect about 5 million children and young people in the Region, the majority living in poorer countries. More than 300 000 live in institutions, often remaining for life. Unless urgent action is taken, this number is expected to rise by about 1% per year over the next 10 years.

The declaration builds on some fundamental principles. Children with intellectual disabilities and their families need effective and comprehensive care from community-based services. Providing this entails a major shift

from models based on institutional care to those that give priority to community-based living and social inclusion.

The declaration also challenges the public health community to draw a true picture of the problem and its scale. Accurate and meaningful data on disabled children are hard to find. Official statistics rarely reveal much about their situation or the problem's extent.

National legislation and policies need further development. Few European Member States have policies that explicitly address the needs of intellectually disabled children and young people.

To fill these gaps, the declaration includes an action plan covering 10 priority areas with concrete interventions for groups of young people differentiated by their age, vulnerability and evolving capacities. The first results of carrying out this plan are expected towards the end of 2015.

World Health Organisation, 26th November. Visit [www.euro.who.int](http://www.euro.who.int) for more information



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Please forward this newsletter to other professionals interested in Mental Health and Intellectual Disability

The beautiful artworks in this newsletter are taken from the participants of the **Operation Art** project at the Children's Hospital at Westmead. You can find out more at [http://www.pau.nsw.edu.au/Visual\\_arts/Operation\\_Art/index.htm](http://www.pau.nsw.edu.au/Visual_arts/Operation_Art/index.htm)

A sincere thankyou to all children and adults involved in the production of these artworks and this newsletter. Remember; **Think Kids**

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