

CHW



Link

mental health and intellectual disability...

coordinator's message...

Welcome to the 2nd edition of our newsletter for 2012,

The Children's Hospital at Westmead School-Link Initiative has been working with Ageing, Disability and Home Care, Department of Family and Community Services (ADHC) and several Department of Education and Community Schools for Specific Purposes across NSW to deliver the Group Stepping Stones Triple P parenting program. Stepping Stones is delivered to groups of parents or carers with children with a developmental disability (aged 0-12 years) to reduce problem behaviour. The program is delivered over the course of 9 weeks involving 6 x 2½ hour group sessions and 3 x (15-30 minute) individual telephone consultations. School staff (school counsellors or teachers) were trained and accredited by Triple P in 2011 and then paired with a trained staff member from ADHC to co-facilitate the program to a group of parents in their school. Groups are only just finishing up but preliminary reports from the facilitators are that the groups have been very successful. We will report more on this project in the next edition.

In this edition, Dr David Dossetor takes a look at Fetal Alcohol Spectrum Disorders and the implications that drinking during pregnancy can have for a child and some creative work that has been done to highlight this disorder to gain the attention of the public, including the United Nations. Dr Phil Ray describes some research into neglect and the developing brain illustrating the importance of those first few years of life. Kellie van Sebille shares her recent experience in completing some play therapy training where the child takes the driving seat during the therapeutic process. Having trouble finding time and resources to attend all those interesting conferences on offer? Lesley Whatson, Debra Corfield and David Dossetor share the highlights from two interesting conferences they attended recently. ●

Happy Reading. Jodie Caruana, School-Link Coordinator
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a note from David Dossetor...



Fetal Alcohol Spectrum Disorders (FASD): Raising awareness of a preventable disability in our midst.

Associate Professor David Dossetor, Child Psychiatrist with a special interest in Intellectual Disability and Autism, Area Director for Mental Health, The Children's Hospital at Westmead.

Tristan is a 13 year old boy from Fitzroy Crossing, a community of 2500 in the Kimberley, 400km east of Broome, who travelled to Admiralty House, Sydney, to meet the Governor General Quentin Bryce on 5th April this year along with his foster parents including Marmingee and Geoff. The occasion was the launch of a short movie **"Tristan"** on Fetal Alcohol Spectrum Disorders (FASD) (Kirby, 2012). Members of the Lilliwun research and film team including Elizabeth Elliott, Jane Latimer, June Oscar and Marmingee Hand were also invited in May to present the film to the United Nations Permanent Forum for Indigenous Issues in New York to promote awareness of the dire consequences of drinking in pregnancy. In 2008 Elizabeth Broderick, Australia's Sex Discrimination Commissioner and Commissioner responsible for Age Discrimination and her sister Jane Latimer **took the group's first movie called *Yajilarra* (to dream)** to the UN. This film charted how, after 55 deaths including 13 suicides in the community in a year, two female Aboriginal elders from Fitzroy Crossing, June Oscar and Emily Carter, started a chain of reforms and persuaded the WA liquor licensing

board to ban the sale of full strength take away alcohol. This calmed levels of violence, eg. a reduction of alcohol related presentations to hospital by 42%, and brought the community of 5 Aboriginal language groups together through the Marninwarntikura Womens Resource Centre and Nindilingarri Cultural Health Services, to provide leadership in their challenge - FASD. This led the community to want to understand the importance of FASD, which was aided by another short movie *Marulu* (a Banuba word that means precious, worth nurturing). They invited a **research team from the Children's Hospital at Westmead**, the University of Sydney and the George Institute to do a study of child health and development in Fitzroy Crossing and the surrounding communities called *the Lilliwun project* (Kimberley Kriol for 'all the little ones') (Elliott et al, 2012) (Kirby, 2012). Mick Gooda, Australia's Aboriginal and Torres Strait Islander Social Justice Commissioner, has promoted this project as a best practice model of Aboriginal led research resulting in change (Gooda, 2010).

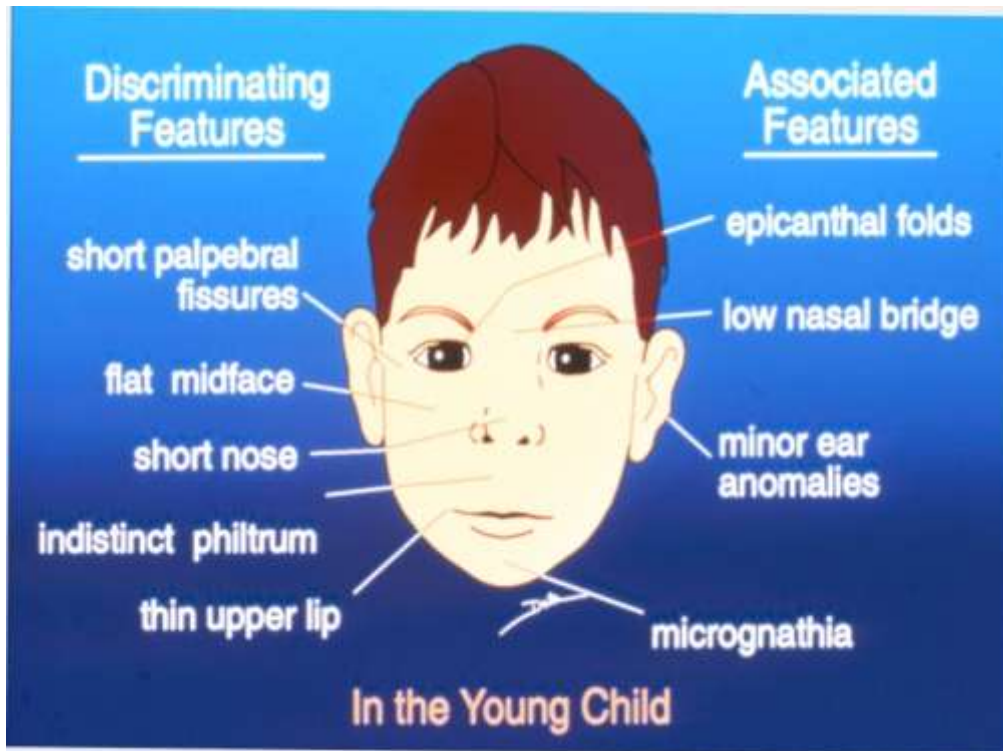
Tristan is a likeable and generally happy boy who uses repetitive sensory activities to help him concentrate and keep calm and has major problems of memory and connecting thoughts. This makes it difficult for him to engage in peer friendships. He has major learning difficulties needing individual support in school. He has high energy levels, with problems of distraction and benefits from plenty of outdoor activity such as being linesman for the local AFL team. Amongst his physical abnormalities is hydrocephalus, treated with a shunt. Marmingee (his aunt) and her husband Geoff are both teachers and highly skilled in providing a supportive environment for Tristan and his 2 younger foster **brothers (Marmingee's grandchildren)** who are also affected by FASD. Poignantly, Tristan wishes he was normal. His birth mother is now able to admit she was wrong in drinking during pregnancy. June Oscar describes how recognising FASD can make others more understanding of the condition and how this takes off some of the pressure of unrealistic expectation and gives children a chance for community support and acceptance.

Of course FASD is found in all populations and ethnic groups. Preliminary data suggest that 50% of indigenous women in the Fitzroy Valley drank in pregnancy - mostly at very risky levels - but other studies

show that 60% of non-indigenous women report drinking in pregnancy. The rising culture of teenage binge drinking means that teratogenic* harm to a developing baby can be done before the mother is even aware of being pregnant. Surveys show 25% of 14 to 19 year olds have had a drink in the last week and that 11% of females aged 18-24 years indulge in high risk drinking. Intake of 7 or more standard drinks a week in pregnancy has been associated with attention deficits in the child. Some studies suggest that alcohol in pregnancy is now the leading cause for intellectual disability with an incidence of 2-4% suggested! However lack of professional knowledge, enquiry and recognition limits identification.

“The rising culture of teenage binge drinking means that teratogenic harm to a developing baby can be done before the mother is even aware of being pregnant...”

A workshop I attended at the 2011 American Academy of Child and Adolescent Psychiatry Annual Meeting described the rising concern in USA and Europe. It has been known for 50 years that alcohol is teratogenic to the developing brain in animals and humans. Fetal Alcohol Syndrome was first described in 1973. The full Fetal Alcohol Syndrome is characterised by growth retardation, characteristic facial features as outlined in the diagram, and structural abnormality or functional impairment of the central nervous system and may include defects in heart, kidney, bone development. The organic brain damage can include microcephaly, intellectual disability and seizures and can occur in the absence of other physical features. The neuropsychiatric features or Alcohol Related Neurodevelopmental Disorder (ARND) may also occur without identifiable physical features. The term Alcohol Related Birth Defects (ARBD) is used to describe physical effects of prenatal alcohol and can occur without ARND. FASD is the umbrella term that includes the three groups of fetal alcohol related abnormalities. First trimester alcohol exposure may cause facial dysmorphism and growth deficiencies, while 2nd and 3rd trimester effects on brain development include disruption to neurogenesis, neuronal differentiation, migration, arborisation, synaptogenesis and functional synaptic organisation, and neurotransmitter



system development. Animal models even show a transgenerational effect of maternal alcohol use, for example leading to offspring having an increased craving for alcohol or even a different coat colour. ARBD may account for approximately 20% of all birth defects.

Susan Rich, a child psychiatrist from Washington DC, highlighted the multidirectional interactions between multifactorial elements of FASD: the cognitive dysfunctions and learning disability, the poor academic and social performance, school failure, the adverse home and social environment and violent and persistent antisocial behaviours. She divides the neuropsychiatric deficits up into: 1. language and social skills deficits, 2. mood and autonomic arousal dysregulation, 3. multisensory functional and perceptual deficits, and 4. cognitive and executive dysfunctions. Identifying FASD helps professionals understand the co-occurrence of such a wide range of complex deficits. She classifies ARND severity: Mild - with evidence of complex learning disorder, with or without language disorder, psychiatric disorder and deficits in adaptive functioning or executive functioning or Moderate - with evidence of complex learning disorder with or without intellectual disability; chronic psychiatric disorder unresponsive to standard treatment approaches including medication; neuropsychological deficits in working memory, executive functioning, judgement and decision-making, and deficits in adaptive functioning. Severe ARND is also known as static encephalopathy, with evidence of structural brain damage, brain dysfunction or seizure disorder.

A practicing American lawyer, William Edwards, described his work with juveniles on death row, where many seem to have FASD. His work suggests that mothers will routinely deny use of alcohol in pregnancy and that discrete information from other informers is necessary. The major neuropsychiatric problems described in FASD are often seen in recidivist juvenile offenders, who do not have the insight to alter their own trajectory. The reports that they often end up in foster and institutional care are alarming, but difficult to substantiate without more longer-term studies. The Australian NHMRC health recommendations on alcohol use reports that there is no safe lower limit of drinking in pregnancy (NHMRC 2009). Prof Elliott reports that many young female drinkers **don't heed this advice. The simplicity of the recommendation of "no alcohol in pregnancy" enables other members of the community to show concern and help women who continue to drink when pregnant. This mirrors the Surgeon General's warning in the USA (2005) that a woman who is pregnant or considering becoming pregnant should abstain from alcohol.** Further, since nearly half of all births are unplanned, women of child-bearing age should consult their physician and take steps to reduce the possibility of prenatal alcohol exposure. Health professionals should inquire routinely about alcohol consumption by women of childbearing age, inform them of the risks of alcohol consumption during pregnancy, and advise them not to drink alcoholic beverages during pregnancy. The tragedy is that most women are unaware that drinking in pregnancy can do lifelong harm to their child. Public awareness and prevention is a most important intervention, but must

be supported by moves to restrict access to alcohol through pricing, taxation, availability of low strength options and limitation of the number of alcohol outlets and their opening hours.

Kieran O'Malley, an Irish child psychiatrist, said both the lack of recognition and treatment of FASD contributed to the grim long term outcomes (O'Malley, 2007). For example, in Ireland, which has as high a level of alcohol consumption as anywhere in the world (13 litres/person over 15 years old/year) and where 44% of women report an episode of binge drinking in the last month, national data report no identified cases of FASD! Australia has a similar and growing national level of alcohol consumption. An Australian study of case identification through reports by paediatricians only identified 92 new cases of FASD over 4 years (Elliott et al, 2008). O'Malley (2011) reports that ARND may be 10 times more frequent than FAS.

Streissguth and O'Malley (2000) reported on the dreadful long term outcomes of one cohort followed into adulthood: at 21 years 90% had mental health problems, 80% had dependent living and problems with employment, 40% had problems with the law, sexually inappropriate behaviour, and disrupted education, 30% had a period of imprisonment and 20% had drug and alcohol problems! Brain scan abnormalities include loss of cortical volume especially in frontal lobes (associated with problems of executive function), changes to the corpus callosum and hippocampus (affecting motor coordination and memory) and basal ganglia (affecting perseveration and executive function). Executive function skills can be classified as: complex cognitive functions, future orientated skills and integration of various perceptual processes. Deficits in the dopamine and noradrenergic neurotransmitter systems are found in those with attention problems. There is also disruption of the balance between the GABA inhibitory and the glutamate excitatory neurotransmitter systems. Phil Ray, Clinical Neuropsychologist, will report on the neuropsychological abnormalities in a later article.

Assessment of the child exposed to alcohol *in utero* should include evaluation of cognitive and language skills, behavioural and psychiatric problems, and sensory processing especially in the under 5s. Although IQ is, on average, impaired by 20 points, scholastic skills and adaptive functioning are more severely impaired, by 30-40 points. Problems of working memory, abstraction, planning, organisation, judgement and insight are critical, along with problems of emotion recognition and expression and social understanding and

interaction. Variability between domains of skills is the rule. O'Malley's summary of common psychiatric presentations highlights the complexity of these cases: regulatory disorder including hypersensitive or sensory seeking/impulsive behaviour presents in first 3 years of life; co-occurring PTSD and developmental trauma disorder; ADHD (40-60%) with co-morbid learning disorders of mathematics, reading and writing; and ADHD not uncommonly associated with social communication disorder or Autistic Spectrum Disorder. Other disorders secondary to alcohol exposure *in utero* include sleep problems, anxiety, mood disorders (40%) with suicide threats and attempts, intermittent explosive disorder, conduct disorders, psychoses (30%), drug and alcohol problems and personality problems. Infants and young children are prone to Attachment Disorders, Affect Disorders, Anxiety Disorders and Regulatory Disorders of Sensory Processing. O'Malley uses the diagnostic classification of mental health and developmental disorders of infancy and early childhood for Regulatory Disorders of Sensory Processing: 1. Hypersensitive: Type A fearful/cautious; Type B negative/defiant. 2. Hyposensitive/under responsive: withdrawn/difficult to engage; self-absorbed. 3. Sensory stimulation seeking/impulsive (Zero to Three, 2005). In summary these youngsters are vulnerable to neurodevelopmental disorders, neuropsychiatric disorders and drug and alcohol disorders which may be made worse by environmental contributors.

O'Malley describes the importance of a range of medications to reduce psychiatric impairment, with the caveat that applies for all youngsters with significant abnormalities of development of the brain: lower rates of success and greater sensitivity to side effects compared with a mainstream population, plus the added risk of syndromes related abnormal cardiac function

and seizures. More than one medication may be needed to treat attention with co-morbid conditions. There is control trial evidence in FASD on the use of stimulants, fluoxetine, valproic acid and risperidone. Other medications that may be useful are other treatments for ADHD, other mood stabilisers, SSRIs and major tranquillisers and others medication types include buspirone, clonidine, tryptophan, melatonin, longer acting benzodiazepines, and naltrexone. He also cites evidence for the role of neuroprotective agents for drinking mothers, such as vitamins, folate, magnesium, zinc and choline to diminish the harm of alcohol on the developing fetus.

Treatment needs to be multidisciplinary, multimodal and multiagency, tailored to the individual child and family. O'Malley lists: detailed diagnostic assessment followed by individual treatment, dyadic therapy, family therapy, group therapy, residential/housing, vocational/rehabilitation, dental care and advocacy. The individual therapy may include: sensory/motor training, non-verbal play therapy, cognitive behaviour therapy, reality-based therapy and trauma-based therapy. Speech and language therapy may be important, but recognition of special needs and appropriate support from the education system is a pivotal influence to the subsequent developmental trajectory. The criminal justice system also needs to be proactive in identifying and seeking treatment for such young people (Paley & Auerbach, 2011). A couple of new books on "Fetal Alcohol Spectrum Disorders: Interdisciplinary perspectives" and "Educating children and young people with fetal alcohol spectrum disorders: constructing personalised pathways to learning" by Blackburn, Carpenter & Edgerton, will be reviewed in subsequent editions.

Over the year I have met two youngsters in my clinic who are in good quality foster care and have an unfamiliar pattern of complex co-morbidities of learning and development and extreme psychiatric impairment, and who have been inordinately difficult to treat. We have made a putative diagnosis of FASD in the context of inadequate maternal history in pregnancy, supported by the neuropsychological and neuropsychiatric findings that fit the descriptions from the literature summarised here. This article highlights the breadth of challenge. Meeting their needs requires collaboration from paediatrics, allied health, child and adolescent mental health, education, welfare and the criminal justice system, and of course the community. The first challenge is for clinicians to think of the possibility of the diagnosis. Tristan and his community have shown us courage and leadership, bringing "Hope in the Valley" and are an example to all Australians (Elliott et al, 2012). The raising of awareness will be important for us all, as we come to appreciate the scale of this new silent epidemic of damaged and troubled youngsters and adults in our midst. As June Oscar says "the attitude of society to FASD has to change, since the children with the condition can't". ●

*Teratogenic: adj. Of, relating to or causing malformations of an embryo or a fetus.

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Hope in the Valley

James Fitzpatrick, winner of Derby Bush Poetry Competition, 2011

*There's hope in the Valley, it flows slow and deep
a river of life floods the plains
It softens the tears that the grandmothers weep
like a desert refreshed by the rains
There's pride in the Valley, those women stood strong
to stop that damned river of booze
While businessmen, countrymen swore they were wrong.
But the women had too much to lose
See the children were damaged before they were born
the alcohol poisons the brain
The grandmother grew them up, tired and forlorn
while the parents went drinking again
Now the river of grog is a trickle out there
and the young people hunt through the skies
For the spirits of old men with wild untamed hair
and that wise patient gleam in their eyes
There's hope in the Valley, it flows deep and slow
like culture- where life finds its themes
The river of hope has a long way to go
but its flowing and so are their dreams.*



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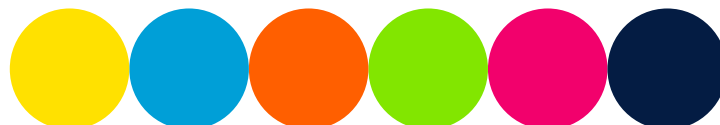
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conference review; disability studies: every body in...



Lesley Whatson
(Team Coordinator) and
Debra Corfield
(Senior Clinical Consultant)
Statewide Behaviour Intervention Service,
Office of the Senior Practitioner (OSP)
Ageing, Disability and Home Care

During the latter part of November 2011, Debra Corfield and Lesley Whatson from the Statewide Behaviour Intervention Service (ADHC) attended the Disability Studies Inaugural Conference, at Otago University in Dunedin. The conference drew together many people with disability and their families, academics, and people working in the field. It was a refreshing and inspiring conference as attendees were drawn back again and again to the UN Convention on the Rights of Persons with Disabilities and our progress thus far in addressing the content of its 39 Articles. The World Report on Disability, produced jointly by WHO and the World Bank, also added texture to presentations and discussions. For those who haven't had a look yet, the link is: http://www.who.int/disabilities/world_report/2011/en/index.html

Debra presented a paper titled Transition: Linking Theory and Practice. This presentation provided information about current research in this area and described a practice review initiative being undertaken by Statewide BIS and ADHC's Western Region. Lesley presented two poster sessions on the School Link Initiative, which encompasses a number of projects being implemented across Department of Education and Communities, the Children's Hospital at Westmead and Statewide BIS and the final data associated with the Training Curriculum Project: A Framework for Professional Practice.

Amongst the presentation highlights was a keynote address by Tom Shakespeare entitled *How Disability Research can Change the World*. This presentation, though very witty and entertaining, tackled the ethics of disability research and provided much food for thought. It was a

particularly relevant presentation given the OSP's interest in undertaking disability research. Professor Shakespeare challenged his audience to think about the notion of "nothing about us without us" – how we might investigate disability issues in partnership with people with disability, rather than on people with disability. He reminded us that "the duty of the researcher is to ask the difficult questions and to find the best possible answers, even when the truth is inconvenient, challenging or unwelcome". This presentation should be available for download on the web soon.

"Person Centredness is not about tools and templates; it's about building a community of practice that values listening and communication, empathy and collaboration, choice and decision-making..."

The theme of inclusion was carried through all streams of the conference and for clinicians it raised issues about genuine collaboration with clients in their assessment and intervention work. There were a number of wonderful presentations that offered possibilities in this regard, such as those on the use of narrative assessment and learning stories to support inclusion. Work in this area by the Inclusive and Special Education Research Group (University of Canterbury) is certainly worth reading.

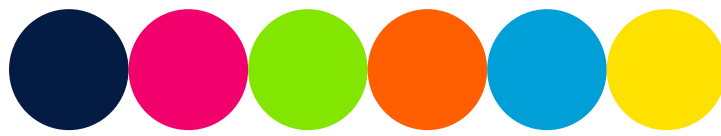
Professor Patricia O'Brien gave a number of valuable presentations including one on Person Centredness, which she delivered on behalf of Rachel Dickson and collaborators at the Centre for Disability Studies (CDS), Sydney. This presentation reminded us that Person Centredness is not about tools and templates; it's about building a community of practice that values listening and communication, empathy and collaboration, choice and decision-making (not

just having choice, but honouring choices made) and offers support to those with and without disability in the network. Professor O'Brien reminded us that Person Centredness is a way of life that requires a shift in thinking and personal philosophy. She spoke to the research currently being undertaken at CDS and shared some of the emerging themes of this work.

Professor O'Brien's keynote address, *Every Body In or Everybody In*, was truly inspiring. This presentation looked to the arts – drama, dance, painting and music – to define disability and used museum studies and the Australian indigenous experience of Dadirri (deep listening and quiet) to explore the beauty of disability. It was a moving presentation and a wonderful start to the last day of the conference.

Perhaps the most powerful presentation of the conference was one by People First, a self advocacy organisation run by and for people with a learning/intellectual disability. This presentation used a light-hearted means of challenging some of the myths about people with disability. A hugely funny version of *Who Wants to be a Millionaire* had "contestants" playing for a Passport to Life. ●





reading list...

AIHW 2011. The use of health services among Australians with disability. *AIHW bulletin* no. 91. Cat. no. AUS 140. Canberra: AIHW.

This report by the Australian institute of health and welfare is the second in a series about health of people with a disability. It examines the use of health services among Australians with disability based on national population health survey data. Visit www.mhsa.aihw.gov.au/home/ for more information about Mental Health Services in Australia.

Dempsey, A.G., Llorens, A., Brewton, C., Mulchandani, S. and Goin-Kochel, R.P. (2012). Emotional and behavioural adjustment of typically developing siblings of children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*. Vol 24, Iss 7, Pp. 1393-1402.

Results have been contradictory, this article supports that the presence of a sibling with ASD may not be considered a risk factor for adjustment problems among typically developing siblings.

Hassiotis, A. and Turk, J. (2012). Mental health needs in adolescents with intellectual disabilities: cross-sectional survey of a service sample. *Journal of Applied Research in Intellectual Disability*. Vol 25, Pp. 252-261.

This study further supports the irregularity of mental health problems and disorders between children and adolescents with an intellectual disability compared to the wider population.

Ling, C.Y.M. and Mak, W.W.S. (2012). Coping with challenging behaviours of children with autism: effectiveness of brief training workshop for frontline staff in special education settings. *Journal of Intellectual Disability Research*. Vol 56, Iss 3, Pp. 258-269.

This study looked at three staff training elements; psychoeducation on autism, introduction of functional behavioural analysis and emotional management.

Ludi, E., Ballard, E.D., Greenbaum, R., Maryland, P., Bridge, J., Reynolds, W. and Horowitz, L. (2012). Suicide risk in youth with intellectual disabilities: the challenges of screening. *Journal of Developmental and Behavioral Pediatrics*. Vol 33, Iss 5, Pp. 431-440.

This paper is a literature review of prevalence of suicidal thoughts of youth with an intellectual disability, suicide risk and assessment screening. It is coupled with a case vignette for some context.

McCarthy, D. (2012). *A Manual of Dynamic Play Therapy: Helping things fall apart, the paradox of play*. Jessica Kingsley Publishers, New York.

This new book describes several clients transformation through the use of play therapy and the process of collapse and renewal. Essential reading for professionals working therapeutically with children and their families. McCarthy has two other books that may be of interest; 'If you turned into a monster'-transformation through play: A body Centred approach to Play Therapy and Speaking about the unspeakable: Non-verbal methods and experiences in therapy with children.

Owen, M.J. (2012). Intellectual disability and major psychiatric disorders: a continuum of neurodevelopmental causality. *British Journal of Psychiatry*. Vol 200, Pp. 268-269.

A good thought-provoking review.

Richards, C., Oliver, C., Nelson, L. and Moss, J. (2012). Self-Injurious behaviour in individuals with autism spectrum disorder and intellectual disability. *Journal of Intellectual Disability Research*. Vol 56, Iss5, Pp. 476-489.

Characteristics of ASD show a relationship with self-injurious behaviour. This study also breaks information down into type of injury with type of disability.

Sermier Dessemonest, R., Bless, G. and Morin, D. (2012). Effects of inclusion on the academic achievement and adaptive behaviour of children with intellectual disabilities. *Journal of Intellectual Disability Research*. Vol 56, Iss 6, Pp. 579-587.

This is a current issue for us NSW residents as mainstream classes become more inclusive. A good read to the start of a hot topic, if you have opinions on this we would love to hear them.

Stuart, H. (2012). United Nations convention on the rights of persons with disabilities: a roadmap for change. *Current Opinion in Psychiatry*. Vol 25.

This study considers the United Nations convention on the rights of persons with disabilities as a tool for promoting the full social inclusion of people with a mental or intellectual disability.

Take a look at the current *Journal of Intellectual Disability Research* for an overview of all the presentations of IASSID 2012. It gives a great listing for those of us not attending the proceedings. *Journal of Intellectual Disability Research*, 2012.

neglect and the developing brain...



Dr Phil Ray,
Clinical Psychologist &
Clinical Neuropsychologist
The Children's Hospital at Westmead

Over the last twenty years, strong evidence has emerged regarding the association between child maltreatment and neurological and neurodevelopmental effects. Previously, a strong focus was made of the effects of non-accidental physical abuse, sexual abuse and the effects of witnessing traumatic incidents. However, the most recent evidence alludes to the often unrecognised, insidious effects of neglect. The effects of neglect are not only psychological but neurological both in the structure and volume of the brain itself and the efficiency of its multitude of connections. In this article I will give a brief summary of the effects of neglect on the development of the child and how particularly intentional or unintentional neglect early in life can have serious consequences for their physical, psychological, cognitive and intellectual development.

Glaser (2000), defined child abuse and neglect as preventable phenomena that affect the survival and development of the child. Child abuse and neglect are not predicated on an intention to harm the child and must be at a level which would be considered outside of the normal and usual interaction one would expect. The Australian Institute of Family Studies defines child **maltreatment as any "non-accidental behaviour by parents, caregivers, other adults or older adolescents that is outside the norms of conduct and entails a substantial risk of causing physical or emotional harm to a child or young person. Such behaviours may be intentional or unintentional and can include acts of**

omission (i.e., neglect) and commission (i.e., abuse)."

Child maltreatment is divided into five main subtypes: physical abuse; emotional maltreatment; neglect; sexual abuse; and the witnessing of family violence. Neglect refers to the failure by a parent or caregiver to provide a child (where they are in a position to do so) with the conditions that are culturally accepted as being essential for their physical and emotional development and wellbeing (Broadbent & Bentley, 1997; Bromfield, 2005; WHO, 2006). Neglect encompasses physical neglect, emotional (or psychological) neglect, educational neglect and environmental neglect (Dubowitz, Pitts, & Black, 2004).

Over the last twenty years strong evidence has emerged regarding the association between child maltreatment and neurological and neurodevelopmental effects. When considering this literature one should be mindful of the concepts of multi-finality and equi-finality. Multi-finality suggests that different children may undergo similar experiences but those experiences will affect them psychologically and biologically in different ways. Whereas equi-finality suggests that the psychological and neurological consequences of an event will be exactly the same for every child. One should be mindful of these differing concepts when discussing the literature. The research often talks as if the findings are equi-final. In other words, that every child will follow the same developmental trajectory if these certain events do or do not occur. The reader should be mindful that this is not always the case and that multi-finality must always be considered. Two children may endure the same levels of neglect but this will often affect them and their development very differently. Therefore when reading this article remember that suggestions of reliable causality may be misplaced.

Other things to consider regarding any kind of abuse and its effects on the victim are the characteristics of the abuse itself. This would include the severity, frequency and chronicity, all of which affect the outcomes. **The child's characteristics are also vital to influencing outcomes. These include the child's age, gender, temperament, level of physical, developmental or intellectual disability all affect their level of vulnerability which may influence the kind of abuse suffered and the nature of its effects. Finally the characteristics of**

the abuser themselves will influence outcomes. Whether they have been abused themselves, their socio-economic status, physical health, and the family or home context are all factors to consider.

Myers *et al* (2002) reviewed longitudinal studies of emotional neglect by parents who were typically emotionally unavailable. These children during high school years were often found to be socially withdrawn, inattentive, and had lower cognitive abilities. In school, they were also found to be underachieving compared to their peers. Weinberg and Tronick (1998) investigated the effects of maternal depression and found that the children were often compromised in their behavioural, cognitive and emotional functioning. Detrimental effects were **found to remain long after the mother's recovery.**

“Severe deprivation and neglect in the first five years of the child's life results in global disorganisation and development of the brain...”

Glaser (2000) reported that the process of early brain development is constantly modified by these environmental influences. Child abuse and neglect present the developing brain with experiences that potentially adversely affect the **child's current and future functioning.** The younger the child the more these environmental factors are mediated by the caregiver. At the centre of this are neurotrophins which are chemicals in the brain vital for the creation and maintenance of neurons which are responsible for transmission and receiving of information around the brain. Neurotrophins are dependant on neuronal activity which itself is dependent on environmental input. Therefore, it is suggested that while the brain and neurons get into place automatically their ability to develop, work, interconnect, and function is directly **related to the child's environment.**

During first 2 years of life there is this sequential growth in the brain as synapses and connections are made. This is a competitive process where survival of these synapses and connections is dictated by use. This is where the environment and its potential to cause permanent

neurological damage comes in. Absence of the usual experiences associated with love and attachment can contribute to the failure of many synaptic connections being made. Perry *et al* in 2007 found that severe deprivation and neglect in the **first five years of the child's life results in global disorganisation and development of the brain.** Some such children have been found to have enlarged ventricles and Atrophy.

Bateson (1979) described this competition and need for environmental influences as a **'Brief Opening' of a "Window of Need"** which exists both in animals and humans. Greenough & Black (1992) said that these external events that dictate our neurobiological developmental functioning can be categorised into two levels of priority. **"Experience Expectant"** experiences are those events that have to happen. This is development that will not take place unless particular experiences occur during predetermined critical periods. For example, infants learn self-regulation and arousal levels when new stimuli is presented to them in a way that is **"safe, nurturing, predictable, repetitive, gradual and attuned to the infant or child's developmental stage's"** (Perry *et al*, 2007). Such experiences also include being handled, developing a responsive gaze, and being spoken too. Therefore, experience expectant events are predetermined stages of interaction that the caregiver must give the child if their neurological, psychological and cognitive functioning are going to develop to at least a basic standard. Importantly, if one stage is missed it can have a knock on effect in further development.

Further synaptic growth can develop if experiences over and above basic care are then offered. Greenough and Black (1992) describe these as **"Experience Dependent"** experiences that might be advantageous to further development. An example might be teaching your child to play the violin at an early age. This **experience isn't vital to the child's basic development** but is certainly advantageous. To further demonstrate this Greenough and Black discuss studies where rats weaned in a complex group environment had 25% more synapses per neuron than those who just experience basic care.

Therefore, care giver interaction is vital to **the child's development. This is no more important than in developing well regulated levels of arousal and self-regulation.** This is vital in the infant being able to

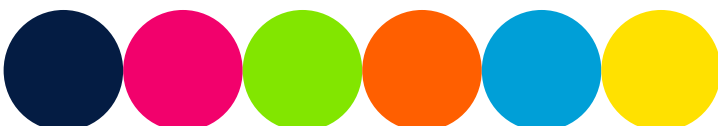


experience and enjoy pleasurable activities. The role of the caregiver is to modulate displeasure, for example, calming the infant after a traumatic incident, so that the child develops a model of the world as safe and predictable. Courchesne *et al* (1994) reported that in studies of depressed mothers who were withdrawn and disengaged from interactions with their children, the child brain was often unable to self-regulate affect. Due to the closure of the critical periods discussed earlier, the possibility acquiring these abilities later in life, once the mother recovered, was also found to be very limited. Courchesne reported that **"misconstruction" was often found to be "completed"**.

Attachment behaviour such as this is defined as proximity seeking behaviour by the dependent infant when he/she experiences discomfort. **The parent's role** should be to reduce discomfort and give the child love and protection in a safe and predictable environment. The child develops an internal model of the self, the parent, the world and the predictability of life. Gunnar *et al* (1996) said that the role of attachment is to buffer the potential ill effects of over production of glucose in early years which can cause brain damage. Izard *et al* (1991) even found that there is a complex relationship between attachment and other biophysiological indicators such as cardiac functioning. Rats exposed to prenatal stress demonstrated long lasting symptoms of hypertension. In humans this would increase the risk and severity of any cardiovascular disease (Neigh *et al*, 2009).

ing stressed or agitated states and is the so-called **"stress hormone"**. It acts to dampen the fear response and to prevent overreaction to fear. Cortisol also serves to increase glucose levels. Fear messages come from the amygdala and hippocampus with direct links to the brain stem for heart and blood pressure rate adjustment. Children with low stress thresholds are particularly vulnerable when they have insensitive or punitive caregivers. Shields *et al* (1994) found that children exposed to repeated stress led to suppression of the stress response and reduced cortical activity. This can explain the passive fear which is often seen in children who have suffered long-term abuse. In 1998 Gunnar conducted a famous experiment where cortisol levels were found to not change when a baby is left with a friendly, warm babysitter. However, if the caregiver was insensitive and cold, cortisol levels rose suggesting that the more neglectful the carer is, the more elevated the cortisol levels and the more potential damage to the brain. Perry *et al* (2007) discusses a study where infants with secure parental relationships did not have elevated cortisol levels when left with a stranger but cortisol levels rose when unpredictably the parents tried to force them to play.

High cortisol levels have been found to be associated with memory deficits. Gunnar and Nelson (1994) found a negative correlation between memory functioning and cortisol levels with some suggestion of a five per cent reduction in hippocampal volumes. A similar finding was made by Lindauer *et al* (2006) who found in clients with Post Traumatic Stress Disorder (PTSD) that higher cortisol levels were associated with memory deficits and low-



The hormone cortisol is released in the body dur-



er hippocampal volume although the exact causal relationship was unknown. Sapolsky (2003) also found a significant correlation between sustained stress, excess cortisol activity and hippocampal “memory” damage. It was suggested that hippocampal neurons respond adversely to cortisol activity and in some studies reduces volumes of up to 12 to 17 per cent. Perry (2007) cited DeBellis *et al* (1999) who studied 44 maltreated children with PTSD with a mean age of 12. Seven per cent of these children had smaller cerebral volume including the cortices and ventricles which was purported to be due to raised cortisol levels. Intellectual ability throughout the study population was lowered.

The risks of stress on the developing brain are possibly applicable even in the womb. Brennan *et al* (2008) found increased baseline infant cortisol concentrations suggesting in utero exposure by depressed mothers. It is suggested that this may alter the hypothalamic-pituitary-adrenal axis, a major mediating pathway of the stress response. It was suggested that exposure to stress during developmentally critical periods results in persisting hyperactivity of the physiological response to stress increasing the risk of stress related diseases.

Nolin and Ethier (2007) studied seventy-nine children aged six to 12 years old who were currently under the care of local social services due to one of two types of maltreatment (neglect with physical abuse and neglect without physical abuse). These children were compared with a control group of 53 children matched for age, gender, and annual family income. All were administered a neuropsychological assessment which focussed on motor performance, attention, memory and learning, visual-motor integration, language, frontal/executive functions, and intellectual ability. Children who were neglected with physical abuse showed cognitive deficits in auditory attention and response set, visual-motor integration, problem solving, abstraction, and planning. Children who were neglected without physical abuse differed from the control group in that they obtained lower

scores in auditory attention and response set, and visual-motor integration. The authors indicated that “surprisingly”, these same children demonstrated a greater capacity for problem solving, abstraction, and planning than the physically abused neglected and control children. The results support the heterogeneity of cognitive deficits in children based on different types of maltreatment and suggest that neglect with physical abuse is more harmful than neglect alone although the latter is still significant.

In summary, neglect can lead to significant behavioural, psychological and cognitive deficits in the developing child. Of core importance is the environment which can have a significant influence on brain development. Damage can occur as a result of issues such as poor attachment, inconsistent care giving, and fearful and stressful experiences. Cognitive effects can include deficits in memory, arousal, mood, fear response and many other functions. However, this is not an exact science. Every child will have varying levels and types of vulnerability resulting in differing levels of causality. As a result one should always be mindful of the potential effects of neglect on the child’s development but aware of the individual differences which affect outcomes. ●

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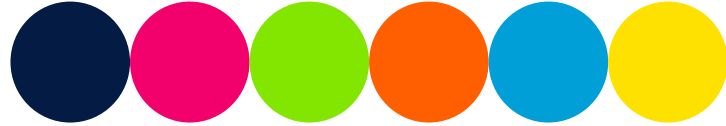
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Intellectual Disability:

Australasian Society for Intellectual Disability (ASID) NSW ACT conference. *Through the Looking Glass*. 17th August, Liverpool Catholic Club. \$160. Visit www.asid.asn.au for more information, the program and to register.

47th Australasian Society for Intellectual Disability (ASID): Research to Practice conference. *Unity in Diversity: different perspectives, common purpose*. 7th-9th November 2012. Wellington, New Zealand. \$825. Visit www.asid-2012.org.nz to register.

TABISS Presents Stress and Coping for Parents/Carers of someone with an intellectual disability and behaviour difficulties. 24th July 2012. Castle Hill. 10am-2pm. Contact tabiss@interactiondisability.com or phone 1300 668 123.

Autism Spectrum Disorder:

South Western Sydney Local Health District School-Link presents *Professor Tony Attwood one day workshop*: further develop clinical skills of ASD and mental health comorbidities for professionals. 17th August 2012. \$120. Liverpool. Enquiries to Vivian Benjamin 02 9616 4251 or vivian.benjamin@sswahs.nsw.gov.au.

ASPECT *Recipe for Success*. A unique Autism specific Positive Behaviour Support workshop. 7th and 21st August, 4th September-Springwood. 31st October, 14th and 28th November-Penrith. Free for Carers, \$150 for professionals. Contact bis@autismspectrum.org.au or 02 89778325.

The **Geneva Centre for Autism** has an online training section with a training calendar. Their website is a great source of information www.autism.net

Other:

Redbank House Annual Conference. *What does it mean to 'Work Systematically'*. 30th November, 2012, Westmead. \$135. for registration and enquiries contact RedbankConference@swahs.health.nsw.gov.au or 02 9845 6577.

Fragile X Awareness Day. 22nd July 2012. Visit www.fragilex.org.au to see how you can support the initiative.

Early Childhood Early Intervention Australia (ECIA): *'Pathways to Participation: Engagement and Choice for Children and Families'*. Perth. 9th - 11th August. \$720. For further information and registration visit www.eciaconference2012.com.au

Arts activated conference: Desire and Destination. 30-31st October 2012. Chatswood. please contact Sophie Clausen, Access Coordinator 02 9251 6499 ext 107 or sclausen@aarts.net.au

Australasian Special Education Principals Association Conference. *Lessons from the past, Visions for the future*. Fremantle, Western Australia. 17th-19th September. \$795. For more information and to register visit www.gemsevents.com.au/asepa2012

Drumbeat Workshops: discovering relationships using music-beliefs, emotions, attitudes and thoughts. Lismore, 23-25th July, Canberra, 25-27th July and Albury 6-8th August. \$750. Visit www.newcastle.edu.au/drumbeat

Indigenous Triple P Extension Training for practitioners who have attended group triple P who work with Aboriginal families. 19th October, Ashfield. Contact Casey Lovelock 9716 2966 or casey.lovelock@facs.nsw.gov.au or Annalisa Hedger 9716 2020 and annalisa.hedger@facs.nsw.gov.au.

Mental Health:

MHPD is an Australian evidence-based online learning resource for people working in mental health. There is about 70 hours of material on 45 topics including dual disability. Register online to undertake topics. www.mhpod.gov.au

13th International Mental Health Conference. 6-8th August 2012. Surfers Paradise. \$855. The theme is a *Positive Change*, with the federal Minister for Health and Ageing opening the conference proceedings. Visit www.anzmmh.asn.au for more information.

The Children's Hospital at Westmead Education Research Institute (CHERI) conference. *Promoting Resilience: Stacking the odds in Kids' favour*. 6-7th September 2012, Parramatta. \$465. Visit www.cheri.com.au/conferences.html for more information.

RANZCP Faculty of child and adolescents psychiatry bi-national conference. *'To infinity and beyond'*. 3-5th October 2012. Manly. \$1050. Visit <https://www.ranzcp.org/resources/events> or contact 0413 016 300.

Disability:

Nepean Disability Expo. September 14th and 15th. Penrith Panthers, Penrith. Their website has information for attendees and prospective stallholders alike. www.disabilityexpo.org.au

Metro North Day and Post School Programs Forum presents: *A Climate change: Towards individualised funding for the disability industry*. 23rd and 24th August, Sydney. \$350. Contact Melissa Terheegde mterheegde@peckys.org.au or 02 9688 3268.

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www.schoolink.chw.edu.au

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

ADHC, play therapy and the yellow brick road...

*Kellie van Sebille
Senior Clinical Consultant
State-Wide Behaviour Intervention Service
Ageing, Disability and Home Care*

I had never done a training course for fifteen days straight before, but the opportunity to complete a certificate in Therapeutic Play absolutely outweighed the two weekends I would miss in completing the course. Although I had done several wonderful one and two day Play Therapy courses, it became apparent a few days into my training with Play Therapy International (PTI), that being submerged in the Play Therapy world for two weeks was going to provide a much more meaningful learning experience. The course provided participants with the opportunity to explore the use of clay, sand tray, craft, drawing, music, storytelling, movement, role play and visualisation as therapeutic tools.

After fifteen days, five ADHC colleagues and I emerged from our Play Therapy training not just equipped with new techniques and knowledge but with a much sharper awareness of our selves and our triggers. We also took with us a deeper understanding of what it may feel like to be a vulnerable client and a sense of the level of attunement a young client may seek in their therapeutic relationship with us. With all of this on board we were ready to embark upon phase two of the ADHC Play Therapy Pilot, hopeful to build upon the success of phase one, bravely initiated by Lucinda Mora (OT and Senior Clinical Consultant – SBIS) back in 2008.

In a nutshell, Play Therapy aims to help children to help themselves with emotional and behavioural problems, in a way that is most natural for them, without rely-

ing on words. The experience is different from that of playing with friends, siblings or parents in that the therapeutic relationship provides a specific environment.

This helps to improve self-esteem and self-confidence which then allows the child to resolve inner conflict, experiment with change, and learn about choice and self direction. Unlike 'talk' based therapies, in Play Therapy, the child leads and the therapist follows, while maintaining a few essential boundaries and reflecting back, so the child gains insight.

“In a nutshell, Play Therapy aims to help children to help themselves with emotional and behavioural problems, in a way that is most natural for them, without relying on words....”

Play therapy began to emerge in the first half of the 20th century as therapists and theorists like Anna Freud, Margaret Lowenfeld and Melanie Klein attempted to gain insight into a child's inner emotional world through play. Virginia Axline (1969) inspired by Carl Roger's client centred approach, developed eight principles which continue to guide the work of play therapists today. Two of these therapeutic principles which differentiate play therapy from other approaches include that the child is accepted 'as is' and the responsibility to make choices in therapy is theirs.

Although as occupational therapists, psychologists and behaviour clinicians the

Play Therapy Team had worked extensively with children within their respective fields, in many ways starting work with children as trainee play therapists has seemed like a brand new experience. One of the most significant differences in utilising this therapeutic model has been moving from the **driver's seat, to the passenger seat and going on the child's journey, where ever** that may be. This experience has given the **phrase 'going with the flow' a whole new** meaning. Personally, I have found the work refreshing because it is truly child centered. It has been exciting to see such quick shifts in clients in just a few sessions and to hear from parents the changes they can see happening for their child. Early qualitative feedback is suggesting that changes already occurring for these children include decreased anxiety, improved self confidence and increased communication.

In my experience, although sitting with a child and talking about their worries and concerns can be helpful for them, Play Therapy is advantageous because it opens up other ways of communicating, giving the client options depending upon their needs, abilities, preferences and mood. Some clients may choose to talk in a Play Therapy session. The beauty of this approach is that whether they talk, paint or thump a piece of **clay, it's always their choice. It is having** this choice that seems to be so empowering for clients and the improvement in their self confidence from week to week in most cases is astounding.

The Play Therapy Team members meet once a month as a group and once a month individually for supervision to reflect upon the content and process of the work, to develop understanding and skills and to connect theory and practice. This supervision is critical because it provides valida-



tion, and assists those on the team to utilise their personal and professional resources. Most importantly, supervision offers a space to reflect and clarify what is evoked by the work and to explore the **therapist's reactions to these experiences**. In this way the quality of the work being done with clients within the pilot is monitored.

There are several pathways that can lead to becoming an accredited play therapist. The Academy of Play and Child Psychotherapy (www.apac.org.uk) can provide information about international certification, including courses with Play Therapy International (www.playtherapy.org). To practice within Australia specifically, The Academy of Art and Play Therapy (www.artandplay.com.au) provides a vocational graduate diploma. Play Therapy Australia also offer courses in Perth (www.playtherapyaustralia.com). Play Therapy courses are becoming more available in Australia. Practitioners considering becoming Play Therapists will need to investigate providers and their accreditation options thoroughly. A short course in play therapy will not equip practitioners with all they need to work effectively and safely with children as Play Therapists. Play Therapists are certified by recognised professional organisations and participate in clinical supervision specific to Play Therapy.

The ADHC Play Therapy Team are currently accepting referrals for any child or young person who is an ADHC client, living in the Metro North region, aged between 3 and 17 years with a developmental delay or intellectual disability and an emotional age of at least 3 years. Our Play Therapy clients typically experience issues related to ASD, **withdrawn or 'acting out' behaviour, communication, academic performance, attachment, nightmares, trauma, abuse, bereavement and loss, separation and divorce, social exclusion, being bullied or bullying others.** Children with an emotional age of 3 will have some pretend play skills, may like to play alone or alongside others, may like to use mediums like paint or use play dough, can follow a few simple directions and knows a parent or carer will return. ADHC Met North Intake can be contacted on (02) 98419350.

The evidence base within the Play Therapy field is growing. However, in relation to children with a disability, the research is minimal. The ADHC Play Therapy Team is hoping to change that by providing Play Therapy specifically for children and young people with intellectual disabilities. This exciting work, it is anticipated, will further research within the Play Therapy and disability fields. ●

Introductory Reading

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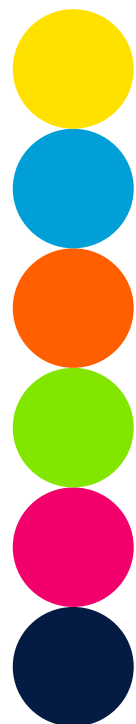
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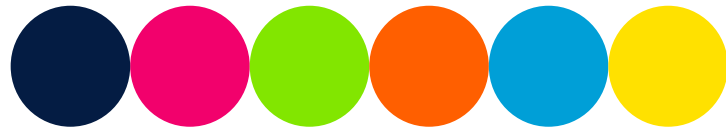
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Department of Family and Community Services | Ageing, Disability and Home Care | Statewide Behaviour Intervention Service | T 02 8876 4000 | F 02 8876 4041 | Building B, Level 1, 242 Beecroft Rd, Epping NSW

resources...

- The *Australian institute of health and welfare* has an online **Indigenous Observatory**. This is an Australian, Aboriginal and Torres Strait Islander health and Welfare statistics observatory. It includes information across the lifespan, child safety and much more. Visit www.aihw.gov.au/indigenous-observatory.
- The **BBC** have an entertaining blog called *BBC The Ouch! Blog*. A great international perspective on disability, visit www.bbc.co.uk/blogs/ouch/. There is now a podcast available from *BBC The Ouch!*, so download and enjoy.
- The **Association for Children with a Disability NSW** (ACD NSW) is a non-profit organisation run by parents of children with a disability seeking to help other parents. They have two publications available for purchase, 1. *Helping you and your Family \$5*: a pocket-sized publication designed for families with a child who is newly diagnosed with a disability. 2. *Through the Maze \$15*: a comprehensive guide to disability services in NSW. It covers the stages of diagnosis of a disability through to adulthood. Visit www.acdnsw.org.au to order your copies.
- www.socialneeds.net.au provides an easily navigable and searchable directory of key reports and submissions concerning **Social Needs in Australia** since 2007, with an emphasis on those released in the last 4 years. Each of over 500 reports and submissions can be directly accessed through the directory by clicking on the report or submission name.
- Every resident of NSW will have direct telephone access to expert mental health advice for the first time following the launch of a 24 hour telephone line by the Minister for Mental Health, Kevin Humphries. The NSW Government has established the 1800 011 511 Mental Health Line to ensure that people with a mental health problem, their families and carers can access the care they need whenever and wherever they need it.
- The **Museum of Contemporary Arts at Sydney's circular Quay** offers a variety of programs for students with specific needs. The *Bella program* for students with specific needs includes free, fun workshops for students who have a physical, intellectual, emotional or behavioural disability. Learn more about the *Bella Room* on the museums website www.mca.com.au/learn/specific-needs.
- **Relationship Skills: a photo resource**. A photo kit to support carers, counsellors and trainers in discussions with and education of people with disability. This kit can be used in developing friendship and relationship skills and a positive awareness of sexuality and personal safety. The kit includes 18 relationship photo cards (size A5) and a supporting booklet with activity suggestions, a cartoon friendship guide and dating guide, worksheet and handout. Cost: \$54, includes postage. To order email liz@relationshipsandprivatestuff.com.
- **IACAPAP** (*International Association for Child and Adolescent Psychiatry and Allied Professions*) has released an online textbook of Child and Adolescent Mental Health. This is a fantastic free resource, visit <http://iacapap.org/iacapap-textbook-of-child-and-adolescent-mental-health>





Bringing developmental disability into focus.

by David Dossetor

The Australian Association of Developmental Disability Medicine (AADDM) was founded in 2002. In its first ten years, AADDM has had a significant leadership role in the betterment of the health and mental health of people with an intellectual disability.

The core of AADDM's work includes advocacy, research, education and service development at both national and state levels. The 2012, AADDM conference brought all this to the fore.

Although people who work in this area often feel (like their clients) that they are in an unheard minority, this 3 day conference held at University of NSW, brought together people with an intellectual disability, carers, advocates, academics, clinicians, managers, administrators and politicians from health, disability, Education, NGOs and government.

This generated an energy and an optimism that together we can change attitudes, understanding, access, knowledge, circumstances and outcomes, albeit through multifaceted incremental change.

Kevin Humphries, NSW Minister for Mental Health and Healthy Lifestyles opened the conference. He expects the NSW Mental Health Commission to be able to bring

a focus on the needs of people with mental health problems, including those with intellectual disability and those most vulnerable in the care systems such as those from the criminal justice system.

Andrew Constance NSW Minister for Aging Disability and Home Care, emphasised the coming of individualised packaging of funding, increasing the power of choice to the client and family over their priority of services.

Jane Halton, Secretary from the Department of Health and Aging, described the significance of the Health Care Agreement (HCA). The HCA committed the Federal Government to sharing the funding of the future expansion of health care services with the states. She also highlighted the importance of the interagency agreement for the collaboration between hospital based services and community based services such as Medicare Centrals.

Prof Tony Holland, at the inaugural Trevor Parmenter lecture, described the evolution in UK of the legal framework to enable people with disability to be supported to make their own decisions with sensitivity to the task and context, and a framework for protection through the development of Safeguard of Vulnerable Adults Boards. The UK reports on abuse, neglect and lack of access to health care led to the Mental Capacity Act of 2005 and a rights framework. Thus Prof. Holland contended, the recognition of rights of autonomy and a legal framework for this complex area has

done more in promoting the wellbeing of people with an intellectual disability than the more highly publicised advances of science.

Prof Eric Emerson, from comprehensive British birth cohort data, demonstrated the extent to which intellectual disability is associated with poverty, adverse life events, other adversities and poorer access to health care.

One example is marked increased rates of weekly bullying in school. These adverse environmental circumstances account for more than half of the variance in poor health, emotion and behaviour problems, obesity etc.

Improved access to health care such as annual checks can help, as can a range of prevention initiatives, including building resilience and changing social attitudes with inclusive approaches eg to employment. The Medicare Item for annual GP health check ups is one such success here in Australia.

Curiously the risk of persistent conduct disorder in those with Autistic Spectrum Disorder (ASD) was not related to these environmental drivers! Prof Bruce Tonge presented data from the Australian longitudinal data of those with ID, also illustrating that ASD has even higher rates of disturbance than ID alone, with a peak in problems in social relating and depression in ASD in adolescence, while hyperactivity declines over time in both groups. A mental health examination of a cohort with ID at 20 years found psychiatric disorder in 42% which was related to early childhood family environment, a range of adverse life events and a family history of depression (in those with depression).

In those with ASD evidence is mounting on the need for transition planning for secondary school or leaving school to reduce rates of disturbance.

Drs David Mowat, Caroline Ellaway and Tony Holland gave stimulating presentations on the future potential of new targeted **treatments for Tuberous Sclerosis, Rett's Syndrome and Dementia in Downs**, and how these conditions help us to understand the complexity of the genetic and metabolic pathways of the brain and their relationship to cognition and behaviour. Yet where is the specialist service capacity for each genetic phenotype, especially when they become adults?



Prof Les White presented on the NSW health initiatives over the last 7 years leading to the development of the Agency of Clinical Innovation Disability Network and the 3 pilot sites of specialist health services for ID. David Coyne from the Office of the Senior Practitioner of ADHC, NSW Family and Community Services reported on the initial experience of the Memorandum of Understanding between Mental Health and ADHC with encouraging signs of increased collaboration at a senior managerial level. This was supported by some joint clinical presentations at a local service level and the establishment of joint systems of data analysis. The presentation from SW Sydney illustrated how complex some of these cases are, but how collaboration over a few years can still reap good outcomes.

Maria Heaton, parent and co-chair of the ACI Disability Network Executive Committee gave a beautiful, illustrated presentation on how family compassion and love, and dogged persistence really gave her son Tristan a great quality of life, despite his rare severely disabling condition that included deafness, blindness and no verbal communication skills. This achievement has been in the face of inaccurate medical advice and pessimism and a lack of person centredness in disability service provision.

A presentation on medical education illustrated a similar point whereby a young person with a disability presented to medical students, not about her disability, but her pleasures and expectations in life. One medical student responded by say-

ing that her aims for fulfilment were the same as his; something no professional could teach!

Fiona McKenzie, the chair of the Council for Intellectual Disability, who has an intellectual disability (ID) gave a talk on how **she goes about consulting on others' experience** in order to speak up on behalf of people with ID and mental health problems.

Brian Smyth King, Head of Disability for the NSW Department of Education and Community, described the changing challenge of getting the special skills of managing complex disability into the classroom. Over time, increased educational demands on children has drawn attention to disability of different sorts eg ASD, yet more parents want their child to be appropriately educated in mainstream classrooms.

Prof Julian Trollor, the inaugural chair of Mental Health and Intellectual Disability at UNSW, described how the last 2 years working with people with intellectual disability, their carers and advocates had shaped his understanding of some of the components needed to improve the mental health of people with ID. This includes concerted changes in workforce and service development, policy, research and clinical processes. People with intellectual disability need to be specifically considered in every mental health strategy. A key component is education and attitudinal change to face the challenge to hear and understand the needs of those with disability: for doctors of all types, other

caring professions, including teachers, and indeed the wider community.

Perhaps with the web-based and videoconference learning it is becoming feasible to give access to the advancing knowledge and skills to meet the needs. Conversely the attitude and skill to relate to and engage with disadvantaged members on our community including the indigenous people, the homeless, those with mental health problems as well as those with intellectual disability is something anyone entrusted with authority should have and indeed should be expected as a right.

I cannot do justice to the 100 presentations over 3 days (including from our CHW school-link team), which for the curious is currently available on the website: <http://www.aaddm2012.com>. ●



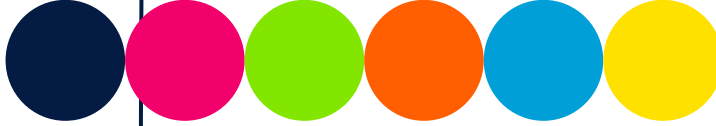
The Reach Out Teachers Network is a free site, originally launched in 2007 in response to the growing need to support teachers to understand the mental health issues impacting on young people they were working with. The site was re-launched in 2010 with an expanded focus on delivering teachers more quality teaching resources for use in their work.

Our site provides educators with access to up-to-date information on a range of mental health issues that may affect the students they are working with as well as fact sheets and curriculum resources and lesson ideas on a wide range of issues that young people may experience that can impact on their health and wellbeing, including alcohol and drugs, sexuality, leaving home and cyberbullying.

The Reach Out Teachers Network is an accredited professional development provider and has developed and delivered a range of training sessions at schools and conferences throughout Australia. The Network has developed a series of self-paced online training modules that you can view any time, any place. Our site provides a place to explore ideas and opinions around youth mental health issues with other educators through our online blog. We are pleased to have guest bloggers joining the team from the education sector, mental health field, as well as young people.

Become a member now and stay up to date with all the new content, conversations and resources that are being developed. Not only can you stay up to date with the Teachers Network through the website, you can also follow us on Twitter and Facebook. By joining the network you will also receive the monthly eNewsletter - *HeadsUp*.

Visit <http://teachers.reachoutpro.com.au/> or contact sarah@inspire.org.au (National Manager Schools) for more information



reviews...



Book Review:

Making It a Success: Practical Strategies and Worksheets for Teaching Students with Autism Spectrum Disorder – Sue Larkey

This book provides strategies to help teachers effectively integrate students with special needs into the classroom. The book includes photocopy worksheets, ideas for activities and teacher notes. Sue Larkey presents ways of helping children with autism spectrum disorder (ASD) improve their social skills, reading, writing and maths, play and general behaviour. This book also provides solutions for dealing with constant questioning in the classroom as well as managing children's special interests and obsessions.

This book is a good starting point for educators and their support staff.

Sue Larkey runs related workshops around Australia. Her website is www.suelarkey.com.



Website Review:

www.netbuddy.org.uk

Netbuddy is a website full of handy tips and bright ideas from parents, carers, teachers and therapists with experience of intellectual disability and autism. The site collects ideas in one place to create a great resource offering practical solutions to everyday issues from brushing teeth to challenging behaviour.

It is continuously growing as more parents/carers contribute and share ideas. The website also has a free expert forum, called Ask an Expert. The professionals who dedicate their time include an OT, speech pathologist, parenting sibling advisor, audiologist and an assistive technology expert.

Netbuddy also has a large social networking following with more sharing via Facebook, Twitter @netbuddyoptips, Google+, YouTube and their own blog. This is a creative resource for all.



Organisation Review:

Children with Disability Australia
www.cda.org.au

CDA is the national peak body which represents children and young people (aged 0-25) with disability and their families. The organisation is an advocacy body that works alongside families of children and young people with disability.

CDA's vision is that children and young people with disability are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met. CDA undertakes education of national policy makers and the broader community, advocacy on behalf of children and young people with a disability, inform children, young people and families about their rights and also celebrate their achievements.

Visit their new website and follow CDA on Facebook to learn more.

Have you been to a conference, read a book or visited a website that you loved? Send us an overview to: schoollink@health.nsw.gov.au

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 www.artsunit.nsw.edu.au

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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