



mental health and intellectual disability...

Link

coordinator's message...

Welcome to the third rich edition of the newsletter for 2012.

Familial relationships are a central theme in this edition. Dr Dossetor from the Children's Hospital at Westmead (CHW) writes about the value of families in working with children and adolescents with an intellectual disability and highlights the link between improved parenting skills and the prevention of maladaptive behaviour and psychiatric disorder (pg 2). Accordingly, CHW School-Link has entered phase two of our Group Stepping Stones Triple P Parenting Pilot. We have trained selected staff from an additional ten schools in Group Stepping Stones and look forward to the implementation in partnership with ADHC in 2012. We will be analysing data from our sample to discover any trends and add to the evidence base for this intervention.

Bereavement within the family as experienced by a person with an intellectual disability is explored by Helen Goltzoff from ADHC (pg 10). With the use of a case study Vincenza, we have a wonderful insight into how to help prepare (when possible) and involve a person with ID in the grieving process.

In our medicine cabinet Judy Longworth from CHW takes a closer look at sleep and the **role that psychotropics play (pg 14)**. Look out for Judy's explanation at the traditional remedy of milk and honey before bed!

Another population facing multiple challenges are people from refugee backgrounds. Gemma Jenkins from DEC discusses refugees, mental health and intellectual disability with recommended resources and assessment tools (pg16).

We would like to thank Alison who left our School-Link team recently. Alison has been an invaluable member of our team over the last year and will be greatly missed. We wish her all the best in her future endeavours.

Apologies if you are viewing this online and the font is extremely small. There appears to be an error with some versions of pdf reader that some people are accessing this newsletter with. Please try to update your adobe software. If you are still experiencing problems then let us know schoollink@chw.edu.au. ●

Happy reading.

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 www.schoollink.chw.edu.au



a note from David Dossetor...



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.

How much do we value families and what impact does this have on children with intellectual disability?

Part I The complexity of families

Many years ago, during my training the eminent child psychiatrist Sir Professor Rutter taught that you can't tell a family by its external appearance. The qualities of parenting and of parent-child relationships are unpredicted by other measures such as parental income, or quality of housing or indeed family constellation. It certainly means you cannot judge a family by your prejudices. Indeed it is remarkable how children bring out the best in people. People make extraordinary sacrifices for the sake of their children, and are often open to modifying habitual behaviour if they come to appreciate its potentially harmful influence on their offspring. All parents want the best for their children.

The opposite is also to some extent true. Families are the source of the most intense relationships, not just for nurture but also for harm. For example, almost a quarter of all homicide are between spouses (Wallace, 1986). We have witnessed the measurable rise of child physical and sexual abuse with 1 in 10 children being notified as at risk in NSW, and the number of children in care going up by 60% 2002-8 to 16,000 (Wood,

2008). There are similar increases of domestic violence, and of parental and teenage depression and drug and alcohol misuse (Wilkinson & Pickett, 2009).

Parents influence children and children influence parents

Witnessing family relationships gives a richness of experience to child psychiatry, but over the course of early and middle childhood, family relationships have more impact than all other factors in how most children turn out (Barker, 2007). This is not as simple as it sounds because genetics and biological differences affect children and these manifest attributes in children bring out different attributes in parents (Reiss & Neiderhiser, 2000). Everyone knows how a disruptive child who externalises the explanation of their behaviour ('its not me', or 'you made me') is more difficult to like. Children who are sickly or anxious are more likely to elicit protective parenting behaviour, which for the period of stress is beneficial. Indeed it has been shown that parental behaviour is influenced by the genetic attributes of the child. What this also means is that where such "instinctive behaviour" in parents becomes entrenched it reinforces maladaptive behaviour. Conversely, the learning of empirical skills of optimising childhood development by parents is the best thing we can do for our children. There is widespread research that shows that improving parenting skills, rather than relying on parenting instincts, is the best intervention for the population in preventing maladaptive behaviour and psychiatric disorder in children (Guralnick, 2006, Ferguson, 2009). We also know more about how maladaptive childhood behaviour also has significant impact on the further development of the brain. It makes sense of why factors of childhood adjustment and resilience have a lifelong impact for example on adult mental health, especially when it goes wrong. This makes sense of another of Mike Rutter's dictums: poor peer relationships are the best measure of childhood adjustment and is the best predictor in childhood of mental health problems as an adult.

The paediatrician Donald Winnicott said there is no such thing as a perfect parent, and we should aspire to be "good enough parents" (Winnicott, 1965). Partly, he was describing that aspiring to being perfect as a parent, can take away the fun and flexibility needed for children. Life is com-

plex and stressful with recurrent adversities, but better functioning families are more likely to cope with and resolve problems (Dattilio & Epstein, 2003). The emotional capacities of these complex human units have greater survival capacities than individuals especially in supporting and enabling youngsters.

Relationships and mental health

There is considerable research available on how excessively emotional/depressive or critical/hostile relationships in your next of kin is harmful for any type of mental disorder (Hooley, 2007). Such emergency emotions in relationships are critical stressors particularly to those in close relationships. In fact, the quality of relationships in the context of a mental disorder has more effect than medical treatment. Although Schizophrenia is generally considered a genetic disorder, the genetic risk for this major mental illness is as strong as it is for Tuberculosis. That is to say, although Tuberculosis is caused by a different environmental factor, an infectious bacterium, the susceptibility to becoming infected is similarly significantly genetic. Thus all illnesses are a combination of genetic risk and environmental factors. The current focus of research on genetics is due to the new technology increasing our specificity of this component of knowledge. The lack of scientific progress on human relationships is due to their complexity.

Relationships are important for everybody. The NSW Commissioner for Children and Young People's survey found that even for those children who were homeless and rejected by their families, their family relationships were still the most important to them (NSW Commissioner for Children and Young People, 2002). Occasionally we witness how devastating the most severe forms of deprivation can actually cause intellectual disability, autism and failure of language development. One example was a child that was raised in a bamboo cage and given food on the end of a stick from the age of 2, as the villagers thought she had Rabies. At the age of 8 she was rescued by nuns but remediation had only a moderate effect (Bartlett & Limsila, 1992).

Changing family values

How much are family values critical to our national and cultural success? I suspect that most families ascribe a high importance to the influence of their values to their children's development, from the value they put on learning and education, to the value they put on altruism and caring for others. Conversely, one also hears about how politics can have a dramatic effect on family values. For example the

communist take over of East Germany or of China dramatically affected the way children were valued. Family loyalty and nurture declined and allegiance to the power of the state as the source of child-care and education. So how much are politics and economics altering family values in Australia?

We all talk about the changes in family values. But which changes are harmless or positive adaptations to modern lifestyle, and what changes really affect family culture and the way we bring up children? We measure national success by the rise in Gross National Product of the country, rather than measure the health, mental health and social failures arising from the rise in relative social inequity. Much of the rise in prosperity has been due to the rise in the number of families in which both parents work. Yet the corollary is that the amount of time parents spend with children has gone down dramatically in the last generation, approximately by 20 hours per week. It seems that parenting is considered of little or no cost or value. The **notion of a two speed economy doesn't** seem just relevant to commerce, but to education, health, the justice system and welfare. Maybe there are no votes in children, but successive governments have failed to incorporate an office of children, whereby the interests of children are considered centrally in every piece of legislation.

Similarly, some colleagues are concerned that the new *youth* mental health concept of services is providing services for teenagers and young adults but at the exclusion of their families. Certainly a lot of kids seem to grow up quickly, with an independence of thinking, and a greater electronic connectivity with other youth. It may be that families feel they have less influence over them. Neurobiology suggests they are still developing mentally and remain vulnerable till their early 20s. Has the value of caring for young people declined, so that kids are no longer brought up by a community, as a sense of community declines (Putnam, 2000)? The decline in community care contributes to the rising of childhood homelessness, whereby these days a refuge is the place of safety provided for a 12 year old by government care and protection agencies.

One of the problems is that economic figures are easily measurable. The rise of violence, delinquency, substance abuse and depression are also measurable. Even though the cost of Autism in UK has been measured at 27 billion pounds/year to the economy (Knapp et al, 2009). In Australia, Autism was considered too infrequent a problem to be measured in the last Na-

tional Mental Health and Well-being Survey (Sawyer et al, 2001).

The problem is that relationships are complex to measure scientifically. Firstly, although you can describe the behaviour e.g. violence or drunkenness, in a partner, you cannot reliably know what someone else is thinking and feeling, unless they are open and honest with you, and vice versa. Secondly, family relationships increase in number by a logarithmic scale, not a linear scale. The table below describes the number of relationships there are according to the number of members in a family there are (assuming each direction is a separate relationship):

<i>Number of relationships in a family depending on the number of family members (each direction is a different relationship).</i>	
Family members	Number of Relationships
1	0
2	2
3	6
4	12
5	20
6	30
7	42

This illustrates why families are extremely if not infinitely complex, especially when scientific research has really struggled with reliability and validity, or the reality and meaning, in even single relationships. Accordingly working with children and families is a humanist challenge. Although our concepts of families and relationships have grown, it is bolstered by smatterings of specific science to strengthen a practitioner's knowledge.

There certainly is epidemiological data providing associated risks. For example, the financially disadvantaged suffer from increased risk or rates of learning problems, emotional and behavioural problems, life events and live in less safe communities, with less access to services, and a poorer response to treatments (Emerson, 2009). However these are risk associations not established causal mechanisms. We also know that these problems can be faced by anyone. Families are also expensive, as only adults are allowed to work, which places families immediately at a greater risk of economic disadvantage.

So as our economy becomes more efficient and more competitive, so the availability of caring adults for children declines. Schools are also expected to perform better providing higher expectations on children and putting more pressure on growing up quickly. Some schools are remarkable in the achievements, resilience and quality of relationships they engender. However with this performance pressure, **it doesn't surprise me that biological vulnerability in children is more evident for example with the rise in recognition of Autistic Spectrum Disorders and such children are more likely to develop emotional and behavioural disturbance.** Against this tide of complex changes, an eminent paediatric colleague observed that **"the future welfare of our children will be more important to the future of Australia than climate change". Yet the welfare of children is not a central part of politics.** At a state level, all the main child orientated agencies work to different geographical areas, as if to make it intentionally difficult to work across government agencies. Over the last decade the Federal Government expenditure was focused to support a free market economy approach to health, and to act to limit the costs rather than strengthen the public health framework of the state health systems. Yet public health systems have provided the most cost effective health outcomes for the country.

This is a child psychiatrist's view of the background to understanding families with a child with intellectual disability. In NSW a start is being made to ensure that for the mental health of children and adolescents with intellectual disability that mental health, education and disability meet to discuss the problems of managing the mental health of the children and adolescents and consider evidence based approaches to improving the situation, one of these is the CHW School-Link, part of NSW School-link.

Part II Families with an intellectually disabled child

Working in this area of child psychiatry, has brought me in contact with a highly caring, committed, thoughtful, knowledgeable and determined group of parents. There are some particular differences about these children and families that **distinguish them from "mainstream" families.** They have special needs but the numbers of families with a child with severe (1%) intellectual disability has always made me feel this is a discrete population that a community should be able to optimally provide for. In NSW that would be approximately 80,000 of whom 25,000 are less than 20 years. Unless there is a



debate as to what should be done for and by these families, and what services we should be providing, then nothing will be done.

Early in my specialist training in 1987-9, I interviewed extensively an epidemiological sample of 92 families with a teenager with intellectual disability, in Leicestershire, UK (1990/91) (Dossetor, 1991). Leicester is a university town with a large health district, with slowly growing services for children with intellectual disability. Meeting a community sample, separate to those who presented to my mental health practice was an important learning experience. It also gave me first hand insight into what family life is like with a teenager with intellectual disability. It is interesting to see how much has changed with progress, albeit on this side of the planet. After all, NSW Government has given over \$2 billion over the 5 years to 2014/15 to improving services for people with an intellectual disability in Stronger Together 2, indicating political will, and there has been a definite growth of professionalism in the disability services.

In 1990 (Dossetor & Nicol) I reported that families wanted information about what services are available. Knowing what was available should they need it contributed to them coping with the present and being able to anticipate a feasible future. The second wish was to have a case manager to provide consistent support and to guide them through the challenges, enabling access to other more specialised services as needed. The families feared what the future held for their teenager with ID, and the lack of options should they be unable or unwilling to continue caring. This was illustrated by 7% saying they would rather kill their disabled teenager than allow them to go into an institution.

The recently released Ombudsman report on services for families with a child with disability (2011) also reported that avail-

ability of services had increased, but their survey of families still reported the lack of available information on what was available. Further, there is a recurrent challenge to obtain a case manager due to the strict adherence to protocols of eligibility criteria, and then to keep one for any length of time before the case file is closed again.

In my 1990 study these families were not distinguished by their family relationships or their social contacts, and in these **terms they were basically 'normal families'**. There were however a number of differences. First is the burden of care, estimated to be an average of 7 hours a day 7 days a week caring for the dependency needs of their young person with intellectual disability for as long as they live with the family. The second was the lack of practical assistance for that burden of care. Whether the family had a friend or relative who was available and able to care for their teenager with ID (even for a couple of hours a week) was highly predictive of the mental health of the primary carer, the quality of the relationship between the carer and the young person with ID, and their need for hostel based respite care (that being the only source of funded respite care). I felt that more family orientated sources of respite were needed.

The burden of care is still present with carers reporting 2-3 times greater financial burden of care for care, treatment and education and reduced income capacity, over half of carers (59%) experienced a decline in physical health and two-thirds felt that their mental and emotional health was affected with depression, anxiety or stress (Cummins et al 2007).

It impresses me that we now have "in-home" respite care widely available. However until recently it has not been possible to use friends or relatives to provide

funded respite. This is a major achievement of the recent pilot respite study run by Burnside (reference?) as it required **legislative change and formal 'working with children' police checks etc.** Unfortunately this project has been ceased as so few families now had friends or relatives to introduce to the project. Despite an active media recruitment process, few families came forward interested in becoming respite carers for young people with an intellectual disability.

Families often feel there is still completely inadequate support, and therefore make the mistake on depending only on themselves, and giving up on what community support may be available. I suspect that this contributes to understanding why approximately half of the parents I meet have significant burnout, anxiety or depression. The extent of the feeling disconnected from the wider community reaches alarming levels with the frequency with which I encounter parents with murder suicide ideation. I suspect this is a disconnect at multiple levels. I do not accept that although behaviour disturbance in intellectual disability is known to be widespread and persistent that nothing can be done about it. The longitudinal data is gloomy and suggests that despite some variation, and slight diminishment over time, that 20 years later disturbed behaviour is still the best predictor of disturbed behaviour. With our growing economy compelling both parents to work, there is major service threat: that for every 10% decline in informal care requires a 40% in formal care.

In my 1990 study 35% of a group that we sampled, mainly with teenagers with moderate/severe intellectual disability, still reported that life with their teenager with ID was **"OK" or "enjoyable"**. This contrasted with cohorts studies of children with Downs Syndrome where this figure went up to 80%. It suggests to me that we need to tackle challenge of ID with its associated features with a program strategy.

Nankervis and colleagues (2011) identified through case file and stakeholder audit, the factors that led to families relinquishing care. These were divided into individual factors (high support needs, high medical needs, limited communication and young adult age), family factors (psychological distress, single parent family, parental expectations, marital breakdown), support factors (social isolation, **desire to have 'normal' life, availability of respite care services, availability of appropriate informal supports, relinquishment being used as a strategy to gain out-of-home permanent accommodation**) and service factors. Families had been stating for a considerable period of time to staff before relinquishment that they could no longer cope and that they would relinquish care. Offering respite was the main intervention used which was a band aid to a long term failure of policy and intervention service provision. Staff reflected on interventions that could enhance the **carer's ability to cope: "value adding" interventions to decrease challenging behaviours and increase skills in daily living, parent training, linkage with informal supports.**

The recent early cohort study of families with a child with borderline intelligence or intellectual disability (Emerson et al, 2011) suggests that even by 4/5 years of age, maternal stress and burnout is widespread and it is the combination of disruptive behaviour in the child with ID and maternal burnout and associated emotional hostility that leads to disruptive behaviour persisting.

Components to a family orientated comprehensive universal approach to mental health and intellectual disability

This situation is asking for an early intervention program to be implemented. First active case management/ mentoring are needed, to support the mother/parents and to provide support and advice over time. Such a process of engendering hope needs to lead onto building skills to optimally manage the burnout and behaviour disturbance. Stepping Stones, the level four version of Triple P is specifically developed for children with intellectual disability and or autism. It introduces parents to special behavioural skills for reducing difficult and promoting prosocial behaviour and communication. It also focuses on looking after the parent and promoting community integration. This specialist intervention introduces state of the art behaviour management skills but is family orientated and normalising for the behaviour of the child with ID and the wellbeing of the family. Such parent skill promotion programs need to be made

universally available in the preschool years. One of the remarkable developments of the last 20 years is how frequently I come across incredibly skilled parents, who know more about minimising the behaviour and building the skills in their child than most professionals (Carroll et al, 2011). Making knowledge and skills available is the most cost effective way on making a difference to even the most complex and extreme behaviour problems.

Muir (2006) identified the complexity of the resilience processes for a family with an intellectual disabled young child. First the family experiences a traumatic event or stressful situation that can place a family at risk, second the family has protective factors, to help them adjust to the event, and third the family recovers by adapting their functioning (even though there is a chance that the family does not adapt). The most important protective factors are: family problem solving and balanced relationships; family hardiness; social support; family time and routines; hope; flexibility; financial management; truthfulness and transparency of information; equality and empowerment; finding meaning; good health and practical family support in medical care. UK evidence suggests that service provision can be most effective when **co-ordinated by a 'key worker', followed up by a prevention and intervention framework.** These key workers, who inform, link, co-ordinate, follow-up and refer families, have been found to decrease stress and protect families. Thus a key worker service model should be followed by supporting parenting skills. This could also be part of the introduction to early intervention programs such as those for promoting independence and communication skills. This in turn should also naturally transit to specialist education that promotes emotional literacy and social skills in the education environment (Dix et al, 2010). However it is arguable that skill promotion is only a means to an end of developing awareness of others and building the connections of social relationships. Equally important is understanding and helping with maladaptive behaviour.

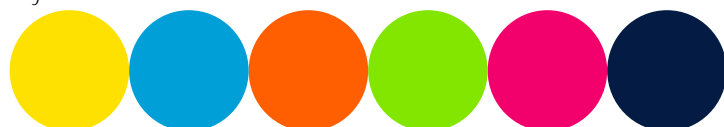
In addition a child with ID may have additional disadvantages of health problems which may be associated with chronic pain, recurrent hospitalisations, abnormal neural systems eg with epilepsy or behaviour due to specific biological drivers such as found in behavioural phenotypes. In the 1990 cohort study where 50% had significant emotional behavioural problems 22% had seen a psy-

chiatrist. In the Australian longitudinal cohort study of the 40% of the cohort had significant psychiatric disorder, yet only 10% of them, ie 4% had seen specialist mental health services. Services have further improved in Leicester.

In NSW, Disability Services have provided a start up of 5 years of funding for a chair in the psychiatry of intellectual disability and funded 9 one-year mental health fellowships to psychiatrists to develop a special interest in intellectual disability. It evidently is a concern of disability services who talk of it being a priority for their clients. Equity of access to mental health services mainly means they can be seen in the emergency mental health services, but mental health has not recognised their priority of need or recognised the need to fund specialist mental health services. The recent publication of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities (Dossetor et al, 2011) is designed to enable a multi-disciplinary, multi-agency evidence based, family orientated holistic framework for the mental health needs of these children.

Human nature has a habit of providing surprises. Just when you think no one cares about you and your problem, it is remarkable how often a caring figure materialises from your neighbourhood. Building respite resources, particularly from friends or relatives or other member of the community can be done, despite the growing tide of economic rationalism and selfishness. That children need care remains true and with resolve, it remains possible to influence community attitudes. Not only can we help people believe that they contribute to the wellbeing of children with intellectual disability and their families, but we need to be more skilled at enabling them with special skills and supporting them with attractive means of engagement and funding.

The "Listen to us: Supporting Families with Children with Disabilities: Identifying Service Responses that Impact on the Risk of Family Breakdown" (2002) report on behalf of the National Disability Administrators reiterates the above messages: "in the context of the UN Rights of the disabled child, there is a need for a range of quality services for families with children with disabilities, and for more consistent policy goals (both across services and across early childhood and school age periods), that address both child and family outcomes. The value of early intervention services is highlighted, along with the possible need for broadening of early intervention models and practices,





to include stronger focus on parent-child relationships, social competence in children and prevention of challenging behaviours.” **The review stresses “the importance of both change-oriented/interventive and supportive/facilitative strategies being available at primary, secondary and tertiary levels of intervention”.** **The report further highlights the importance of “informal support systems for families and the impact that community attitudes to disability have on the adaptation and capacity to support within the extended family and friendship networks.** It is acknowledged that Australian service systems have not yet explored the capacity and limits of informal support... To create informed and inclusive communities, education in disability awareness should be undertaken for the following groups: the general community; family members and friends with potential to participate in support; the disability services workforce, and health, education and wel-

fare professionals; and support be given to community building and community development initiatives designed to enhance support to families and their **community membership.”** **Such a government sponsored report comprehensively and concisely summarises what is needed for children with an intellectual disability.**

The recently proposed National Disability Insurance Scheme (NDIS) is clearly a much more ambitious proposal for all forms of severe and profound disability with age at onset up to age 65, but presents a chance to correct the failing of our community to recognise the needs of **those with “severe or profound core activity limitation”.** **People with a profound or severe disability are those who always or sometimes need help with a core activity or task.** They would be eligible for life. Each group represents 3% of the population and on 2009 prevalence of this population is about 600,000, with condition groupings as follows: congenital anomalies and intellectual disability (82,000) nervous system disorders (41,000) injury (15,000) mental illness (206,000) sensory conditions (12,000) physical conditions (223,000). This is a small proportion of the 20% of the population who otherwise suffer a mild degree of impairment and the 21% who suffer a chronic illness without on going impairment. Although those with profound and severe disability are the primary target, the report does consider other degrees of disability. The funding would be brokered to coordinate services based on need for care and support including respite, aids, equipment, transport, home modifications and a range of community and day programs. There would be an emphasis on early intervention and access to education and training to maximise long-term independence and potential. People with disability and their families would have certainty and clarity about options from the point of determination of a disability. Eligible people would be entitled to services determined on an individualised plan and needs basis, giving them access to an appropriate whole-of-life suite of services and support. Families would have more choices about the combination of work and informal care for family members at various life stages, as in other families. The proposed scheme addresses the current unmet and under-met need for care and support and the unsustainable reliance on carers. For the first time there would be clear incentives in the service system to invest in timely interventions that promote independence and produce long-term benefits. The NDIS would double the total funding for disability services by adding a further \$6 billion. Despite the size of the budget, the NDIS reports that

there is a large and expanding unmet need for care and support for people with severe/profound disability, and also a large unpaid volume of care and support provided by family and other informal carers – an estimated 2.5 million carers providing nearly 650,000 full-time equivalent carers (with a replacement value of \$35 to 40 billion per annum). Health systems are also undergoing concomitant radical change, moving from treating potentially fatal illness (which do not dominate our lives now) to the need to minimise chronic and complex disability and the diseases that create them. NDIS predicts that improving chronically disabling diseases will consume 80% of the \$100 billion health budget by 2020. It is projected data like this that indicates why the NDIS is essential to the further growth of our economy and doing things better and smarter for our communities.

Judy Brewer a parent and disability/autism advocate described the necessity for every parent of a disabled child to advocate for all children with disability (Carroll et al, 2011). Since my early career study in 1990, it is gratifying to see how far this public debate has come with so many sources of information, from governments, economists, university academics and parents articulating a common approach on what the community needs to do to enable a better quality of life for children with intellectual disability and their families. It is now time for action. ●

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facts and figures...

Interesting Facts to Know!

As of 1 July 2011, children who are aged under 6 years and have been diagnosed with Down syndrome, cerebral palsy, Fragile X syndrome, or a moderate or greater vision or hearing impairment, including deafblindness, can be registered to access early intervention funding. –FaHCSIA www.fahcsia.gov.au

Around 20% of the world's children and adolescents are estimated to have mental disorders or problems. Yet, regions of the world with the highest percentage of population under the age of 19 have the poorest level of mental health resources. Most low- and middle-income countries have only one child psychiatrist for every 1 to 4 million people. – WHO www.who.int

Expressive language disorder means a child has difficulty with verbal and written expression of language. The child may have problems with producing sentences, recall of words and vocabulary. The cause is often unknown; it may be associated with other developmental difficulties such as Down syndrome, autism or hearing loss. –Better Health Channel www.betterhealth.vic.gov.au

In 2007, the World Health Organization (WHO) argued that the world faces a critical problem with the growing number of people with mental and neurological problems, including autism, which accounts for 11% of global disease. The number is projected to reach 14.7% by 2020 – WHO www.who.int

Depression and anxiety are the most prevalent mental disorders experienced by Australians. Depression alone is predicted to be one of the world's largest health problems by 2020 – *The Global Burden of Disease*, World Bank Harvard School of Public Health, Geneva 1996

upcoming training...

Intellectual Disability:

Intellectual Disability and Mental Health Webinar. *Mental Health Professionals Network* presents an online webinar. Download the webinar from their website <http://www.mhpn.org.au/News/Events/>.

Other webinars are also available. You can also view post-webinar resources.

Hope and Resilience presented by Richard Elms. This professional development will focus on counselling/therapy that fosters hope and resilience across a range of issues including intellectual disability. 17th and 18th of November, 9am-4pm. \$350 Westmead. Contact richarde@pnc.com.au or Riverlands Therapy Services on 02 4731 8111.

The *Association of Psychologists working in Developmental Disability* 20th anniversary conference. 25th November, Rose Hill. 8.30-5pm. Visit www.psychdd.com.au for more information.

Autism Spectrum Disorder:

Assessment and Treatment of Anxiety in Children with Autistic Spectrum Disorders. Presented by Dr Anne Chalfant. Contact *Macquarie University Centre for Emotional Health*. 18th November 2011. 8:45-5:15pm. <http://shop.accessmq.com.au/shop> or enquiries to Melissa McKibbins on 02 9850 4084.

Autism Spectrum Australia (Aspect) presents **Recipe for Success; A positive Behaviour Support Workshop**. Penrith. This is a three part workshop; 19th October, 2nd and 16th of November. Free to carers, \$150 for professionals. Contact bis@autismspectrum.org.au or 02 8977 8325.

Disability:

Building a Bridge to Positive Behaviour: Parenting and Caring for a child or young person with a disability. *Central Coast Disability Network* present Dr Lee Sturgeon. 8th November, 9.00am-1.30pm. Tumbi Umbi. Contact Anne Boyle 02 4324 2355 or anneb@ccdn.com.au.

Greystanes Disability Service and Blue Mountains Grammar School annual art exhibition that features the works of people with disabilities. The launch will be held on the 7th of December. 10am-5pm. Lost Bear Gallery, Leura post office building, 5/148 Leura Mall, Leura. Contact Debra Brown for more information on 02 47841118.

Other:

Youth Health 2011: Its totally important! The 8th Australian and New Zealand Adolescent Health Conference. *The NSW Centre for the Advancement of Adolescent Health, the Children's Hospital at Westmead and the International Association for Adolescent Health*. 9-11 November, 2011, Darling Harbour, Sydney. \$720 early bird. Visit www.youthhealth2011.com.au to register. Contact Rouel for more information 02 9286 7221.

Triple P parenting course is being held for free in Term 4 as part of St George Community Services. Course runs from the 4th of November until the 2nd November, Fridays at 10am-12pm. Contact 02 8558 4000 or check the website on www.stgcs.com.au

STARTTS Clinical Master class: Impact of Trauma on Language Development presented by Devon Barnes and Sejla Tukelija. 9th November 2011, 6-8pm. Free at Carramar or live broadcast for \$5.99. Contact 02 9794 1900 or email startts@startts.org.au. You can watch the live broadcast at www.startts.org.au

Challenging Behaviour:

Managing Angry Adolescents Differently (MAAD). Presented by Ken Nathan and Carol Musgrave. Parramatta. 21st October, 7th November and 16th of December. *Uniting Care: Institute of Family Practice*. Register contact 02 8830 0755 or email info@ifp.nsw.edu.au or see www.ifp.nsw.edu.au

Redbank House Annual Conference 2011. **Conduct Disorder; yes, but... Deconstructing Conduct Disorder**. 25th November 2011, 9am-5pm. Westmead. Contact for registration and enquiries redbankconference@swahs.health.nsw.gov.au. Kerry Hart or Michelle Minney on 02 9845 6577.

TABISS presents **Writing Social Stories** by Dianne Leggott and Michael Caballero. A course targeting parents, carers or professionals who work with people with challenging behaviours. 29th November, 10:00am-12:30pm. Free for parents. Contact Interaction Disability on 1300 668 123 or visit www.interactiondisability.co/TABISS.

Mental Health:

Don't let Sleeping Dogs Lie: A stabilisation method for severe and chronically traumatised children and adolescents. Presented by Arianne Struik. 17th November, Sydney. 9.30am-4.30pm. \$280. Contact Sonja Parker on 0439 985 406 or sonjapa@inet.net.au.

Mental Health Connect: Mental Health Skills for Community Workers. This course will help workers gain insight into how they can assist people experiencing mental distress. *Mental Health Coordinating Council*. 6-7 October Lismore, 19-20 October Orange, 21-22 November Queanbeyan and 24-25 November in Sydney. \$300. Contact training@mhcc.org.au or 02 9555 8388 ext. 106.

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reviews...



Book Review:

Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A Framework for Professional Practice.—Dossetor, White and Whatson, 2011

This book illustrates all that is special and interesting about the field of intellectual and developmental disabilities, most specifically about the mental health needs of children and Adolescents with such disabilities. The book is interdisciplinary in its authorship; it acknowledges the need for many different perspectives within the bio-developmental-psychosocial framework; it is inclusive in recognising the knowledge and wisdom of those who have cared for a son or daughter with a disability; it is a resource for those interested in the science that underpins our present understanding; it provides guidance on services and interventions. In combining these various perspectives it undoubtedly provides a comprehensive 'framework for professional practice'—extract from the forward by Professor Tony Holland, Cambridge Intellectual and Developmental Disabilities research Group, University of Cambridge. See back page for more details.

Website Review:

www.abs.gov.au

The Australian Bureau of Statistics website is quite a powerful tool with many uses. There are many topics that you can browse and search to help you with any research you may be doing. The website has a portal to information, guides, fact sheets, and other learning resources to assist in understanding statistics on a range of topics and to use these effectively for specific purposes. They also offer training and online video tutorials. You can search basic information or request custom information for a fee.

The website is quite comprehensive and offers more than the census data. Take a look online and browse by state, topic, title or release date. There is a first visitors section for the not so statistically inclined which can help you navigate.

Take a look at our resources section to see a link to the ABS website specific to Autism data in Australia. We are a bit addicted to statistics at the moment.

Organisation Review:

www.bestbuddies.org.au

Best Buddies Australia seeks to enhance the lives of people with intellectual disability by providing opportunities for friendship and integrated employment.

Each volunteer (Peer Buddy) is paired to a person with an intellectual disability and together they organise and enjoy everyday activities, such as a trip to the movies or dinner at a restaurant. These activities have a profound and positive effects on the Buddies and Peer Buddies.

Peer Buddies are paired up with a person who is about the same age, same gender, live close by and have a mild to moderate intellectual disability. Buddy pairs are trained and given guidance about the social expectation of friendships. They are supported by program managers. There is a focus on the development of a friendship rather than mentoring. This provides mutual benefits by shifting both parties understanding of disability and social inclusion.

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

Conference Review:

Earlier this year, the Mental Health and Intellectual Disability School-Link conference was held at the Liverpool Catholic Club in South Western Sydney.

This one day conference provided a holistic overview on the mental health needs of children and adolescents with an intellectual disability. The conference discussed mental health promotion, prevention and various interventions suitable for delivery in the school environment and aimed to enhance mental health, well-being and improve quality of life for young people. The objectives of the conference was to increase participants knowledge and understanding of various issues concerned with mental health and intellectual disability in children and adolescents; and their confidence in working with this population in a school environment. The keynote presentation by David Dossetor (Child Psychiatrist with a special interest in **intellectual disability, The Children's Hospital at Westmead**) focused on the barriers to a holistic framework of professional practice for children and adolescents with intellectual disability and mental health problems which was a very detailed and informative session.

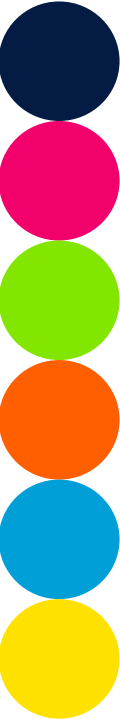
This was followed by Jodie Caruana (School-Link Coordinator, **The Children's Hospital at Westmead**) who gave us an understanding of mental health prevention, promotion and early intervention for children and adolescents with intellectual disability.

The team from State-wide Behaviour Intervention Service, Department of Human Services NSW, Ageing, Disability & Home Care including Lesley Whatson (Team Coordinator), Debra Corfield (Senior Clinical Consultant) and Kellie Van Seville (Senior Clinical Consultant) focused on risk and risk management when working with this population. This was followed by a school-wide approach for supporting exceptional children by Phillip Whitefield, Department of Education and Communities which gave us a great insight into PBS and some examples from schools implementing this approach.

The afternoon was a series of breakout sessions which covered four areas, these include developmental paediatrics by Dr Roger Blackmore, Area Child Development Paediatrician who discussed what is important in determining the needs of children and families with neuro-developmental disability. Lisa Chapman, School-Link Coordinator for Justice Health presented on the func-

tion of dysfunctional behaviour which highlighted the health and well-being of the young offender population and explored the behavioural presentation of frequently "**hidden**" health issues that impact on a young person's successful participation in the school environment. She illustrated the evidence specific to the protective health function of school engagement and the association between poor school engagement and offending behaviour. Carl Warren, a principal from the Department of Education and Communities discussed a practical approach to behaviour management.

The final breakout session was presented by Dr Michelle Wong, Clinical Psychologist at **the Children's Hospital at Westmead**. Her presentation focused on Emotion Based Social Skills Training in Schools. This described the rationale, program components and delivery of EBSST, a program developed for children with ASD and their parents and teachers to promote social and emotional well-being in over 60 NSW DET schools. The program was well received by participants and the day was completely sold-out. We hope that another conference will be conducted in the future to focus on this target group.



supporting individuals with intellectual disability through grief, loss and bereavement...

Helen Goltzoff

Speech Pathologist with a special interest in intellectual disability, mental health and bereavement support
Ageing, Disability and Home Care

Note: This article is a two part series. Part one, focuses on the literature and adult case study whilst part two will focus on a child case study. Part two of this article will be presented in an upcoming edition of the newsletter.

The area of grief and bereavement experienced by people with intellectual disability has historically received little attention, but is now gaining more momentum, thanks to a small group of researchers (Hulbert-Williams & Hastings 2008). People with intellectual disabilities are now living much longer (Paja et al; 2000 cited Dodd et al 2005) and as a result, are experiencing and enjoying many more varied relationships both within their families and in the community at large (Dodd et al, 2005). The place of care has changed from living in large institutions to care out in the community (Bennett 2003).

Almost two-thirds of people with intellectual disability live at home with parents, relatives or foster carers often for many years. This results in the level of care, the degrees of attachment and dependence between a child or adult with an intellectual disability and his/her caregiver becoming very strong. When these close bonds are broken, by the death of the parent/caregiver there can be serious repercussions for the mental health of that individual (Dodd et al 2005). Following a bereavement, if grief is not recognised or expressed by an individual with an intellectual disability complex reactions may occur which prolong the grieving process and are likely to manifest as challenging behaviours (Emerson 1977 cited MacHale & Carey 2002). The research suggest that such grief needs acceptance and normalisation among people with intellectual disabilities.

Participation in mourning rituals helps to convey the finality of death and also helps to facilitate adaptation to loss and the resolution of grief (Read 1999 cited Dodd et. al 2005). Research has shown that exclusion from mourning rituals in an attempt to protect an individual with intellectual disability from possible emotional discomfort places the individual at a

higher risk of developing significant subsequent emotional discomfort and distress (MacHale & Carey 2002, cited Dodd et al 2005).

Yet, often the preparation which a child or adult with an intellectual disability receives about the impending death of a loved one is very minimal. Information about the caregiver's illness, particularly if terminal, is frequently withheld. Time or privacy to grieve is denied and the individual may further excluded from the funeral and other rituals. Raji et. al (2003).

Exclusion from cultural rituals associated with death may result from the caregiver's lack of knowledge and understanding of the bereavement and grief processes experienced by people with intellectual disabilities. Murray et Al, 2000, cited Dodd et. al 2005). Caregivers often hold inaccurate beliefs or lack understanding of the ability of people with an intellectual disability to grieve. Caregivers often believe that people with an intellectual disability have little or no awareness of death or the grieving process therefore feel that it is much better to distract them from the grief until the deceased is forgotten about (Deutsch 1985, cited Dodd et. al 2005). The end result of this can be that the grief expressed by an individual with an intellectual disability will be misunderstood and inappropriately handled either with medication or some kind of behavioural intervention (Hollins & Esterhuyzen 1997, cited Bennett 2003).

A study by Emerson (1977) which explored the incidence of bereavement and the onset of marked behaviour and mood change in adults with intellectual disability (ID) found that caregivers had minimised the significance of the death or had misunderstood the reactions to it. Despite observing a wide range of responses to bereavement when asked, typically commented that there was 'no response to the death' by the person with intellectual disability. Research points to the contrary that understanding the concept of death *is not* a prerequisite for experiencing the emotions associated with grieving (Dodd et al 2005). Absence of the person who has died is the tangible manifestation of his/her death and a person with an intellectual disability will recognise and feel the absence of someone they love. They will grieve for this loss with or without nec-

essarily having the comprehension of the abstract nature of death (Dodd et al 2005).

It is a well known fact that people with intellectual disability are particularly vulnerable to psychiatric illness. Day (1985) specifically examined over 200 new admissions to a psychiatric unit for people with intellectual disability. He found a **high incidence of 'reactive depression' and 'anxiety state' in this group with 50%** of these breakdowns clearly precipitated by the death or serious illness of a family carer (Dodd et al 2005). Day suggested that the onset of these psychiatric disorders might be viewed as '**bereavement reactions'** A more recent study by Stoddart and colleagues (2002) evaluated the effect of bereavement on a group of 21 individuals with intellectual disability. Scores for depression and scores for anxiety were found to be significantly elevated following the bereavement.

Education programs for people with intellectual disability tend to be around preparation for life in the community with a strong focus on community access activities. There is very little focus on addressing the emotional needs and issues which are common to the wider population (Bennett 2003). Yet studies over the last 15 years have recognised the need for both preparation and support for people with ID who have been bereaved including the right to be told the truth and to grieve (Bennett (2003). Although preparation for loss and change is not an easy topic to discuss, it is one that can lead to increased emotional growth, self awareness and empowerment for the individual concerned. Death is a universal experience that we all must face at some point in our lives (Leick 1991 cited Bennett 2003).

What also needs to be appreciated and understood by those who work and live with people who have an intellectual disability is that when they lose a parent or primary carer they are not just experiencing a single bereavement but often multiple losses. They not only lose their parent and confidant but their family home, possessions, bedroom, pets, familiar routines, neighbours and neighbourhood, day program, school, support services, contact with other family members and friends. When they lose their primary carer they essentially become homeless and maybe hurriedly moved into residential care usually into a group home. They will usually be placed into interim accommodation until a permanent home can be

found. Often they have more than one interim accommodation place and encounter a number of moves. This usually occurs with very little preparation and transition support and they awake to find themselves in completely unfamiliar surroundings with a myriad of new faces around them. One can only imagine how overwhelming this must be. Both interim and permanent placements may often be in a completely new and unfamiliar area,

When they lose a parent or primary carer they are not just experiencing a single bereavement but often multiple losses

with familiar support networks lost. Such extensive losses MacHale & Carey (2002) state only serve to further complicate the bereavement process for individuals with intellectual disability. This is why Crick (1988) identified six areas of best practice to help support individuals with ID through bereavement.

1. Prepare the person for anticipation of loss and bereavement
2. Provide a full explanation of death and dying
3. Ensure there are communication techniques and supports in place to help the person to express their grief.
4. Have an empathetic confidant on hand that they can talk to or feel close to during this time.
5. Acknowledge and recognise the person's feelings and need to grieve
6. Reduce as much as possible the associated multiple losses

The following case study provides a very effective approach for supporting individuals with intellectual disability through grief, loss and bereavement.

Case Study: Vincenza

The following case study illustrates how one family supported their sister and sister-in-law Vincenza through bereavement following the death of her mother early this year.

Vincenza is a 56 year old lady of Italian background. Vincenza has a severe intel-

lectual disability and Turners syndrome. Vincenza has lived with her parents her whole life. Her father passed away more than 20 years ago and that was her first experience of losing a loved one close to her. Vincenza accompanied her mother to the cemetery after her father died for many years and this helped her to gain some understanding of death. Vincenza was cared for by her mother and they had **a very close bond. When Vincenza's** mother became very ill, the family anticipated that the loss of her mother would be very difficult for her and decided that Vincenza needed to know and to be well prepared that her mother was going to die.

Vincenza's mother started to prepare her by telling her that she was sick and that she was going to die and that Vincenza would go to live with her sister and her family. Vincenza saw her mother slowly deteriorate over the last 2 years and the family believe that she sensed the impending loss and was sub-consciously grieving. Vincenza also became very aware of the change in care arrangements when her mother was no longer able to provide that care to her and **Vincenza's sister took over.**

The family involved Vincenza in caring for her mother in the final weeks before she passed away. She spent a lot of time sitting next to her mother's bed, would bring her heat bags, rub her back and put her nebuliser away. This active participation in caring for her mother also helped Vincenza to understand that her mother was very ill.

Vincenza was present with her whole **family at her mother's bedside when she passed away. At first she didn't quite realise** that her mother had passed away. A person with a severe intellectual disability needs a lot more time to process information than the average person. When other family members started to arrive at the house and were crying, Vincenza then understood that her mother had passed away. Seeing the open display of other **people's emotions was a much more concrete and visual way of letting Vincenza know** that her mother had passed away than by just telling her in words.

The family involved Vincenza in their mourning rituals and customs from the very start of the bereavement. When the funeral directors came to the home to **take her mother's body away Vincenza** was encouraged by her sister to wave goodbye to her. Vincenza went outside to the back of the hearse and again

waved goodbye to her mother.

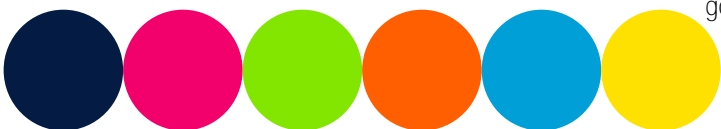
Vincenza accompanied her sister and family to the mortuary for the dressing of **her mother's body. Initially it was expected** that Vincenza would just sit and watch the process. However she came **over and started to touch her mother's** leg and her sister did not deter her from doing this. Viewing and touching the body, for someone who has an intellectual disability provides them with the strongest cues to understanding what it means when someone dies. They can see and feel that the person is no longer breathing, talking or moving but lying very still and once again this provides the most concrete experience of death.

In keeping with traditional Italian customs **the coffin with her mother's body was kept** in the family home for two days before the funeral. Vincenza had many opportunities to view and touch her **mother's body. She was encouraged to** wave good morning and good night each day.

On the day of the funeral, before the coffin was sealed Vincenza was given one final opportunity to view and touch her **mother's body and to wave goodbye to** her. At the church service Vincenza walked with her sister and led the coffin into the church and out of the church.

Vincenza was there with her family at the **cemetery. Vincenza saw her mother's** coffin being placed into the vault and was again encouraged by her family to wave goodbye. This again was a very important part of the process to see exactly where her mother was laid to rest. It is not essential for a person with intellectual disability to understand the more abstract meaning or belief around death for example **that the person's soul goes to** heaven, there is an afterlife or whatever belief an individual may hold about death. It is important for a person with intellectual disability to physically see **where the person's body goes** - whether the body is buried, cremated or encrypted. This provides a further sense of finality and closure.

In the weeks following her mother's passing the family supported Vincenza in many ways to grieve the loss of her mother and to express her feelings. Her sister continues to take her to the cemetery each week, where Vincenza places flowers and looks and touches the photo of her mother on the vault. Before she leaves the cemetery both Vincenza and her sister wave goodbye to the photo of her mother.



At home Vincenza has been provided with many opportunities to remember her mother. There are special photos of her mother taken with other family members around the house that she can go and look at anytime she feels like. Her sister **has kept some of her mother's clothes** which Vincenza likes to wear sometimes. Vincenza has also been shown the power point presentation that was shown in the **church on the day of her mother's funeral** and this has further helped her to understand that her mother is no longer there.

Vincenza, unlike many other adults with intellectual disability was spared the experience of multiple bereavements and losses following the death of her mother. Her family were very mindful of keeping many other aspects of her life constant. Her sister and her family made the decision to move into the family home where Vincenza has been living her whole life. This decision was made so that Vincenza could remain in familiar surroundings and not have to adjust to a completely new environment. She has kept her own room with all her familiar possessions. She has continued to go to the same day program which she has been going to for the past 30 years. This has helped to keep Vincenza in the routine that she has been used to. She also has made many friends and has close ties with staff and other program participants and her family understood how important it was to Vincenza to maintain those connections. The day program also supportive in wanting to help Vincenza through her bereavement. Vincenza continued to attend the day program **in the days before her mother's funeral** and immediately after which reduced disrupting her usual routine. Maintaining a regular and predictable routine during time of great change is very important particularly for a person with severe intellectual disability as it gives them a continued sense of security and consistency that not everything in their life has changed.

I visited Vincenza at her home and spoke with her sister several weeks after her mother had passed away to see how she was coping with the loss of her mother. Vincenza appeared quite settled and pleased to see visitors coming to her home. She did not appear to show any obvious signs of unresolved grief, emotional discomfort, distress, depression, anger, anxiety or any other behaviours. **Vincenza's acceptance of her mother's death** can be attributed to how well her family supported her through the process by:-

- Preparing her for the anticipated loss of her mother when her mother first became sick.
- Giving her many opportunities to express and say goodbye to her mother after she had passed away. Each opportunity would have given Vincenza a sense of finality and closure.
- Involving her in all the mourning rituals and in the funeral service from the start.
- Giving Vincenza several opportunities to see and to physically touch her **mother's body to help her understand** that her mother had died.
- Letting her see where her mother was physically laid to rest.
- Taking her regularly to the cemetery to place flowers and to touch and wave **goodbye to her mother's photo**.
- Letting her remain in her family home in which she had lived with her mother all her life and to receive continued care from her sister and her family in surroundings which were the most familiar to her.
- Having her sister and other family members as her confidants that she felt close to during that time.
- Being able to see photos of her mother around the house and having access to special mementoes of her mother.
- Maintaining her regular routine and her connections with staff and participants in the day program which she has been attending for many years.

Vincenza's family has clearly shown that her level of intellectual disability in no way determined their decisions as to how much **she should be told about her mother's death** or how involved she should be in the mourning rituals. Her family afforded her the same dignity and respect to mourn the loss of her mother and to grieve as they afforded to themselves. Her inclusion in every aspect of the bereavement process is what has clearly helped her to accept **her mother's passing and to move forward** without there being any adverse effects on her mental health and wellbeing. ●

We would like to extend our gratitude and sincere appreciation to Vincenza and her family for being so gracious in allowing for her story to be told in order to help other families to better understand how to support someone with intellectual disability through grief, loss and bereavement.

Thank you

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resources...

- Book in Hand is an Australian bookseller that focuses on books and resources for the ASD community. You can sign up to their e-list at www.bookinhand.com.au.
- An interesting snap-shot of Autism in Australia by the Australian Bureau of Statistics. The publication aims to present an overview of the prevalence of Autism in Australia and the impact the condition has on the everyday lives of those implicated by the condition. Visit www.abs.gov.au/ausstats/abs@.nsf/Lookup/4428.0main+features22009. The information covers prevalence, geography, Autism and education, disability and need for assistance.
- The Cool Kids © Child Anxiety Program: Autism Spectrum Disorder Adaptation is now available. The program is for children aged 8-12 years with an Autism Spectrum Disorder (Including Asperger's and High Functioning Autism). The program has been specifically developed for children who have an Autism Spectrum Disorder (including Asperger's disorder and High Functioning Autism) comorbid with an anxiety disorder. The program consists of a therapist manual, children's workbook and parent's workbook each with handouts, activity guides and visual supports. The program is available from Macquarie university www.centreforemotionalehealth.com.au. The therapist kit is \$65 and the workbook sets are \$315 for 10 sets.
- www.psychevisual.com is a comprehensive website of online professionals development sessions. You can pay and view online for a session with topics that range from Addiction, Depression, Brain Injury, Psychosis, Trauma and many more. You can view some sample videos and subscribe for regular updates.
- The AAIDD (American Association of Intellectual and Developmental Disabilities) website has a series of free webinars. You must register with their website to view them. Of special interest is 'Individualised supports planning for students with intellectual disability' which is based on the book *Intellectual Disability: Definition, Classification and Systems of Supports*. Visit http://www.aidd.org/IntellectualDisabilityBook/content_4670.cfm for more information, webinars and to register.
- Following consultation with over 300 parents and carers of children with disabilities across NSW, this NSW Ombudsman report highlights the key issues raised by parents and carers of children with disabilities, outlines recent developments, and indicates the areas that are being pursued with government agencies. Download a copy at www.ombo.nsw.gov.au/publication

reading list...

The Journal Current Opinion in Psychiatry has an edition that has a great focus on mental health and intellectual and developmental disabilities. I could not fit all the article titles in here so I have put in a couple of my favourites below; Current Opinion in Psychiatry, Volume 24, Issue 5. You will also find some literature on the epidemiology of intellectual disability in a number of countries.

Chaplin, R. (2011). Mental Health Services for People with Intellectual Disabilities. *Current Opinion in Psychiatry*. Vol 24, Iss 5, Pp. 372-376

This article highlights the need for specialised services and the positive outcomes that these services have produces.

Lindsay, W.R. (2011). People with Intellectual Disability who Offend or are Involved with the Criminal Justice System. *Current Opinion in Psychiatry*. Vol 24, Iss 5, Pp. 377-381

This is a great read if its your first port of call about Intellectual Disability and offenders. It covers assessment and treatment and a great reading list.

Briwn, L.K. and Briwn, M. (1998). *When Dinosaurs Die: A Guide to Understanding Death*. Little Brown and Co. This illustrated book covers a range of topics which can be read individually or as a whole.

Neece, C.L., Baker, B.L., Blacher, J. and Crnic, K.A. (2011). Attention-Deficit/Hyperactivity Disorder among Children with and without Intellectual Disability: an Examination across Time. *Journal of Intellectual Disability Research*. Vol 55, Iss 7, Pp. 623-635.

This longitudinal study illustrates the heightened risk for mental disorders for children with intellectual disabilities.

Palmer, P. (2000). *I wish I could Hold your Hand: a Child's Guide to Grief and Loss*. Impact Publishers.

This book helps grieving children identify their feelings- from denial and anger to guilt and sadness- and learn to deal with them.

Ryan, K., Guerin, S., Dodd, P. and McEvoy, J. (2011). End-of-Life Care for People with Intellectual Disabilities: Paid Carer Perspectives. *Journal of Applied Research in Intellectual Disabilities*. Vol 24, Pp. 199-207.

This article describes issues that contribute to the development of staff stress when providing palliative care and draws attention to areas of need.

the medicine cabinet: sleep glorious sleep..

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Sleep disorders are extremely common in children with developmental difficulties with reports ranging from 40 to 80% when compared to typically developing children (Cortesi *et al*, 2010). Often these patients prove extremely refractory to behavioural measures and other psychosocial interventions and thus resort to medication to help alleviate both personal and family stress.

Intrinsic biological and genetic abnormalities that alter neuronal pathways in the brain may contribute to Autism Spectrum Disorder (ASD) sleep problems (Cortesi *et al*, 2010). Various exogenous or environmental factors can affect sleep from the amount and intensity of light during the day to medications as well as exercise. So a multifactorial evaluation needs to be done prior to prescribing medication. Medications act on different pathways to generate the drowsiness to lead to sleep and these can also affect the different stages of sleep.

Table 1. Changes in sleep content and length with age (ref Lavie *et al*, Sleep Disorders,

	Sleep time (h)	Stages 1-2 (%)	Stages 3-4 (%)	REM (%)
Infants	13-16	10-30	30-40	40-50
Children	8-12	40-60	20-30	20-30
15-25y	6-9	45-60	15-25	15-25

2002)

As sleep and wakefulness are associated with different brain neurotransmitters, food as well as medications can affect the balance of these signals and thus how alert or drowsy one feels. Caffeinated drinks such as Coca Cola® and Mother® and drugs such as cold and flu decongestants especially those containing pseudoephedrine can stimulate the brain and cause insomnia. Many antidepressants suppress REM (rapid eye movement) sleep which also affects temperature regulation during REM sleep so extreme hot or cold temperatures will affect sleep quality. During the REM sleep is the time of increased production of proteins which also stimulates the brain regions used in learning.

Sleep initiation and maintenance prob-

lems resulting in reduced sleep duration are the most common concerns expressed on parental interview. Some studies report children with ASD taking more than an hour to fall asleep. Periods of nocturnal awakenings lasting 2-3 hours have also reported by parents of ASD children. Besides medications affecting quality of sleep, there are some that are also used to help with sleep initiation and maintaining restorative sleep.

Even before medication would be trialled, establishment of normal sleep hygiene through behavioural interventions is important as adherence to positive and consistent bedtime routine is associated with reduction in sleep problems (Cortesi *et al*, 2010). Sleep problems can also pose a challenge to independence and separation from parents, although it is not the avoidance of waking in the night but the capacity to sleep on one's own and return to sleep if aroused. Identifying the maladaptive sleep habits and educating parents and carers in basic sleep hygiene principles is cornerstone for success. These include a selection of an appropriate bedtime and wake time, establishment of bedtime routine and no-reinforcing interactions with the child during night arousals (Johnson *et al*, 2008).

Children with significant sleep problems often lead to daytime dysfunction and as a result sleep difficulties should always be investigated as part of an assessment for the daytime impairments. The recognition that interventions can improve sleep and may result in better daytime functioning has fuelled a growing research interest (Johnson *et al*, 2008).

Medications to Aid Sleep

Melatonin (N-acetyl-5-methoxytryptamine)

Some hypothesise, one of the reasons for sleep dysregulation is an alteration in hormone/neurotransmitter (melatonin/serotonin) production. Melatonin is an endogenous or natural hormone produced by the pineal gland from the essential amino acid tryptophan, in response to falling light levels as picked up by the eyes. Over a series of pathways melatonin is then converted to serotonin or dopamine in the brain.

In North America, synthetic melatonin is classified as a food supplement whereas in Australia it is a prescription product. It is important to distinguish the synthetic melatonin from the homeopathic product which is available in Australia in homeopathic strengths in health food stores or community pharmacies. Homeopathic



strengths refers to the strength of the melatonin and then the dilution factor such as 3mg 10x means that 3mg of melatonin has then been diluted 10 x 10 fold ie 10⁻¹⁰, which is almost nothing.

All studies have used full strength melatonin in an immediate release form. There is a product available on prescription which is a controlled release form under the trade name of Circadin®. Studies using this form have mainly been carried out in adults over 55. Studies of immediate release melatonin use in children with ASD provide good evidence for its effectiveness and safety.

Melatonin has poor bioavailability when given orally and young children appear to metabolise melatonin more rapidly when compared to older children. The peak blood level is obtained within 1 hour of administration and half the melatonin has been eliminated by 40 minutes. Melatonin can be highly beneficial, short term, rapid onset and safe treatment for intractable sleep disturbance. Although there was a report that melatonin affected epileptic control this has now been refuted.

To increase the body's own melatonin LED (light emitting diodes) equivalent to 2000 to 2500 lux have been used in the mornings usually between 6am to 9am for 30-60 minutes especially for delayed sleep phase syndrome (Chesson A *et al*, 1999)

Clonidine

Clonidine is a noradrenergic alpha 2-agonist that is widely used in paediatric and psychiatric practice. Originally used as an agent to control blood pressure, it is commonly used to target the sleep delay in children with ADHD as well as reducing the symptomology of restlessness, reactivity,

impulsivity and anxiety in some patients with ASD as well as PTSD.

Benzodiazepines such as Diazepam, Temazepam

Although these induce sleep, tolerance and dependence may develop very quickly. These should only be used for short term use.

Chloral Hydrate

Usually only used for short term sedation such as for a procedure as the effect can wear off after only 2 weeks and it is also known to cause drug dependence in adults. The use of chloral has been superseded by the benzodiazepines.

Antipsychotics and Antihistamines

These are used for controlling challenging behaviours such as risperidone, olanzapine and quetiapine, as mentioned previously some can have sedating properties. These in time can lessen as the body adjusts to the medication and a slight medication decrease or change in dosage form or timing of doses can be helpful if the daytime sedation is problematic. They can also help by reducing anxiety and agitation.

Some have sedative actions such as Promethazine (Phenergan®), Trimeprazine (Vallergan®) and Dexchlorpheniramine (Polaramine®) due to the effect of the histaminergic receptors which also increase appetite and lead to weight gain. Weight gain can affect sleep by causing obstructive sleep apnoea which in turn leads to a disrupted night's sleep. So long term use of antipsychotics to improve sleep is not ideal. Although these medications can be purchased from the community pharmacy there are now more restrictions on the purchase due to small difference between a toxic dose and a therapeutic dose. Also when investigated by Food and Drug Administration (USA) there was a very poor level of effectiveness as cold and cough medications and risks in the under 2 years far outweighed the potential for benefit.

Complementary and Alternative Medications

1. Valerian is likely to be safe to use as large adult short term studies have been shown to be safe. Use is usually for anxiety based sleeplessness and there are reports about effectiveness in sleep latency (initiating sleep) and quality of sleep, these studies have not been done in children with ASD although widely used by clinicians. Valerian is

also standardised to valerianic acid constituent but most trials do not specify the strength of the valerianic acid component used. So efficacy can change when changing brands.

2. St Johns Wort is primarily used to mild to moderate depression so for the insomnia associated with depression. It has been shown to be effective in adult patients for mild depression. But it does interact with many other medications not just other serotonergic antidepressants that also have a small risk of a serotonin syndrome. As with valerian the active component of the products can vary between brands and one stick to the one brand and take according to the instructions.
3. Hot chocolate/ hot milk increase tryptophan. L-tryptophan as the precursor to serotonin (one of the body's neurotransmitters) has also been shown to be effective as an aid to initiation of sleep but has been associated with a significant adverse reaction – eosinophilia myalgia and even deaths in 1990s. There is some evidence to suggest that this might have been due to contamination of the raw ingredient. Now the main source of L-tryptophan is food such as dairy, soy, nuts and red meat products. Calcium in milk helps the brain convert the tryptophan in the milk to melatonin thus the warm milk drink just before bed aids in sleep initiation. Together with honey this combination of complex carbohydrate, calcium and protein is an traditional remedy for bedtime insomnia.

Sleep that is Affected by Medications

Besides those medications that are prescribed to help with maintaining sleep or initiating sleep there are many medications that can affect sleep. Some are widely known such as the psychostimulants – methylphenidate and dexamphetamine and the sedating antihistamines but there are others that affect sleep due the adverse effects of the medication on the body. Although the list is not comprehensive if there are medications that are affecting the daily living of a person then these effects should be mentioned to the prescriber.

Selective serotonin reuptake inhibitors (ie. sertraline, fluoxetine and citalopram) have all been reported as causing insomnia. As these are taken once a day the best time to take them would be in the morning so sleep architecture is not affected. They may also cause sedation in which case they should be taken at night.

Antiepileptics or Mood Stabilisers

Although being used to controls seizures or stabilise mood, both sodium valproate and carbamazepine have some sedating properties especially early in treatment. Lamotrigine although primarily used for epilepsy is also used as a mood stabiliser can also cause insomnia, if troublesome then discussion about changing or reducing the dose of the antiepileptic might be needed. Topiramate another common antiepileptic is also known to cause fatigue in adults if bothering then this should be raised with the prescriber.

Corticosteroids

These are often used for severe allergic conditions such as asthma or short term for croup or topically for eczema although the conditions may also have effect on sleep when given to children they can have a stimulatory effect leading to insomnia.

Beta Agonists

These inhaled medications are used for asthma and can have the effect of being excitatory and thus causing insomnia.

So to achieve a good night's sleep there are many factors that may affect the actual sleep initiation and staying asleep not just pharmaceutical. Having a good routine and following basic sleep hygiene recommendations helps even when given medication to help with the sleep. Once it is decided to use a medication it is important to use the time while taking the medication to help achieve good sleep hygiene habits so that when off the medication, sleep can be achieved.

A combination of multiple sedatives could lead to excessive sedation and there is the potential to cause impairment in judgement. ●

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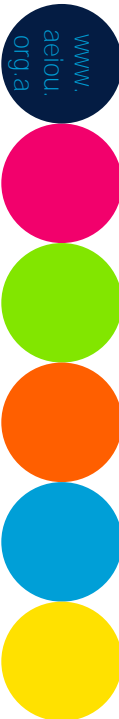
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Research suggests that people from refugee backgrounds experience higher rates of post-traumatic stress disorder, depression and anxiety disorders than the general population (see Davidson et. al., 2008).

Australian findings indicate that mental health and wellbeing outcomes for refugee populations are influenced by a number of factors, such as the complexity of pre-displacement, displacement and resettlement experiences (APS Paper – Review of refugee mental health and wellbeing: Australian perspectives, 2008).

It is common for refugees from war torn countries to have suffered physical abuse, violence, injury, loss of limb or torture. Many refugees have also witnessed similar mistreatment of others, including family members (Department of Education and Communities, 2009).

Refugees who have not been exposed to physical torture or trauma may have experienced trauma in emotional and psychological forms. Individuals may be affected even though they themselves were not directly involved in fighting or did not suffer the direct violence or abuse (Department of Education and Communities, 2009).

People who have experienced trauma may experience the following behaviours:

- Persistent memories and nightmares, disturbed sleep
- Difficulty thinking, concentrating, remembering
- Distrust and fear of strangers
- Emotional distancing or numbing, lack of trust
- Fear of being alone or of dark places
- Being constantly 'on guard' for danger
- Overreacting to situations
- Inability to manage anger or stress
- Lack of control over violent or impulsive behaviour, tantrums
- Physical symptoms such as headaches, loss of appetite
- Emptiness, apathy, despair
- Increased anxiety about relationships
- Fierce self-sufficiency or clinging dependency
- Over-protectiveness and suspicion of danger
- Self-harm, self-degradation, self-blame,

hopelessness, suicidal thoughts
(<http://www.strongbonds.jss.org.au/workers/cultures/migration.html> accessed on 18/8/2011)

Impact on Physical and Mental Health

Many refugees arrive in Australia in need of treatment for unmet medical and dental needs. The health, mental health and physical condition of refugees may manifest in a number of ways, including sensory problems, anxiety, depression and Post Traumatic Stress Disorder (Department of Education and Communities, 2009).

Benson (2005) proposes a “culturally sensitive consultation model”, a practical approach when working with refugees. The Strengths and Difficulties Questionnaire (SDQ), which is available in many different languages, may be used as a brief behavioural screening tool.

Counselling and psychotherapeutic approaches such as Cognitive Behavioural Therapy (CBT) and Interpersonal Psychotherapy (IPT) are effective when working with refugee students. CBT challenges thoughts and behaviours that may be causing or maintaining inappropriate behaviours or emotions. This intervention includes problem solving, relaxation training, cognitive restructuring etc (for more information see Cardemil, 2010; Bernal et al, 2009)

In addition narrative and art therapies are effective. These therapies allow for **understanding a person's story, expression of emotions and identifying the person's strengths** to help with difficult situations/emotions. These therapies can help raise a **young person's self esteem, acquire new skills and insights** and reduce anxiety (for more information see Ncube, 2006).

Strong community support networks assist in the settlement process and support recovery from trauma. Professionals are encouraged to work collaboratively with refugee communities to optimise mental health and wellbeing, and to ensure the breadth of the human experience (particularly strengths) is utilised in resettlement. (Australian Psychological Society, 2011)

Medical, dental, general health and mental health needs can consistently or intermittently disrupt the learning of refugee students at school.

Disrupted Previous Education

Depending on the conditions in their country of origin or in the refugee camps they come from, many refugee students may have been unable to attend school for some time. Some students may never have been to school. Few refugee students will have had recent experience with classrooms, schools or formal learning environments similar to those in Australian schools (Department of Education and Communities, 2009).

It is important to note that disruption to education or no western-style education does not necessarily suggest the student has an intellectual disability. As a result of serious disruption to education, refugee students may have significant gaps in their literacy and numeracy development, or limited skills in expressing academic concepts in their first language (Department of Education and Communities, 2009). No experience with western-style education poses its own problems for refugee students when experiencing school for the first time.

Some behaviours and learning characteristics observed in students from a refugee background may be similar to students with learning difficulties. For example, inattention/off task behaviours may result from the young person not understanding what is being communicated and thus not understanding when or what to do.

In addition, refugee students may need to develop their fine and gross motor skills and their social and emotional skills. However, many refugee students are making a successful transition to school, having experienced limited disruption to their schooling (Department of Education and Communities, 2009).





Psychological Testing and Intellectual Disability

It is important to consider the cultural appropriateness of psychological tests when assessing a young person from a refugee background.

Cognitive Assessment

The use of non-verbal tests of intelligence (for example, the Universal Nonverbal Intelligence Test, Raven's Progressive Matrices, Wechsler Nonverbal Scale of Ability) can provide an indication of cognitive functioning. However, results must be interpreted with caution as the young person may be unfamiliar with the task or content, or the concepts tested are not directly transferrable across cultures. Other contributing factors such as hearing loss, vision impairment, poor nutritional diet etc. would also normally require consideration when undertaking an assessment.

Intellectual disability is a developmental disorder and identification should be motivated by the need for advocacy, flexibility and individualised support, and the provision of appropriate learning opportunities (Hudson, A. & Radler, G., 2005). Some refugee students may arrive with a diagnosis of an intellectual disability. In other cases family members may have some recognition of development delay in their child.

Refugee students need time to adjust to their new environment. Once the family has settled, issues of possible disability may be raised within the school context. However, if the school attempts to initiate diagnosis too quickly, the student may be misdiagnosed or the family may feel over-



whelmed and become disengaged. It is important to initially develop a safe and trusting environment for the student and their family.

When considering a formal cognitive assessment care must be taken to compile a comprehensive picture of the students functioning using a number of sources of information. Assessment which may ultimately result in diagnosis ideally should include interviews, observations, informal assessment and formal norm referenced assessments across all domains.

In addition, there are some behaviours that overlap with learning difficulties, second language acquisitions and refugee experiences (for example, inattentiveness, withdrawal, poor concentration, anxiety/frustration). Tangen (2009) argues that overlapping behaviours compound the difficulty professionals have in determining the essential cause for concern with learning and behaviour and thus, the appropriate action to take.

Summary

In summary, refugees come from diverse cultures and backgrounds, but share common experiences of disadvantage that impact on their capacity and readiness to learn and express emotions.

Collaborating and consulting with students, their families and the community is an important first step in creating a safe and trusting environment in which to work.

Resources

- Australian Government: Department of Immigration and Citizenship <http://www.immi.gov.au>
- Foundation House www.foundationhouse.org.au
- NSW Refugee Health Service www.refugeehealth.org.au/clinics
- NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS) <http://www.startts.org.au>
- Transcultural Mental Health www.dhi.gov.au
- Victorian Transcultural Psychiatry Unit (VTPU) www.vtpu.org.au

For information about psychological testing see:

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getting on track in time: “Got It!” ...



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In March 2009 the NSW Government released *Keep Them Safe - A Shared Approach to Child Wellbeing* – a whole of Government response to the Report of the Special Commission of Inquiry into Child Protection Services in NSW. *Keep Them Safe* recognises the importance of the wellbeing of all children and young people, with the aim of providing appropriate support to families earlier, to prevent children and young people requiring statutory child protection intervention. Getting on Track – *Got It!* is funded under *Keep Them Safe* and specifically addresses one of the *Keep Them Safe* actions, that NSW Department of Education and Communities and NSW Ministry of Health examine strategies for expanding counselling services for parents.

Got It! is a new school based early intervention program that is being implemented by NSW Ministry Health, Child and Adolescent Mental Health Services (CAMHS), in partnership with the NSW Department of Education and Communities. It aims to reduce the frequency and severity of conduct problems and prevent the development of severe behaviour problems such as conduct disorder in young children. It also aims to improve schools capacity to respond to children with conduct problems. The program will achieve these aims by delivering comprehensive and sustainable evidence-informed interventions to children, parents and teachers in the early years of school.

The program has been adapted from the Child and Adolescent Mental Health Services and Schools: Early Action Program (CASEA), which involved collaboration between Child Adolescent Mental Health Services and primary schools in Victoria. Like the CASEA Program, *Got It!* is a multi-level, multidisciplinary early intervention program targeting children in selected

schools from Kindergarten to Grade 2 (approximately 5 to 8 years of age) who exhibit elevated levels of conduct problems. *Got It!* is located in the catchments of the three Keep Them Safe pilot Family Referral Services located at Mt Druitt, Dubbo and Newcastle.

Got It! involves mental health clinicians working with children, parents and primary school staff to plan, promote and deliver early interventions to children and their families. The program is delivered over two school terms (six months) with screening and assessments in one school term and interventions offered in the second school term. *Got It!* will include nine intervention components across mental health promotion/primary prevention and secondary prevention. The model is described below.

Mental health promotion and primary prevention interventions will involve:

1. Intensive professional development for teachers addressing the management of conduct problems and delivery of universal interventions to all children in the first three years of primary school.
2. Delivery of Social Emotional Learning classroom programs by teachers to promote social-emotional development of all children in the first three years of school.
3. Parenting information campaign for parents of all children in the first three years of school, to promote effective parenting strategies, to normalise and destigmatise participation in parenting programs, and to introduce the *Got It!* program.
4. Screening of all children in the first three years of primary school regarding their behaviour using Strengths and Difficulties Questionnaire (SDQ; Goodman 1997) as rated by both teachers and parents.

Secondary prevention interventions will involve:

5. A comprehensive assessment by mental health clinicians for children exhib-

iting elevated conduct problems and their families using standardised parent-rated questionnaires and clinician-rated tools.

6. An 8-week child-focussed group intervention delivered in the school for children with elevated conduct problems. These programs, led by mental health clinicians and supported by school staff aim to reduce conduct problems by improving awareness and management of difficult emotions such as anxiety and anger, improve social skills, promote self-esteem and enhance problem solving skills by identifying and building on existing strengths.
7. An 8-week group parenting intervention, based on social learning theory, for parents of children with elevated conduct problems, led by mental health clinicians and supported by schools staff.
8. Individual behaviour management support for children exhibiting extreme levels of conduct problems.
9. Streamlined referral of identified children and their families to CAMHS or other appropriate services for further assessment and intervention.

An external evaluation will be conducted over three years to assess the implementation and outcomes of *Got It!* in three pilot sites in NSW. The evaluation will commence in 2011 and will inform the potential for a state-wide rollout of the program. ●

For further information about *Got It!* contact:

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Mental Health and Drug & Alcohol

MH-Kids

Hosted by the Sydney Children's Hospitals
Network (Randwick & Westmead)





asia pacific autism conference (APAC)...

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The Asia Pacific Autism Conference (APAC) was hosted by the Autism Association of Western Australia, and held at the Burswood Entertainment Complex in Perth on the 8-10th of September 2011. APAC 2011 was the largest international Autism Conference to be held this year, with over 1300 attendees. It was also the largest gathering of international Keynote Speakers to present at an Autism Conference held in Australia. The theme of the conference was "create and inspire the future".

I had the pleasure of delivering two presentations on behalf of our research team at the Centre for Emotion-Based Social Skills Training (CEBSST), Children's Hospital at Westmead (CHW). CEBSST is currently involved in a large collaborative study with Department of Education and Communities where Emotion-Based Social Skills Training (EBSST) is being delivered to 300 students with Autism Spectrum Disorder (ASD), their parents and teachers by School Counsellors, in a study using a treatment vs. delayed treatment group design. Preliminary outcome data from the treatment group, from the two different versions of EBSST, the first for children with High Functioning Autism and Asperger's Disorder, and the second for children with Autism and Mild Intellectual Disability were presented. Results to

date have been very encouraging and suggest EBSST improves parent and teacher reported emotion-based social skills and also improves mental health. Both presentations generated a great deal of interest and enthusiasm for our important and innovative program of research at the CEBSST.

It was also wonderful to hear presentations across several different domains from speakers throughout Australia and the Asia-Pacific, of which there are too many to describe and summarise individually. International keynote speakers at the conference included Professor David Amaral (US) who presented on the heterogeneity of ASD and his findings from the Autism Phenome Project. At least 100 genes have now been implicated in ASD, although environmental factors account for about 55% of the risk for ASD. Professor Patricia Howlin (UK) presented on the evidence for interventions for young children with Autism, suggesting a 'one size fits all' approach doesn't work for ASD, and clinicians and families must consider the individual needs of the child. Professor Howlin presented again on the longer term outcomes of people with ASD, highlighting the need for an approach to ASD across the lifespan.

Professor Catherine Lord (US) presented on early diagnostic assessments for sibling toddlers of children with ASD, including some fascinating video footage of children assessed on the Autism Diagnostic Observation Schedule (ADOS), (of which she is an author), over time.

Professor Gary Mesibov (US), from TEACCH in North Carolina spoke on the importance of enhancing quality of life and incorporation of positive psychology into evidence-based teaching approaches for children with ASD.

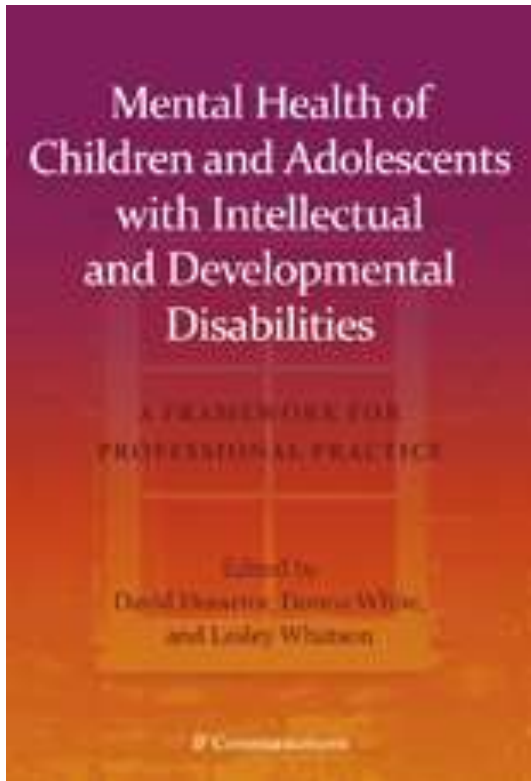
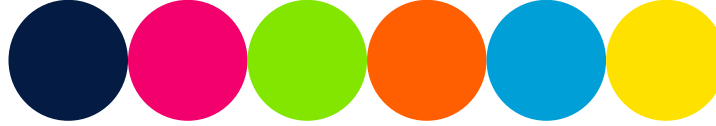
Throughout the conference, there were many opportunities to network with other professionals across the region. The Welcome Reception and Grand Gala Dinner on the social calendar provided a wonderful chance to share knowledge and be inspired by the work of others in this field.

On the final day, Dr Norman Swan (ABC Radio National) hosted a 'hypothetical' with a panel of experts including many of the Keynote Speakers and regional leaders in the field on 'The Future of Autism'. This generated some interesting and thought provoking discussions from the audience and the panel. The emphasis was on empowering children via their families.

Joan McKenna Kerr, Conference Convenor, Chief Executive Officer, Autism Association of Western Australia in an email following the conference wrote "I trust APAC 2011 has given us time to consider leadership and our role in creating and inspiring the future, regardless of whether the future we inspire is for one person, a group of people, or the Autism population as a whole." Indeed, this is what APAC 2011 did.

APAC will be held again in August 2013, hosted by Autism South Australia. ●





Book Release; Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities *A Framework for Professional Practice*

IP Communications, www.ipcommunications.com.au, August 2011

Edited by David Dossetor, Donna White and Lesley Whatson

Children and adolescents with intellectual and developmental disabilities are at high risk of co-morbid emotional, behavioural, and psychiatric problems that may further reduce their functional abilities. For the clinicians who support them and their families, meeting the needs of children and adolescents with intellectual and developmental disabilities and mental health problems is challenging.

In this book, clinicians who work with young people with intellectual and developmental disabilities and mental health problems will find a comprehensive framework for how their complex developmental, emotional, and behavioural needs might best be addressed. Relevant biological, developmental, family, educational, social, and cultural factors are integrated. The evolution of developmental sequence is seen as vital to understanding the mental health problems of children and adolescents with intellectual and developmental disabilities. This view informs multi-dimensional

assessment of behaviour, and addresses conceptual confusion in defining behaviour problems, developmental disorders (including developmental psychiatric disorders such as ADHD and autism spectrum disorders), mental disorders, and serious mental illnesses. Evidence-based interventions to promote skill development and mental health in young people with intellectual and developmental disabilities are described. A model for how interdisciplinary and multi-agency collaboration and co-ordination might be facilitated is outlined. Parents' perspectives are also presented. Fundamentally, though, this is a book *by* clinicians, *for* clinicians.

All clinicians and other professionals who work to improve mental health outcomes and quality of life more generally for young people who have intellectual and developmental disabilities - paediatricians, child psychiatrists, psychologists, speech pathologists, occupational therapists, social workers, behaviour clinicians, counsellors, teachers, agency managers, among others - will find the book invaluable.

About the Authors

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Order your copy at

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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

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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