Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities:
An Educational Resource

Volume Five, Issue Two, 2014. ISSN 1837-8803, SHPN CHW 140458

School-Link Initiative, Department of Psychological Medicine, The Children's Hospital at Westmead
www.schoollink.chw.edu.au

Contents

The aim of this Journal is to improve the mental health of children and adolescents with intellectual and developmental disability through enabling academic debate, research and commentary on the field.

Description and purpose

This journal is a modification of the previous newsletter; a vehicle of expertise about mental health information of children and adolescents with intellectual and developmental disability. As a product of CHW School-Link, this journal is supported by School-Link and a collaborative effort with a multi-agency editorial group from the Statewide Behaviour Intervention team of the Department of Aging Disability and Home Care, NSW Family and Community Services, and NSW Department of Education and Communities. We are extremely proud to present these ideas and invite you as authors to help develop this field and the knowledge base to help support children and adolescents.

On our Website:
www.schoollink.chw.edu.au

The website will be playing a crucial role in the information that CHW School-Link can provide to you.

- *The collection of previous and current editions is located there with the ability to download articles separately.*
- *An invitation for contributions can be found on the website with instructions for authors.*
- *Upcoming training at conferences, workshops and other professional development opportunities will be continuously updated.*

Editorial

Jodie Caruana
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Welcome to the second edition of the journal for 2014.

October is Mental Health Month and in 2014 the Mental Health Association of NSW's theme is **'be YOUnique!'** This theme promotes acceptance and an understanding of the impact that being proud of who we are can have on our wellbeing. It is also a celebration of our own and others strengths and differences that make us unique.

National stress less day is on Sunday 26th October 2014. The aim of the day is to participate in a fun and healthy activity to improve your mental health and wellbeing. The Mental Health Association of NSW has 10 tips to stress less and other inspiration on their website.

In this edition, David Dossetor's article Strugglers and Copers highlights the importance of stressing less and the role this plays on the development of psychotic illness especially for those with 22q11.2. The Stepping Stones Triple P Project (page 8) can help parents of children with a disability stress less, and it is a good reminder for professionals who work with children with a disability in NSW to complete the My Say survey online. Schools and organisations are strongly encouraged to promote this survey in their newsletters, so parents can complete the survey too.

An update on the National Disability Insurance Scheme (NDIS) is available on page 22. This was written after the recent NSW CID (Council for Intellectual Disability) conference on the NDIS in Newcastle. There were many success stories and challenges raised especially in the provision of services to children with complex needs.

Congratulations to Dr David Dossetor, Director of Mental Health, the Children's Hospital at Westmead who on 11th September, 2014, was announced the inaugural "Sydney Children's Hospitals Network Collaborative Leader of the Year." The award acknowledged David's commitment to supporting vulnerable children with Intellectual Disability and Autism. David influences health, disability, education and university sectors, government and non-government agencies, at state and national levels.

Enjoy reading this edition of the journal and please send any feedback or your own contributions to schoollink@chw.edu.au

Jodie Caruana

School-Link Coordinator
The Children's Hospital at Westmead.

Adolescent Strugglers and Copers:

How cognitive stress and anxiety precipitate or protect psychosis in the developmental brain vulnerabilities of 22q11.2 Deletion Syndrome or Velo Cardio Facial Syndrome (VCFS).

Associate Professor David Dossetor

The Children's Hospital at Westmead
Area Director for Mental Health
Child Psychiatrist with a Special interest in Intellectual Disability

A day on current research on Velo Cardio Facial Syndrome also known as 22q11.2 Deletion Syndrome (DS) was held at the Children's Hospital in November 2013, with guest speakers Honey Heussler, Developmental Paediatrician, Mater Children's Hospital, Queensland, Linda Campbell Lecturer in the School of Psychology at University of Newcastle, and Tony Simon a professor of paediatric cognitive neuroscience from University of California, Davis, co-hosted with the VCFS Society.

The rate of adult onset schizophrenia or psychosis in 22q11.2DS is 25-30% (a 30 times increased rate and a similar risk to being an identical twin of someone with schizophrenia). Accordingly, cognitive neuroscientists, psychiatrists and researchers are focused on the behavioural phenotype of 22q11.2DS and funded to research 22q11.2DS as the key to unlock the mechanism underlying risk and protective factors for psychosis in the general population. There are many other significant features of 22q11.2DS: a genetic deletion found in 1/2-4000 live births. These children are at risk of a range of midline abnormalities including heart defects, cleft palate, facial dysmorphism, autoimmune disorders and anomalous brain development.

Heussler gave an excellent review of the biological and medical concomitants. Campbell presented on her extensive survey of parents' experience of service provision compared with Down Syndrome and the lack of multidisciplinary multiagency collaboration, which needs to be continued from childhood to adulthood. An Australian Paediatric Surveillance Unit Study is planned to increase clinician awareness of the needs of young people with 22q11.2DS.

Young people with 22q11.2DS are also at risk of ADHD (50% in preteens and 20% in teens) Anxiety (50-60%) and ASD (20-50%). They have learning problems: IQ 70-85 (+/-15), verbal domains better than non-verbal, receptive better than expressive. Reading and spelling skills are of low average ability but comprehension is poor; rote memory is strong but complex verbal, spatial and working memory is poor. Attention and executive function are impaired.

European Child and Adolescent Psychiatry Dublin Conference held a workshop on some of the longitudinal cohorts of 22q11.2DS, July 2013. Stephan Eliez from Geneva described changes in cortical thickening seen in sequential MRI brain scans: we all have a reduction of cortical thickening in adolescence, which enhances cognitive efficiency (a pruning process) but 22q11.2DS starts with increased thickness and less gyrification or cortical folding and then has excessive and continued loss of thickening beyond controls. In those with ASD and Schizophrenia this effect is greatest in the limbic system or emotional brain; in those with ASD it is more in the superior temporal sulcus and amygdala, for those who develop schizophrenia it is more in the superior temporal gyrus and the anterior cingulate gyrus.

Further, functional MRI scans that record co-occuring activity enable maps of functional connectivity. These show disconnectivity of the anterior cingulate lobe, the superior temporal lobe and the superior parietal lobe. By looking at the vector patterns of disconnectivity he is able to predict which have schizophrenia with 88% accuracy. Stress and excess cortisol activity also increase cortical thinning.

> "Stress management is important for these early presenters..."

Many present with psychotic symptoms, some recover and some progress to psychotic illness. Stress management is important for these early presenters, but some drugs are known to reduce cortical thinning especially of the anterior cingulate, including valproate, SSRIs, and possibly Omega 3 in fish oils. Those with hyperactivity are more affected with cortical thinning in the caudate nucleus and fronto striatal pathways. Jacob Vorstman's 22q11.2DS cohort from Utrecht showed at 13 years of age 25% had psychotic symptoms and 8% had psychotic disorder but by 18 years there were 30% with psychotic symptoms and 30% with psychotic disorder. Conversely 64% of those with psychotic symptoms at 13 had remitted by 18. He postulated that stress factors affected those that recovered or deteriorated. His younger cohort followed from 5 to 10 years show a relative cognitive decline from an average IQ of 79 to 69, with a

greater decline in verbal skills than performance skills.

Another study suggests that although there is further steady decline in adolescence of 10-20 points, in those that decline more abruptly before 16 years of age, this cognitive decline is a herald of the onset of psychosis and eventually lose up to 40 points. Another study suggests that although there is further steady decline in adolescence of 10-20 points, in those that decline more abruptly before 16 years of age, this cognitive decline is a herald of the onset of psychosis and eventually lose up to 40 points.

These genetic phenotype changes in cortical development and IQ over time set the scene for Tony Simon's research: Simon observed that there is great variation across children and across ages despite the 22q11.2DS limitations in competence in numerous domains. Some performed better than testing predicted and others fell short. Screening with the BASC II (Behavior Assessment System for Children), 'Copers' showed lower anxiety and higher real world functioning and 'Strugglers' show the reverse, with higher anxiety and poorer adaptive functioning. He has shown that parent reported Anxiety levels from separation anxiety, physical injury fears, panic, agoraphobia, OCD were related to adaptive functioning, but not social phobia or Generalised Anxiety Disorder on the Spence Child Anxiety Scale. Whereas typically developing children show a reduction of separation anxiety with age, in 22q11.2DS separation anxiety increases in age in some, more anxious, children.

Longitudinal data shows a complex interaction of developmental delay and "sheltering" but after the age of 9 there are divergent trajectories between 'Copers' and 'Strugglers', whereby the 'Copers' have a decline in anxiety and the Strugglers show an increase. His hypothesis is that 'Strugglers' have an excess 'allostatic load', ie in trying to keep up with their educational and social challenges, they induce a stress diathesis which causes significant wear and tear on brain development and function. In keeping with this, it is found that adaptive functioning in 22q11.2DS is not predicted by IQ but by anxiety levels (Angkustsiri *et al* 2013).

Simon shows that on immediate attention perceptual tasks young people with 22q11.2DS show less accuracy on visual and auditory response eg to picking the shorter of two stimuli, (but not in the pitch) suggesting they have greater problems on selection and filtering of visual and spatial attention tasks. He has then compared attentional patterns for faces with neutral, positive and negative affect. Typically developing kids show a 'relative positive emotion bias' in their attentional style (spending more time unconsciously looking at happy faces), whereas those with 22q11.2DS show a 'relative negative emotion bias' (for angry or neutral faces). This difference for a relative positive or negative emotion bias was also related to the anxiety/adaptive function levels. This attentional bias to affect also correlates to whether they are 'Copers' or 'Strugglers' in terms of their levels of anxiety.

On an Autistic Diagnostic Interview (Revised) 40-50% were considered to have ASD from parental report. Similarly, Angkustsiri *et al* also found in a sample of 29 cases of children with 22q11.2DS, high ASD scores in 7 cases on the Social Communication Questionnaire or an Autistic Diagnostic Observation Schedule, but none of the cases were diagnosed ASD on strict criteria. This discrepancy was explained by the negative affect gaze avoidance. Shapiro (2013) found that inhibitory responses (on Go No Go tasks) also got worse in older teens with 22q11.2DS.
Deng looked at Anxiety and ADHD in 22q11.2DS and found a huge overlap: of 79 cases, 73% had anxiety, 51% had ADHD and 42% had both, while only 18% had neither. Beaton showed that children with 22q11.2DS had higher rates of depressive symptoms on the Childhood Depression Inventory and higher salivary cortisol levels (the stress hormone) both before and after a stress test (a mock MRI procedure).

So if an IQ of 75 means operating as a 9 year old in a 12 year old's world for a young person with 22q11.2DS, it is likely that this contributes to 50-60% having significant anxiety, and 20-50% having ADHD, mostly inattentive or combined type. Can the hyper-arousal/hyper-vigilance from anxiety present as ADHD? Does the mismatch in cognitive and social demands result in anxiety and avoidance leading to frequent ASD diagnoses? Could reducing the 'allostatic load' protect against psychosis?

Gothelf and colleagues (2013) found in 22q11.2DS that having an anxiety disorder as a child was predictive of psychosis. Of 10 who developed psychosis, 9 were diagnosed with an anxiety disorder at baseline. Tang and colleagues (2013) also found those with isolated psychotic symptoms, such as 'sees things that are not there', 'has strange ideas', 'hears sounds that are not there', or 'seems out of touch with reality' were more likely to have a mood or anxiety disorder. Yet 90% have one prodromal feature of psychosis which does not predict which will develop psychosis later, rather it is those with high anxiety that are at greater risk. The gene for Catechol-O-methyltransferase (COMT) is part of the 22q11.2 deletion and one of several enzymes that degrade catecholamines such as dopamine, epinephrine, and norepinephrine. The genetic variance of COMT in

“We are able to identify a group of 22q11.2DS who are psychosis prone...”

22q11.2DS causing lower activity may be another part of the process associated with cognitive decline in adolescence.

Accordingly, we are able to identify a group of 22q11.2DS who are psychosis prone, by measures of declining cognitive capacities, high anxiety, and relatively low adaptive behaviour skills. Could cognitive impairment lead to stress and chronic stress lead to anxiety, depression and low self-esteem, and the affective avoidance lead to further slowing of development with increased cortical thinning and loss of connectivity between different cerebral areas and functions? Their group now provides 2 days intensive assessment to identify the family, school, community, cognitive and psychological factors to determine a ‘Coper’ or a ‘Struggler’ trajectory. They then intervene to reduce the ‘allostatic load’ thereby reducing stress and anxiety through changing the child, family and school environments. For the child they use cognitive training, behavioural and CBT and SSRIs. For the school they develop individual educational plans and careful calibration of challenge based on testing. For the family they provide coping strategies for parents, matching parent/child expectations.

This package of assessment and intervention is being subjected to further evaluation, but anecdotally they feel confident that their intervention does change the young people with 22q11.2DS from ‘Strugglers’ to ‘Copers’ and those who look like they were going to develop a schizophrenic psychosis appear to change. Tony Simon believes that intervention really is reducing the statistics on the number of young people with VCSF developing psychosis.

These principles of ‘allostatic load’ and ‘Struggler’ vs ‘Coper’ status are not specific to 22q11.2DS but could apply to many with intellectual disability and emotional behavioural problems, and also those with early psychosis presentations. The concept of ‘Struggler’ vs ‘Coper’ is used in many situations in severe disabling psychiatric disorder, such as somatoform disorders and is frequently central to improved outcome. Tony Simon has developed a metric of cognitive and affective struggling in the context of the behavioural phenotype of 22q11.2DS. This model also seems to link to stress processes and influences on brain development. It may be the genotype that specifies what part of the brain development is most affected. Establishing an evidence base to such a concept may have wide implications to helping young people with the most disabling mental health conditions. Yet again, a behavioural phenotype is able to provide evidence of brain and psychological processes which may have significance for broader clinical practice.

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Learning about VCFS/22q11.DS.
Information from the 22q11 Foundation
Making the puzzle easier
www.vcfsfa.org.au

Velocardiofacial syndrome (VCFS/ 22q11) is a genetic syndrome (a syndrome means a pattern of features occurring together). VCFS/deletion 22q11 is the most common microdeletion syndrome The most common syndrome associated with cleft palates and the second most common syndrome associated with congenital heart disease.

The name velocardiofacial syndrome comes from the Latin words "velum" meaning palate, "cardio" meaning heart and "facies" having to do with the face. Not all of these identifying features are found in each child who is born with VCFS.

VCFS is a multiple anomaly syndrome caused by a submicroscopic deletion of genetic material from the long arm of chromosome 22. In fact, over 180 disorders might occur in VCFS and they cover nearly every organ system in the body with broad reaching effects on development and behaviour, including speech, language, personality, mood, learning, attention, and temperament.

Some associated features include but are not limited to:

- Palate and throat problems
- Heart defects
- Characteristic facial appearance
- Learning difficulties/developmental delay
- Psychiatric disorders
- Renal abnormalities
- Eye problems
- Hearing impairments
- Hypoparathyroidism (low levels of calcium that can result in seizures)
- Immune system deficiency
- Low muscle tone
- Short stature
- Curvature of the spine (scoliosis).

How is the deletion detected?
A diagnosis is usually made by a clinical geneticist based on the clinical presentation of the person and the genetic testing for the deletion. This testing is known as FISH (Fluorescence In Situ Hybridisation).

Scientists developed “DNA markers” which originate from 22q. These markers can be chemically manipulated so that they fluoresce under microscopic illumination, and are

called probes. If added to chromosomes from an individual’s cells they will stick to the part of chromosome 22q11 from which they originated.

Someone with VCFS and a deletion will only show one signal (on the undeleted chromosome 22), whereas as unaffected person will have two signals, one from each chromosome 22. FISH testing is widely available for the clinical and prenatal diagnosis of deletion 22q11.

Is VCFS / Deletion 22q11 Rare?
VCFS is much more common than previously thought.
It is currently estimated that around 1 in 2000 births are affected making it the second most common genetic syndrome (Gothelf & Lombroso, 2001). Due to the variable expression of VCFS the incidence is probably much higher than previously estimated and thus this rate is constantly being reviewed.

- 99% of the VCFS population will have a learning difficulty or disability
- 30% of the VCFS population will develop a mental illness.
- VCFS has more than 180 anomalies associated with it.

VCFS is also known as Deletion 22q11.2 Syndrome, DiGeorge Sequence (DGS), Shprintzen Syndrome, CATCH 22, Conotruncal anomaly face syndrome, Cayler cardiofacial syndrome.

Parent Training to Reduce Behavioural and Emotional Problems in Children with Developmental Disabilities

Kristina Clarke
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Children with developmental disabilities have an increased risk for developing behavioural and emotional problems, with parents reporting difficulties at a young age and at rates 3-4 times higher than for typically developing children. Left untreated, behavioural and emotional problems in childhood tend to persist into adulthood (Einfeld, Piccinin, Mackinnon, et al., 2006). For individuals, these problems are associated with restricted educational, occupational, social, and community participation. Parents report higher levels of stress and depressive symptomatology, along with increased costs of care (Einfeld, Ellis, Doran, et al., 2010; Einfeld et al., 2006). However, only a small percentage of families indicate that they access evidence-based help. There is a need for affordable, effective support for children and their families that is available in accessible community settings.

One approach to managing behavioural and emotional problems has been the implementation of parent training programs tailored for parents of children with developmental disabilities. These programs are designed to target both the child's behavioural problems and the concomitant parent stress and problematic family functioning (Einfeld, Tonge, & Clarke, 2013).

Currently, the program with the strongest evidence base is Stepping Stones Triple P (SSTP; Sanders, Mazzucchelli, & Studman, 2004). Stepping Stones Triple P has been adapted for families who have a child with a disability from the evidence-based Triple P – Positive Parenting Program. It introduces parents to a range of proven strategies to encourage positive behaviour, teach new skills, and to more effectively manage challenging behaviour, within a disability-specific context. Stepping Stones programs are available at a variety of levels so that families can choose the format and intensity which best suits their individual needs and preferences.

The Stepping Stones programs are supported by an extensive body of research. Randomised-controlled trials have shown decreased parent-reported child behavioural and emotional problems and increased parent confidence after participating in a Stepping Stones program (Plant & Sanders, 2007; Roberts, Mazzuchelli, Studman, & Sanders, 2006; Whittingham, Sofronoff, Sheffield, & Sanders, 2009). A recent meta-analysis found moderate to large effects of the combined SSTP program levels on child problems, parenting styles, parent satisfaction and efficacy, and parent relationships (Tellegen & Sanders, 2013). Children with a range of developmental disabilities, including intellectual disability, autism spectrum disorders, cerebral palsy, acquired brain injury, and Down syndrome, have shown improvements in child behaviour, indicating the applicability of the program across a broad population (Brown, Whittingham, Boyd, et al., 2014; Roux, Sofronoff, & Sanders, 2013).

Despite the promising evidence for Stepping Stones programs, they have primarily been delivered in clinical research settings, limiting the widespread uptake of the program by parents and families. A recent trial conducted by the Children's Hospital at Westmead expanded Stepping Stones implementation to community settings. The Group Stepping Stones program was delivered to 151 families of children with an intellectual disability or autism spectrum disorder, by trained school staff within 23 school settings across New South Wales (including mainstream and specialist schools). The results of this trial replicate those of earlier clinical trials, with reduced child behaviour problems and parent stress, and increased parent confidence found after participating in the program. School staff also reported improved parent-school relationships following program delivery (Dossetor, Ray, Caruana, & Saleh, 2014). This trial

paves the way for future community delivery of Stepping Stones programs.

To further increase the availability of evidence-based parenting help, The University of Sydney has launched a new project that will offer free Stepping Stones programs to parents and caregivers of children with a disability aged 2 to 12 years. The Stepping Stones programs will be available across New South Wales in 2015 and 2016, alongside free training for professionals. The SSTP Project will focus on the implementation of the brief Stepping Stones levels – Seminar Series and Primary Care.

The project's first step is a 2014 survey of parents and professionals across NSW to benchmark families' experiences and the need for parenting support. Parents and caregivers who have a child with a disability aged 2 to 10 years, and professionals working with families, can register their interest in the project by completing the *My Say* survey at www.mysay.org.au.

For more information, please contact the research team on (02) 9114 4060 or fhs.steppingstones@sydney.edu.au. You can also visit and 'like' us on Facebook at http://www.facebook.com/SteppingStonesTriplePProject.

"The University of Sydney has launched a new project that will offer free Stepping Stones programs to parents and caregivers of children with a disability aged 2 to 12 years..."

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Conference Review: The 15th Congress of European Society of Child and Adolescent Psychiatry in Dublin July 6-12th 2013.

Dr. David Dossetor

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"In Dublin's fair city"... the locals were very friendly. The meeting was held in lovely weather in the smart new conference centre on the Liffey River in the renovated docklands. This conference brings together the strength of world child psychiatry research and is a great cultural integrator with presenters from so many countries. With anything up to 10 parallel sessions, I suspect it was a different conference according to your interest, but guided by plenary topics and the more relaxed 'meet the experts' sessions.

David Skuse from Great Ormond Street Hospital presented on the changes in diagnostic criteria for Autism (now called ASD) with the arrival of DSMV. His data shows a doubling of the number of children whom parents describe as Autistic between 2007-12 but this is mainly accounted for by those who are only mildly impaired according to the new grading of ASD severity. The DSMV criteria changes are needed to cap the expansion of the diagnosis. His data suggests that 96%, 97%, 77% of those with Autism, Asperger and PDDnos respectively diagnosed with DSMIV criteria still qualify for ASD in DSMV, which is less alarming than other commentators. His data has long shown that social reciprocity and social communication are so highly correlated that they should be one dimension. DSMV repetitive activities dimension includes new elements of sensory sensitivities, and repetitive thinking, and removes impaired imagination while keeping impaired social imagination. All these changes he felt were improvements in the specification of criteria. His data shows that on the new criteria that IQ is not correlated. Less is known about new taxonomic disorder of Social Communication Disorder, which can be construed as ASD without repetitive behaviour. His impression is that those with such a semantic pragmatic disorder as still pretty impaired. Martin Knapp's health economics shows that the lifetime costs (to the state) of ASD with ID is £1.23Million and £800,000 without ID.

Louise Gallagher from Trinity College Dublin presented on the growth in conceptualisation of neurodevelopmental disorders: which includes communication disorders, learning disability, ASD, Tourettes, ADHD, schizophrenia and psychosis, and possibly sensory motor disorders. She used the example of the growth in understanding in Retts Syndrome to illustrate how quickly the science is advancing. This genetic disorder in girls of ASD, seizures and cognitive decline was first described in 1966, had its gene identified in 1999, and a mouse model developed in 2000. Retts has identified deficits of noradrenaline in the locus coeruleus, dopamine disturbance in the midbrain and immature neurone development due to the failure of regulation of the abnormal MECP2 gene which affects the release of BDNF (brain derived neurotrophic factor). BDNF has been shown not only to stop deterioration in Rett Mice but even reverse some effects, and human trials are under way of IGF1 which is similar but crosses the blood brain barrier. It is also reassuring to know that an 'enriched environment' has beneficial effects on affected mice emphasising the importance of environmental intervention despite knowing more about the underlying biology.

The very recent genetic research has (at last) made some interesting reproducible findings from microarray technology. A consistent series of new mutations through copy number variance (CNV) with deletions or repetitions in coding sequence have been found in about 15% of cases in ASD. In mouse models, these specific genes such as Neuroligin 3 and 4 and Shank 2 and 3, Neurexin affect dendrite formation in neurones, and presynaptic GABA and glutamate in the synapse. While it is encouraging to find relevant genes and brain proteins in neurodevelopmental disorders, they are relevant not just for ASD but also for most of the other neurodevelopmental disorders: the problem of pleiotrophy: single identified cause leading to multiple different outcomes.

Mike Owen and colleagues (2011) recently suggested that neurodevelopmental disorders are a spectrum with similar processes occurring at different ages: ID/ASD prenatally, ADHD/Tourette in childhood and Psychosis in adolescence. Louise noted that pharmaceutical companies are no longer developing new psychiatric drugs, but there is a huge library of known substances, to be called on when genetic research suggests. It is even conceivable that stem cell technology could be personalised to an individual's gene deficiency. Matthew State from University of California further elucidated the genetics. We now realise that there are lots of imperfections in each person's genome. CNVs make the genome look "like a swiss cheese" and the challenge is working out which abnormalities are significant. This is done by finding which CNVs are new in an autistic child compared with parents and sibling (the Simon's Simplex Collection). 25% of ASD kids have CNV deletions and 25% have CNV duplications compared to 9% of each in unaffected siblings.

This year there were 3 replication studies reported within a

week for 5 hot spots on the chromosome: 1q21.1 (for ASD & schiz), NRXN1 on chromosome 2 (for ASD, ID & schiz), 7q11.23 (for ASD & ID), 15q11.2 & 16p11.2 (for ASD, Schiz, ID & EP). These are "killer mutations" that are found in 15% of cases, but there may be a total of 100 or 1000 relevant to these conditions. Although a gene is found in every cell, its action depends on the trajectory of gene expression: ie in which type of cell, where about in the brain and at what stage of development. For one ASD gene SCN2A his colleagues were able to say that its effects were in mid fetal period, in a deep brain layer, affecting glutamate development.

Tobias Banaschewski from Mannheim described that there are several types of ADHD and different attentional systems: the frontal executive, and the parietal selective attention. Dopamine is important to improve signal/noise ratio, attentional orientation, impaired attentional resource allocation and response preparation. The anterior cingulate is important for error processing. However there are abnormalities of the amygdala with negative emotion processing, the R cerebellum, parietal lobe, L supra anginual gyrus and the insula and, basal ganglia to L inferior frontal cortex. Medication is seen to improve brain development. There are evidently different aetiological subtypes of ADHD, just like ASD, but we are not ready for a DSM based on aetiology yet.

Stephen Scott from the Maudsley talked of parenting programs. Normal cortisol patterns start high in the morning and go down during the day. Deprived rats have abnormal cortisol stress responses. Some have cortisol levels that stay high and stressed, in some the cortisol drops and loses stress responsiveness. Despite the stability of these abnormal stress patterns good foster parenting can renormalise these cortisol patterns. Recent review of parenting programs show that they improve oppositional behaviour but blinded RCTs don't show improvement in the ADHD features. However parenting programs such as Parent Child Intervention Therapy (PCIT) does improve behaviour and attachment, regardless of severity or callous unemotional traits.

John Walkup from Weil Connell presented on anxiety disorder (age of risk of onset 6-12), depression (13-16) and bipolar (over 16). Although prescribing for anxiety is off label there is scientific evidence of benefit. DSMIII concept of depression was sadness without a cause or melancholia,

"This conference brings together the strength of world child psychiatry research..."

but DSMIV validated depression to include those with a cause. Generally study evidence shows that combination CBT and antidepressants has a higher rate of effect than either on its own. Those that got some treatment effect in a trial also sought further treatment, whereas those with no response tended to drop out. He pointed out that independently funded studies of depression (NH&MRC) had bigger drug treatment effects and lower placebo effects. Industry funded trials had big variability of outcome at different sites and high placebo effects, indicating poorer quality of treatment intervention and greater problems with compliance. Identifying manic episodes is clinically critical, whereas antipsychotics help irritability of all types.

There was a session on the importance of identifying catatonia in children and treating with benzodiazepines or ECT, and of anti-NMDA receptor autoimmune encephalitis which probably should be a routine blood investigation for serious mental illness and can need treatment with IVIG and plasma exchange.

I presented in a session of prevention interventions for special schools with our study on Group Stepping Stones for 4-12year olds with intellectual disability. One presentation emphasised the value of recording ecological (multisource) measures of whether children feel safe in school, rather than of bullying. Management of bullying is a chance to help both bully and victim to develop more accepting relationships. The conference was rounded off with a young teens Irish group who are a recent YouTube sensation called Fresh Re. I concluded my visit with a trip to the 6th floor 360degree bar at the top of the Guinness Factory with a panorama over Dublin and a pint of draught Guinness. In the 1750s Alfred and Winifred Guinness had 25 children, just under half of whom died in childhood. This is a stark reminder of how far paediatrics and health has come.

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The Physical Punishment of Children: Creating social change

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By Terry Sarten – CHW School-link

The 2013 Position Statement from The Royal Australasian College of Physicians (RACP) on the Physical Punishment of Children is relevant to all children with or without an intellectual/developmental disability. It is important for both our youngest citizens and those of the wider world that we demonstrate a commitment to eliminating violence to children (RACP, 2013).

A 2012 report by the Global Initiative to End All Corporate Punishment of Children (GIEACP, 2012) summarises international research and policy on corporal punishment of children with disabilities in the home, school and community. In many countries, the difficulties of growing up with an intellectual disability are compounded by attitudes towards the physical punishment of children that adds another layer of disadvantage.

A study of the Association Between Child Disabilities and Caregiver Discipline and Violence in Low and Middle Income Countries looked at nationally representative samples of children aged 2- 9yrs to examine the relationship between children's cognitive, language, sensory and motor disabilities and caregivers' use of discipline and violence and beliefs about the use of corporal punishment (Hendricks et al, 2014).

The findings support the hypothesis that children with disabilities are more harshly treated. This was linked to the work of Whittingham, Wee, Sanders, and Boyd (2011) that analysed responses from focus groups which noted factors around parenting of children with disabilities that are more challenging than parenting children without disabilities. These included time pressure (especially related to time required to take children to medical and therapy appointments), additional parenting tasks related to helping manage the child's disability, parenting under public scrutiny when the child's disability draws attention to the family, behaviour management difficulties in determining which behaviours are out of the child's control versus which are amenable to change, and parenting without a benchmark because typical developmental milestones may not be applicable standards for children with disabilities (see also Weisleder, 2011). Each of these challenges, in turn, might increase parents' stress and likelihood of responding harshly to the child. The study focused on low/middle income countries as prior to this, research had only been done in high income countries such as Australia, Canada, Israel, New Zealand, Norway, and Poland. There was considerable variation but no country was clearly doing better than the others in reporting behaviours to children with disabilities. The results were considered in line with research done in the US, Canada and Western European countries, providing further evidence that children with a disability are at a higher risk of harsh parenting practices than those without disability.

The authors note the prevalence of child disabilities is higher in countries with high levels of poverty and deprivation than in more affluent countries and childrearing violence is more prevalent in countries with fewer material resources (Hendricks, Lansford, Deater-Deckard, and Bornstein countries (Dercon & Krishnan, 2009) (Lansford & Deater - see Lansford & Deater-Deckard, 2012).

> "Children with disabilities are more harshly treated..."

Although the study focused on whole countries it could be theorised that these socio-economic factors, at a community level within higher income countries, may influence parenting practices.

In Australia, it remains legal to hit a child. Striking an adult is deemed assault and carry's legal penalties. The RACP Position Statement lays out a range of well researched reasons why this requires challenge and change. The key arguments listed in the paper are the limited efficacy of physical punishment as a method of discipline, the potential adverse long term effects of physical punishment, the difficulty drawing a line between physical punishment and abuse and the responsibilities Australia has as signatories to the Human Rights Convention on the Rights of the Child.

The RACP document makes it clear that discipline is essential in good parenting but physical punishment such as smacking is ineffective. Research has made it clear that physical punishment can be harmful in the long term and

risks escalation into serious violence. An oral submission on repeal of NZ legislation that protects the legal right to use force against children from paediatrician and senior lecturer Dr Dawn Elder highlighted this risk. "The majority of cases of child abuse, including fatal child abuse, that we see and assess as child health professionals, are the result of physical punishment becoming more severe than was intended."

A 2002 survey in Australia found 75% of adults agreed with the notion it is 'sometimes necessary to smack a naughty child'. This dropped to 69% in 2006. In New Zealand, where physical punishment was made illegal in 2007, there was strong evidence of a shift in the attitude and practice of parenting with a reduction in the use of physical punishment. The RACP regards the New Zealand and Swedish experience as an indication that change can be achieved with legislative action influencing attitudes.

There have been attempts to legally define the line between physical punishment and abuse. The RACP note that in a majority of child abuse cases it has been found to have been the result of physical punishment becoming severe assault. While smacking/hitting a child may act as an outlet for parental frustration it is often carried out in moments of anger with the risk of escalation resulting in physical and emotional harm to the child.

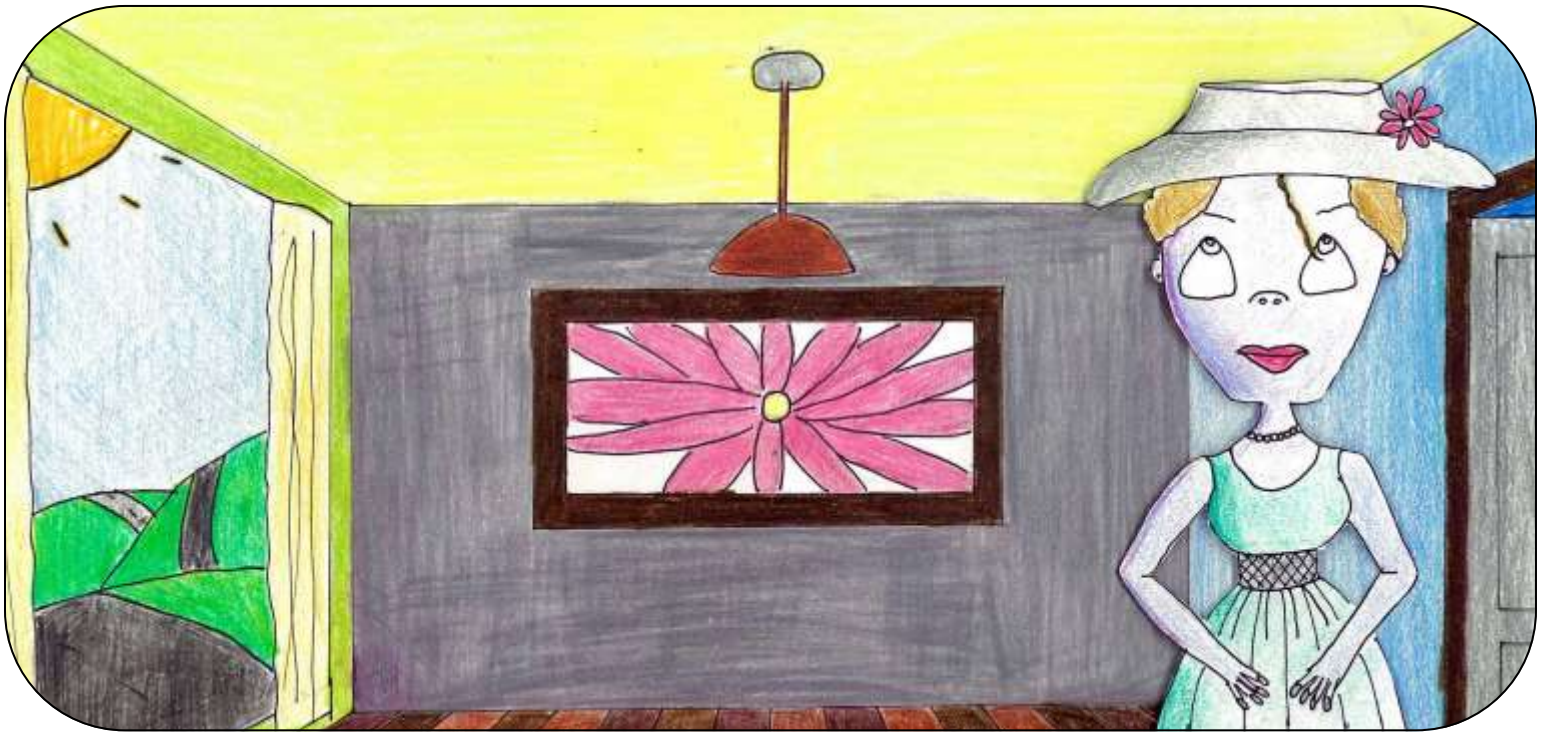
A paper in the MJA reporting on child homicide in NSW between 1991- 2005 found fatal child abuse was the most common reason for child homicide, accounting for 36% of deaths. The authors propose that "measures to reduce the rate of physical abuse of children would therefore have the greatest potential to reduce child homicide in NSW" (Nielssen et al, 2009).

They note how fatal child abuse declined to very low levels in Sweden after corporal punishment of children was outlawed. Following the Swedish example, most countries in the European Union have adopted a total ban on corporal punishment of children after a Council of Europe 2004 resolution.

The RACP position statement acknowledges that most parents, when physically punishing their children do not actually intend to harm them but believe it to be effective discipline. The RACP refer to a systemic review of the research that showed some very short-term effects but these are not sustained with the child learning to avoid being seen doing the behaviour rather than actually changing through self-control and inductive reasoning. Repeated and escalating physical punishment may become the default response, increasing the risks of serious harm.

The review included studies that showed physical punishment increasing rather than decreasing the likelihood of disruptive and 'bad' behaviour. It cites work by Murray Straus and what he describes as 'cultural spill-over' in which violence within a family is linked. He proposes that using physical punishment to discipline a child thereby providing a model for violence to others is more likely to reinforce the power of violence than reduce it. In his conclusion he states that the "research reviewed suggests that in addition to many other benefits, a society in which parents never spank will be a society with less violence and other crime".

Australia is a signatory to the Human Rights Convention on the Rights of the Child. Most Australian states and territories do not allow physical punishment in schools. It still remains legal for an adult to physically punish a child in Australia, often with legislation that describes a 'reasonable' level of force. The RACP would like consideration given to the New Zealand experience where the Section 59 of the Crimes Act 2007, that allowed for the defence of reasonable force to be used in the defence of child assault charges, was removed from the law. This was accompanied by broad public debate and has seen a measurable shift in attitudes



with 63% of those surveyed in 2012 saying they would never, or only rarely, smack their children since the law change was made.

The RACP would like to see a similar legislative approach in Australia and with its Position Statement is calling for wider support from within the health profession and other sectors such as education, disability and child protection agencies. As a further definitive step towards this goal the RACP has put out a Consensus statement which provides a way for other sectors and agencies to formally align with the college's position on the physical punishment of children. .*"Fundamental to this goal is the growing awareness around the world that physical punishment of children is harmful, unnecessary and a breach of children's rights. Australia has committed to protecting children against all forms of violence, including physical violence (UN Convention for the Rights of the Child), yet existing legislation and common law provisions that excuse physical punishment of children clearly contravene that human right".*

Summary

The consensus statement captures in a few paragraphs the importance of this issue in terms of children's health and welfare. Along with the risks of escalation in physical force when used as punishment the RACP notes the "growing body of research showing that physical punishment is linked to aggressive behaviour in some children in their childhood and adult lives and other negative outcomes". It points to the 33 nations that have legislated against physical punishment of children and the evidence indicates that legal prohibitions on the use of physical punishment can create a measurable shift in public attitudes.

The consensus statement makes it clear that effective legislation must also be partnered with support and education for parents. Programmes such as Stepping Stones Triple P and Positive Behavioural Support have proven valuable to parents/carers with children with and without an intellectual disability along with an expanding range of positive parenting frameworks in providing effective alternatives to physical punishment. The RACP have provided a list of positive parenting resources and parent support options in the document.

From the perspective of a NZ Registered Social Worker who observed and participated in the debate around the repeal of section 59 in New Zealand (the defence of discipline in child assault cases) the public engagement with the related issues made a significant measureable contribution to a change in attitude. The mislabelling of the legislation as the "anti-smacking bill" by those concerned about the potential loss of their right to hit children was a part of that debate. In NZ the voice of health and other professions on both the risks and rights of children was essential to legislative progress and the RACP consensus statement provides that opportunity for Australia.

Link: http://www.racp.org.nz/index.cfm?objectid=C27EE461-0D63-6E91-A957F9F7547B74E *For further information please contact RACP Senior Policy Officer Alex Lynch at alex.lynch@racp.edu.au*

> "Effective legislation must be partnered with support and education for parents..."

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Reading List

Trollor, J. (2014). Making mental health services accessible to people with an intellectual disability. *Australian and New Zealand Journal of Psychiatry.* Vol 45, Iss 5. Pp, 395-398.
What a great overview. This gives some insight to the current Australian situation and describes the NDIS and current policy around this area.

The three articles below are great background reading for Julian Trollor's article. These three references discuss the upcoming changes in Disability and Beyond.

Commonwealth of Australia. (2011). *National Disability Strategy 2010-2020.* Canberra: Australian Government Department of Families, Housing, Community Services and Indigenous Affairs. Available at: **www.fahcsia.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf.**

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Bennett, C. (2014). Understanding systematic problems in providing mental health services to people with an intellectual disability and co-morbid mental disorders in Victoria. *Australasian Psychiatry.* Vol 22, Iss 1, Pp. 48-51.
Pleased to read about an Australian context.

Chaplin, E., McCarthy, J. (2014). *Mental Health* in Taggart, L. [Ed] and Cousins, W. [Ed]. (2014). *Health promotion for people with intellectual and developmental disabilities.* Pp. 117-127. xiv, 229 pp. Maidenhead, BRK, England: Open University Press; England.
Don't just read the Chapter, read the whole book. This might be one we have to review in our next edition for our dear readers. Its on the list!

The Medicine Cabinet: Aripiprazole

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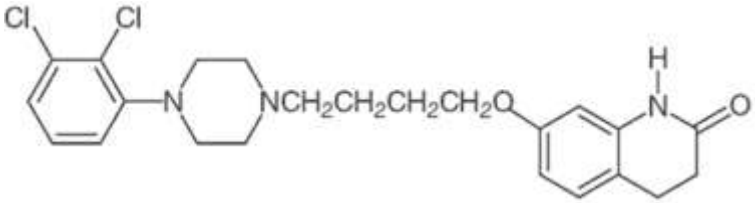

Aripiprazole

In November 2002, aripiprazole or OPC-4392, the first in a new class of atypical antipsychotics was approved by the US FDA for the treatment of schizophrenia for the pharmaceutical companies Otsuka/Bristol-Myers Squibb. US patent was to expire in October 2014 but has now 6 month extension due to the paediatric studies of use in bipolar and challenging behaviours in autism. Once the patent has expired then generic companies can develop generic equivalents and the price of the medication will fall for those paying premium due to inability to access the medication under the PBS. Aripiprazole was the largest selling medication in the world for the fourth quarter of 2013 according to Wikipedia.

According to the dopamine hypothesis, postulated by Avrid Carlsson (Nobel Prize, 2000) dopamine transmission inhibition by antipsychotics block the postsynaptic dopamine receptors leading to an improvement in positive schizophrenia symptoms. Positive symptoms are reported as the delusions, hallucinations, distortions or exaggerations in language and communication, disorganised speech and behaviour, catatonic behaviour and agitation. These were treated with typical antipsychotics such as haloperidol and chlorpromazine and lead to some permanent adverse effects such as tardive dyskinesia (a movement disorder of involuntary, repetitive tic-like movements) (from chronic blockade of D_2 receptors). About two decades ago, a new class of antipsychotics was released onto the market and these included Risperidone (see previous medicine cabinet Volume 2 Issue 1) and olanzapine. These were more favourable as they did not cause the debilitating tardive dyskinesia but have since found they have led to significant weight gain leading to metabolic problems in some patients (obesity medicine cabinet Volume 3, Issue 1). Finally, we have development of the next class of atypicals for which aripiprazole is the current only member in Australia but there are more on the way.

Aripiprazole works in a different way to the previous classes of antipsychotics. Antagonism of postsynaptic dopamine receptors, in particular the D_2 receptor seems to be an important factor for efficacy against positive symptoms of schizophrenia. Aripiprazole is described as a partial agonist of D_2 dopamine receptors. Partial agonism can be explained by being an agonist of dopamine autoreceptors and weak antagonist at postsynaptic D_2 receptors. It is also a partial antagonist of $5HT_{1A}$ receptors and antagonist for $5HT_{2A}$receptors.

As well as these principle receptors, there is also antagonist activity at serotonin $5HT_{2C}$, and $5HT_7$, dopamine D_3 and D_4, histamine H_1 and alpha 1 adrenergic receptors[1]. When concomitant administration of potent CYP3A4 or CYP2D6 inhibitors (such as clarithromycin and fluoxetine) with aripiprazole occurs, the aripiprazole dose should be reduced as the inhibitors slow the metabolism of aripiprazole and more is free in the body leading to more adverse effects. When the concomitant administration of CYP3A4 inducers (such as St John 's Wort or carbamazepine and other antiepileptics) the dose of aripiprazole needs to be increased. This is due to the metabolism being sped up so there is not as much aripiprazole in the body. When the inducer is withdrawn, the dose of aripiprazole should be reduced again. This is why it is important for all prescribers to know about all the medications and complementary medicines being taken by a patient.

With the large scale studies about metabolic syndrome in adults the importance of having a medication that is weight neutral or causes small gains as opposed to larger gains in weight is preferable. Aripiprazole showed in adult trials against risperidone and olanzapine to be weight neutral and thus many patients who have gained significant amount of weight are being transferred to aripiprazole.

Aripiprazole has also shown not to increase serum prolactin as significantly as risperidone and paliperidone. Although uncertainty remains about the long term consequences for elevated serum levels of prolactin (hyperprolactinemia) when there is clinical signs there is probably a need to

> "Aripiprazole was the largest selling medication in the world for the fourth quarter of 2013 ..."

change medication or treat the elevated prolactin.

Aripiprazole trials for children and adolescents with ID/ASD
Marcus, Sikich, Owen *et al*, (2009) reported an 8 week trial of aripiprazole vs placebo for irritability in autistic children and was found to be efficacious and well tolerated with 83% of the aripiprazole group finishing compared to 70% of placebo group[2,3]. This trial then went onto a year long follow-on open trial that also showed efficacy and less overall weight gain.

Cochrane review of aripiprazole in treatment of irritability in autistic adolescents showed from 2 trials there was significantly less irritability, hyperactivity, and repetitive movements in children and youths with autism spectrum disorders although weight gain and neurological adverse effects occurred[9].

Ishitobi *et al,* (2013) had a 12 week switching open label trial of risperidone to aripiprazole in ASD children and adolescents aged 9-22 years. These patients were previously on risperidone 0.6± 0.4mg/d . Risperidone was abruptly ceased and aripiprazole initiated at dose of 2.7 ±1.9mg/d for 2 weeks then increased slowly to mean maintenance dose of 4.8 ±4.0mg/d. reasons for the switching included lack of efficacy, hyperprolactinemia, excessive appetite and long term safety. After the switch, clinical changes included reports of decreased irritability and impulsiveness, decreased prolactin levels as well as improvement in excessive appetite[4].

These multicentre trials led to the licensing of aripiprazole for use in ASD children and adolescents for irritability and challenging behaviours by USA's FDA.

Despite this there are some problems as follows;

- Acute difficulties – nausea, headache and dizziness due to lowering of blood pressure due to action of alpha receptors in brain
- Subacute difficulties – aripiprazole is metabolised by the same enzyme CYP $2D_6$ (which also has genetic variance) as risperidone and thus cross over from one to the other may be problematic
- Long term – need to stick with it as it will take 6-8 weeks for the binding to D_2 receptors to stabilise and thus have optimal effect. As there is very little sedative effect associated with aripiprazole a sedative agent maybe used concurrently initially with the aim of reducing it eventually. Optimal therapy is the least number of medications.

Most of these problems are transient or minor and can be helped by starting at a lower dose and slowly weaning the dose up to ensure the lowest effective dose is used. This can also be achieved as the tablets can be crushed and dispersed in water and a portion taken to ensure a smaller dose (don't rush to crush) as the liquid preparation is not available in Australia

Adverse effects reported in schizophrenia trial adolescent patients (13-17years) over 6 week period with ≥5% occurrence. Somnolence (sleepiness or hypersomnia), extrapyramidal disorder (movement disorder), fatigue, nausea, akathisia, blurred vision, salivary hypersecretion, and dizziness. So tips to help manage these are:-

- Akathsia (restlessness) feeling more on the edge - happier when moving around, try to relax by deep breathing – blowing bubbles or whistles and dressing in loose clothing
- Nausea (stomach upset) - usually transient at dose changes and will last for a few days but if ongoing consult your doctor
- Dizziness and light headness or unsteadiness - take time in standing up from lying position, rest by putting head on desk or lying down when these feelings happen.
- Salivary hypersecretion - if this is happening at night, a plastic cover over the pillow can help as well as additional medications can help alleviate the problem so mention this to the prescribing doctor.
- Constipation - increase fluid intake as well as fruit vegetables and cereals in the diet

So aripiprazole has some advantages over the other atypical antipsychotics especially long term with minimal weight gain but there are problems in introducing a partial agonist. From aripiprazole other medications are now being developed so some of these introduction problems might be eliminated.

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Aripiprazole: Parent /Client leaflet

What is aripiprazole used for?
Aripiprazole (also known by trade name Abilify®) is used to treat symptoms of psychosis, schizophrenia and mania. It has also been used to help in bipolar disorder, challenging behaviours and depression together with antidepressants. Aripiprazole currently is only available as tablets but these can be crushed and dispersed.

When should I take aripiprazole ?
Together with a glass of water at regular times each day according to the medicine label, there are no problems taking it with food if that helps remember to take it.

How long will aripiprazole take to work?
There maybe some response in a couple of days but for total effect to occur it may take a few months. Initially there might a feeling of being unsettled but this usually wears off in time.

How long will I need to take aripiprazole for?
This will depend in why you are taking it. It could be several months or years to ensure symptoms do not come back. Aripiprazole has not been shown to be addictive.

Can I stop taking aripiprazole suddenly?
It is unwise to cease suddenly as this can lead to rebound effects. When ceasing, the aripiprazole dose should be tapered and under the direction of the treating doctor.

What should I do if I forget to take a dose of aripiprazole?
Take the missed dose as soon as you remember, but if the missed dose is within 12 hours of the next dose just remember to take the dose as normal. Do not take catch up doses. If having problems remembering the dose please discuss with your community pharmacist or doctor.

Can I cycle, drive or operate a boat while taking aripiprazole?
If you feel light-headed when initially taking aripiprazole this should wear off before driving or cycling or operating machinery.

Will aripiprazole affect other medication?
There are a few interactions with other medications so make sure the prescriber knows what you are taking before prescribing.

What sort of side-effects might I get with aripiprazole?

- Akathisia (restlessness) feeling more on edge. You may sweat more; try to relax and take deep breaths Usually wears off in a few weeks
- Stomach upset feeling and being sick as well as diarrhoea usually wears off after few days if continuing see your doctor
- Constipation – ensure you are eating enough fibre, cereals and fruit as well as drinking water
- Headache ask about use of paracetamol of other pain medications
- Insomnia let your doctor know so the dose or timing of dose can be changed
- Blurred vision don't drive see your doctor if troublesome
- Tremor usually wears off after a few weeks; if persistent consult the doctor who may prescribe additional medication
- Hypotension do not stand up too quickly and try to lie down when feeling faint or dizzy
- Seizure or fit (convulsion) cease aripiprazole and see your doctor immediately
- Palpitations can be treated if worrisome

This is small list if side effects. Some people get no side effects whilst others may get some side effects that are not listed. If you think you have a side effect then contact your doctor and discuss the symptoms.

Book Review:
A Clinical Handbook in Adolescent Medicine: A Guide for Health Professionals who work with Adolescents and Young Adults.

Steinbeck, K. and Kohn, M. *Eds*. (2013). *A Clinical Handbook in Adolescent Medicine: A Guide for Health Professionals who work with Adolescents and Young Adults.* World Scientific, Singapore.

Review by Hebah Saleh, School-Link Officer, The Children's Hospital at Westmead

When a child is born to new parents, there is so much hope, joy and happiness that the family are overcome with positive emotions. And then the baby wakes up; the adrenalin wears off. The sleepless nights begin and the hard task of parenting ensues. How many times the new parent wishes that this little, cute, wiggly being could have come with a manual. Adolescence then hits, with powerful confusion, agony, and more sleepless nights, this time filled with worry.

Worry no more! An Australian manual has been written for the confused brethren interacting with teenagers that are randomly searching google with questions like 'what is a normal adolescent?' to 'why does my teenager self-harm?'. *A Clinical Handbook in Adolescent Medicine: A guide for health professionals who work with adolescents and young adults* has been written as a manual to help support those that interact with this age group. The 2013 handbook edited by Kate Steinbeck and Michael Kohn starts with a nice description of what is normal in adolescent physical development, the adolescent brain and normal adolescent psychosocial development. This is followed by covering general issues around working with this group such as confidentiality, communicating with parents and carers and issues in education.

The handbook then delves into more intricate issues beginning with health related topics such as drugs, chronic illness, injury, rural and remote health, transition in care, incarcerated care for adolescents, obesity, physical activity and sports medicine, sexuality, dying and the importance of resilience. There is then a shift into disability including deafness, intellectual disability and mental health disorders. The mental health disorders become more specific such as eating disorders, depression and anxiety, psychotic disorders, sleep disorders, and ADHD.

Health issues are then represented with chapters on immunisation, respiratory disorders, diabetes, bone health, neurological disorders. Other health issues include cancer and its effects, genetics, cardiovascular risks, urology, renal medicine and allergic disorders. It was refreshing to see chapters on common adolescent problems including; dermatological problems, haematological problems, cardiology problems, rheumatological problems and common gynaecological problems.

Although this handbook cannot cover everything within the domain of adolescent health, with 52 chapters the editors have covered multiple health and psychosocial areas which helps the reader to understand more about adolescent medicine. Within chapters are also a plethora of issues and disorders that are helpful in answering questions about this group.

Chapter 22, *The Adolescent and Young Adult with Intellectual Disability and Complex Health Needs* includes short discussions of legal rights and advocacy, infancy and childhood, growth and development, Spina Bifida, Cerebral Palsy, associated health conditions and management issues. There is also some discussion around quality of life, progressive health and Down syndrome. There is a short case study and many examples of health conditions. The authors of this chapter Helen Somerville and Cameron Ly discuss complex needs in a summarised chapter.

Chapter 30 is contributed by our own David Dossetor and Rameswaran Vannitamby whom discuss *Mental Health in Young People with Intellectual Disability and Autism.* It is a nice overview with prevalence, aetiology, and most of the chapter dedicated to mental health in the ID population touching on associated health needs, communicaton problems, challenging behaviour, diagnosis, prevalence and specific mental health diagnosis such as depression, anxiety, psychoses, impulse control and organic mental health disorders. It concludes with barriers to mental health care and some notes of models of care.

If you work or interact with adolescents, this handbook with a very high contribution from various health professionals, doctors and esteemed colleagues, might answer a few of your baffling questions.

Further Reading:

Kang, M., Skinner, S.R., Sanci, L.A. and Sawyer, S.M. *Eds*. (2013). *Youth Health and Adolescent Medicine.* IP Communications: Melbourne

Unfogging the future, an update on the National Disability Insurance Scheme

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

Recently I attended the *Getting the Best from the NDIS - Making it Work for People with Intellectual Disability! Hosted by the NSW Council for Intellectual Disability* from 28th to 29th August in Newcastle. This is an excellent time to reflect and summarise on the NDIS in NSW.

Background

What is the NDIS?
The National Disability Insurance Scheme (NDIS) is a form of social security for people with permanent and significant disabilities that affect their participation in everyday activities (NDIS website). The scheme is administered by the National Disability Insurance Agency (NDIA).

Who is eligible?
An estimated 460 000 Australians will participate in the full roll out of NDIS by 2018 (Commonwealth of Australia 2014).

To access the NDIS, the following criteria currently applies. People need to:

- Have a permanent and significant disability that affects their ability to take part in everyday activities;
- Be aged less than 65 when they first access the scheme;
- Be an Australian citizen, a permanent resident or a New Zealand citizen who holds a Protected Special Category Visa;
- Live in a trial site location (during the trial).

The NDIS has three tiers or targets for investment.
Tier 1: Targets everyone in Australia, and aims to create community awareness about people with a disability, and promotes inclusion and opportunities for people..

Tier 2: Targets 800000 people with disability plus their carers, providing general information about the most effective support options.

Tier 3: Targets 400,000 people with an ongoing permanent disability, providing individual funding and resource allocation under NDIS.

How will it work?
NDIS is a whole-of-government, whole-of-life approach, where after meeting eligibility criteria, individuals will make a plan for their future (assisted by NDIA planners if needed)

and choose self-directed funding or a voucher system to purchase services. The government has committed to double the current disability expenditure. The scheme was introduced as a concept in 2011 by the Productivity Commission and began its implementation in several launch sites in July 2013:

- Tasmania for young people aged 15-24;
- South Australia for children aged 13 and under (on 1 July 2014);
- Barwon area of Victoria;
- Hunter area in NSW for people up to age 65.

From July 2014 the NDIS commenced across the ACT, the Barkly region of Northern Territory, and in the Perth Hills area of Western Australia. Roll-out in other areas will commence progressively from July 2016 (NDIS website).

The remaining state disability sectors are funded under a welfare model whereby state government disability agencies receive funding and outsource many services to non-government organisations with grant or block funding until the NDIS is completely rolled out by 2018.

The progress report from the first 9 months reported that 5400 people had drafted plans and congratulated the scheme for giving participants choice and control in how they managed their supports and pursued their life goals. The report also acknowledged several challenges including:

- Transition from state supports to the NDIS;
- Capacity of the disability workforce to support the pace of rollout;
- The interface of the NDIS with mainstream services;
- The definition, development and funding of Tier 2 services;
- Supporting greater economic and social participation;
- Supporting NDIS participants to find suitable accommodation;
- Assisting Indigenous people living with disabilities;
- and providing ongoing advocacy.

(Commonwealth of Australia, 2014).

Commentary

The positive implications of this philosophical policy shift are listed below, however with any new scheme there are also many imperfections.

Self-determination and free choice

Fawcett and Plath suggested that placing the person with a disability at the centre of decision making is an important step towards self-determination (2012). Similarly, choice can lead to decision making which the productivity commission argued can lead to improvements in quality of life (2011). The commission also argued that increased consumer choice can give service providers a greater incentive to innovate and provide better quality services.

Fawcett and Plath highlighted that rural and remote areas may have less choice when it came to services and supports, which is often referred to as 'fake choices' and choice overload when too many 2012.

> "NDIS is a whole-of-government, whole-of-life approach..."

Eligibility and Assessment

In regards to eligibility requirements, what constitutes a permanent disability? In particular, individuals with a psychiatric disability may be at risk of not meeting these requirements. The issue of recovery from mental illness is contradictory to permanent disability (Mental Health Council of Australia). Also, a substantial number of people of working age with disability may also miss out on funded supports because their disability may be assessed as not severe enough (Baker, 2012). Similarly, Fawcett and Plath suggested that this scheme has the potential to alienate marginalised groups such as Indigenous Australians who face historical disadvantages in accessing services and supports (2012).

Fawcett and Plath continued that an assessment approach that focuses on personal engagement and relationship building is desired and can be seen as an empowering process to help identify barriers and need rather than a gatekeeping exercise.

Those with limited capacity to decide for themselves

There needs to be safeguards in place for those with limited capacity to make decisions such as individuals with psychiatric, intellectual or developmental disability and children with various disabilities. There are procedures in place for plans to be made by the person with the disability, their carer or an NDIS independent broker (Fawcett and Plath, 2012). The independent broker needs knowledge of appropriate and effective supports and services for a variety of disabling conditions.

Workforce Issues

As the market is driven by need, workers may be employed on a casual rather than permanent basis in order to meet the ebb in supply and demand for services at different times.. The type of workforce required may also see a radical change. For example, case managers may not be prioritised as a service to purchase by users .

Existing NGO services will adjust to a user pays system. Competition between organisations means that marketing costs will be a new expense to their fragile budgets (Crozier and Muenchberger, 2013). Accreditation and quality assurance of services may also be an issue.

Some Key Messages from the NDIS conference in Newcastle

The following key points were taken from the official conference report (NSW CID 2014) and relate to children and adolescents with intellectual and developmental disabilities. The NDIA needs robust systems to ensure input by people with an Intellectual disability (PWID) into the continuous improvement of the NDIS.

- **Meeting complex needs:**
  - ◊ Comprehensive, person centred, active support is the basis for meeting complex needs.
  - ◊ Robust systems are needed so that skilled professionals can be identified, accessed and act as a close knit team.
  - ◊ Historically, State/Territory disability agencies have developed systems to meet complex and specialist needs. The NDIA should identify and ensure the maintenance of key functions of these systems in a form appropriate to the NDIS environment.

- **Ensuring good health care:**
  - ◊ Strong collaboration between disability and health services is key to addressing the stark inequalities in physical and mental health experienced by PWID.
  - ◊ NSW and some other State/Territory Government disability services fund vital health services for PWID.
  - ◊ Unless the Commonwealth Government commits to continuing these services, they and their funding should be brought under State/Territory health agencies.

- **Finding the right support:**
  - ◊ PWID and their families need guidance and support to access support services suited to their preferences and needs.

- **Tier 2 and ad hoc or crisis support:**
  - ◊ The development of Tier 2 of the NDIS needs to include a focus on people who are not NDIS participants but who need ad hoc support with month to month problems or occasional intensive crisis support.

Conclusion

The NDIS is a unique opportunity to allow people with significant ongoing disabilities and their families or carers the chance to plan for their preferred future and access funds to turn their plans into a reality. NDIA needs to ensure that vulnerable people do not fall through the cracks in accessing plans and much needed specialist services. These services need to be monitored for quality and accessibility. Although a large task, the NDIA is already ensuring processes are in place to manage these issues. There is a unique opportunity in our history to educate all Australians about disability which will hopefully lead to further awareness and social inclusion of everybody in our community.

References:

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Commonwealth of Australia (2014) *Joint Standing Committee on the National Disability Insurance Scheme Progress report on the implementation and administration of the National Disability Insurance Scheme. July 2014.*

Crozier, M and Muenchberger, H. (2013) 'It's your problem, not mine': does competence have anything to do with desire and aspiration to self-direct? In *Australian Health Review*, 2013, 37, 621–623.

Fawcett, B., & Plath, D. (2012). A National Disability Insurance Scheme: What Social Work Has to Offer. *British Journal of Social Work*. (2012) 1-16.

Mental Health Council of Australia (2013) *The National Disability Insurance Scheme and Psychosocial Disability. Advocacy Brief – October 2013. Draft for Consultation.*

National Disability Insurance Scheme (2014) What is the National Disability Insurance Scheme? http://www.ndis.gov.au/sites/default/files/documents/what_is_the_ndis.PDF

NSW Council for Intellectual Disability (2014) Conference Report: Getting The Best from the NDIS. Making it Work for People With Intellectual Disability. Based on the national conference held in Newcastle August 28 & 29 August 2014.

Team Westmead Autism

Dr Michelle Wong
Clinical Psychologist, The Children's Hospital at Westmead

"Team Westmead Autism" is a costumed charity running team formed to raise funds and awareness for children with Autism and the work done in this area at the Children's Hospital at Westmead. Team Westmead Autism comprises of staff from the Children's Hospital at Westmead, their family and friends and on 10 August 2014 the team took on the ambitious quest to conquer Sydney's gruelling 14km City2Surf. Team Westmead Autism ranks included Dora the Explorer (aka CHW School Link Coordinator Jodie Caruana), Where's Wally (aka the Sydney Children's Hospital Network Director of Mental Health David Dossetor), Batman, Tinkerbell, Wonder Woman, Captain America, and a host of other superheroes.

Team Westmead Autism were overwhelmed by the support of over 300 individuals who donated $30,450. These funds will go directly to developing a therapy App to accompany the Children's Hospital at Westmead's own Emotion-Based Social Skills Training (EBSST). EBSST is one of the few evidence-based, theoretically derived interventions that develop social-emotional skills in young people with Autism. This is truly innovative, world-class work.

In the words of one of the doctors who ran with Team Westmead Autism who is also a parent of a child with Autism, "I did cry when I crossed the finish line and it was of happiness to see such wonderful people supporting children with special needs like my son. ... It's so astonishing to see how passionate you and your amazing team are. Thank you."

Team Westmead Autism's 2015 ambition is to invite more people to join the team. If you are interested in joining please contact michelle.wong@health.nsw.gov.au or keep in touch via the team Facebook Page www.facebook.com/autismwestmead

Through the looking Glass: An insight into the future of ADHC as we know it. Interview with David Coyne

Executive Director of Clinical Innovation and Governance, Ageing, Disability and Home Care, Department of Family and Community Services NSW.

David Coyne is the Executive Director of Clinical Innovation and Governance, Ageing, Disability and Home Care, Department of Family and Community Services NSW.

David has worked in Disability/Human Services for over 23 years in a variety of roles including Regional Director, Deputy Regional Director of an ADHC region, Regional Manager Service Development and Planning, Regional Manager and Senior Guardian within Office of the Public Guardian.

David also has worked within the National Health Service in the United Kingdom as a Manager of Clinical Services for a specialist challenging behaviour team. He is a psychologist by training and is registered with the NSW Psychologists Registration Board.

Clinical Innovation and Governance has been established under the Stronger Together Plan to provide leadership and coordination of services to clients with complex needs and challenging behaviour.

Clinical Innovation and Governance:

- Establishes and reviews policy and practice guidelines relating to the provision of support to adults, children and young people with complex and challenging behaviour.
- Provides practice leadership in the areas of physiotherapy, speech pathology, psychology, occupational therapy and nursing and health care.
- Identifies training and professional development requirements in relation to its areas of focus.
- Establishes and reviews policy and develops good practice guidelines for working with people who have patterns of offending behaviour.
- Establishes and monitors the use of restricted practice approval mechanisms by ADHC and the application of such mechanisms across the disability sector.
- Establishes close links and working relationships with stakeholders relevant to the specialist support of challenging behaviour and offending behaviour.
- Provides oversight of the provision of services to people with an intellectual disability and a mental health issue.
- Manages the operation of the State Wide Behaviour Intervention Service, and NSW Integrated Services Program.

We welcome David to this interview and thank him for taking the time to answer our questions.

What has been your career to date? Why did you choose the disability sector?

I think I initially was led to the disability field because when we first emigrated to Australia my mother's first job here was in a respite centre for children with disabilities and I was just finishing high school and started a degree in psychology and on the weekends my mother used to encourage me to visit the respite house. Firstly, so she could keep an eye on me but secondly and far more importantly she felt it was good for these teenagers to have a non-disabled peer to interact with. That was the start of my contact with people with a disability and she was quite influential in starting me down that path.

In terms of background, I finished university and became a psychologist and worked with various communities supporting people with a disability within health/community service/DADHC and also worked in the UK with the NHS as manager of clinical services. In terms of the last ten years I have held a number of roles including: regional manager service development and planning, really focusing on developing partnerships with our non-government organisations Working with them in relation to quality, relationships man-

agement, contract management more recently the Deputy Regional Director and Regional Director of an ADHC region. I commenced in the role as Executive Director, Clinical Innovation and Governance about three years ago.

What most influenced your career?
My mother was the initial influence but then I had the opportunity to work with some pretty important people in the disability field people like Jane Cross, Ethel McAlpine, Mary Ellen Burke, Margaret Oldfield and also some very well respected people in the UK. They were very important in shaping my career and probably Ethel McAlpine in particular as she strongly suggested I move from the region into this role.

What are some of the achievements of the directorate Clinical Innovation and Governance?
Not in any particular order: Certainly the establishment of two chairs at the University of NSW is fairly significant; the appointment of Associate Professor Julian Trollor and more recently the appointment of Associate Professor Leanne Dowse. I think they've been really significant achievements for the directorate and for the agency and indeed for the sector and I think their legacy will become crucially important as ADHC transitions to the non government sector. I'd also suggest that the development and endorsement of the Memorandum of Understanding between Health and ADHC was a fairly significant piece work led by Clinical Innovation and Governance and people like Dr David Dossetor were a key champion on that piece of work along with me; he provided quite exceptional support in ensuring that we got that across the line. We are now in a second stage of implementation now what ADHC and Health have moved to the same local health district boundaries. Now we are in a new phase of reinvigorating the key components of the MoU.

> "The NDIS provides a wonderful opportunity for people with disability to be able to make a range of choices about service delivery..."

Presently CIG has a key focus on "Practice Packages' for clinicians working in the disability field. These practice packages (and core standards) focus on a range of issues, including behaviour support, supervision, health and well being and the working alliance. A number of the packages are in an e-learning format. To support this work, CIG has recently commenced regularly webinars supporting the development of clinical staff across the sector.
In terms of other achievements, I think establishing our learnings and evidence base in relation to working with peo-

ple with complex needs and in particular through the integrated services program and the community justice program really developing a lot of information and knowledge about what the therapeutic components are for people with disability exiting the criminal justice system, but also what the issues are for people with a dual diagnosis of mental health issues and some form of disability. These are some highlights, but there are many more.

"We need to give constructive feedback in order to continue to build a better system..."

What do you feel is the biggest challenge in the disability sector?
One of the biggest challenges will be preparing the sector for all parts of the business and service delivery that are presently delivered by the NGO Sector, by the for-profit sector by government and by a range of other government partners. So I think the NDIS provides a wonderful opportunity for people with disability to be able to make a range of choices about service delivery. The focus of the work that we do in CIG is really around practice leadership and working with individuals with complex support needs. So the challenge I think for the sector will be how we maintain what has been built as part of Office of the Senior Practitioner and Clinical Innovation and Governance and how do we translate that into a NDIS environment. We have recently prepared a discussion paper for the ADHC Executive but also for discussion with the NDIA and the NDIS. What that paper talks to is the need for a Centre of Excellence to be in established with hub and spoke like models across the country. In developing that paper, I led a couple of discussions which were across jurisdictions but most recently a meeting in Melbourne that I chaired with all the jurisdictions, to talk about what functions would be needed in a NDIS environment. Each of the states are going about implementation of NDIS in different ways. We all agreed that essentially there would be six key functions in the Centre of Excellence to support practice leadership for people with complex needs in the real world; essentially they are safeguarding, practice leadership, innovation and research, specialist tertiary supports need to remain somewhere in the system, workforce capacity building has to be an absolute focus on an ongoing basis for the sector and finally there needs to be a monitoring and review function (whether that's in relation to quality of behaviour support planning or implementation or monitoring of restrictive practice authorisation use of psychotropic medication), those things need to be in the system.

Can you describe the changes that are going to be made and what we can expect?
One of the expectations is that the NSW government, the NDIS and the NDIA are in regular discussion about not only the NSW Hunter region trial site, but for implementation in NSW. Directorates like CIG are regularly asked to comment on national position papers on particular issues. As a result of our presentation of a paper to the NDIS and NDIA we have been engaged with several consultants who are working for the federal government who are developing strategies around workforce development and so on. We are inputting into those processes. We are still working through issues at the moment of eligibility for people with complex support needs. We are presently making referrals to NDIS Hunter for a number of people in the Community Justice Program. We have also been liaising with the NDIS Hunter in relation to some ISP clients. As we work through those referrals, we learn more about where the system needs to be changed and how people can be better supported. There is still a lot of work to do and lots of discussions still to have.

How should parents or clients prepare for this change?
I think they should be talking to their local NGO's. They should be talking to their local ADHC staff. They should be getting as much information as possible from the NDIS website about supports available and different funding packages available. I would also suggest that if families, guardians, advocates or clients themselves are not happy with the services they have received then they need to be clear and articulate what it is that isn't helpful. The important thing to stress at the moment is the NDIS roll-out in the Hunter region is a trial. I don't think we can be too quick to judge what has not worked or what is indeed working at the moment. We need to give constructive feedback in order to continue to build a better system.

What do you feel will be the impact on services that cater for the emotional and behaviour disturbance of children, adolescents and adults with an intellectual disability?
There could be further siloing of services such as 'this is a disability support', 'this is mental health support', this is something else'. I think the challenge for us is to ensure that all of the agencies involved in providing support to children with a disability don't become so focused on their own silo's and continue to work across program boundaries. Pieces of work like the MoU continue to be implemented in the new FACS world. The reorganisation has helped to do that now that we are in the same boundaries as Health.

The role of the mental health commission will become more important. The role of the NSW Ombudsman will become more important as a significant government provider as ADHC exits. The work that has been done between the Children's Hospital and State-wide Behaviour Intervention Service continues. These partnerships are really good models in supporting children in multiple and complex support needs.

The challenges potentially will be that we will have more players than before such as the federal government, state government agencies, the for-profit sector, the NGO sector, all needing to deliver services in this space potentially. There will need to be very clear leadership through Health, very clear leadership through CIG while we are still here and it will be CIG and Health's responsibility to reinforce those messages to the NDIS and NDIA. Also, over the next couple of years to continue to work through the curriculum training, through the publishing of journal articles and books to en-

sure there are contemporary resources available so that the sector is clear about what it is this particular client group needs in order to do well.

Some fun questions;
What was the last thing you read?
I spend so much time reading at work, I can't actually remember the last thing I read though I suspect it was something about Emperor Hadrian. He was one of the Roman Emperors who was quite influential in really shaping Roman Britain and was stationed in Britain for a number of years and he was quite an inspirational leader, he was also a gay man who while he had a wife for political purposes also had a male lover so it is interesting to see such an important historical figure and how he basically tamed the British.

Something that you like about your field:
In the area that we focus on in CIG, one of the most important things that we can do is really make a difference to people's lives. In that context I am talking about people who have been homeless, people who have come in contact with the Criminal Justice System, people who have been languishing in psychiatric units for many years. In the work we do here we have a real ability to work with people to assist them and to turn their lives around. To quote Ethel McAlpine, 'to help people get a life' and to assist them to have positive experiences in their local communities and for them to be viewed positively by their local communities.
I think one of the other things that we do and I was made aware of it, probably only six months ago, when a clinician in a district actually came up to me after a presentation and said "Oh I've been watching your career for a while and I've read some of the things that CIG/ OSP produces and I really want to work in a directorate like yours one day" and that was really quite confronting for me but in a nice way. It was such a nice compliment.

The work that we do around skill building and capacity building I think is really important and hopefully when we have exited the service system there will be some sort of legacy we can leave behind in terms of practice leadership and capacity building.

Is there a web link that you'd like to share?
Yes, look we've got lots of web links we could share which house practice packages, our core standards, links to the ID mental health university chair and links to some of the publications that we have done.

http://www.adhc.nsw.gov.au/sp/delivering_disability_services/core_standards

http://www.adhc.nsw.gov.au/sp/delivering_disability_services/behaviour_support_services

"The work that we do around skill building and capacity building is really important ..."

http://www.adhc.nsw.gov.au/sp/delivering_disability_services/specialist_placement_and_recruitment_unit

http://dadhcintranet.nsw.gov.au/client_services/clinical_innovation/university_chair_in_intellectual_disability_mental_health

http://dadhcintranet.nsw.gov.au/client_services/clinical_innovation/statewide_behaviour_intervention_service

The disability sector in the future, what do you see? What's your vision?
In NSW, I think, the building blocks we've put in place over the last decade have been really important building blocks. So the relationships that we have developed with health, the relationships that we have developed with universities, the practice leadership responsibilities that we have developed in the office of the senior practitioner or CIG. I think they are really important pieces of work that hopefully will take us to the next iteration of disability services; which is about more choice, individual funding, living life my way. But also ensuring that the sector has appropriate ongoing support in terms of practice leadership, professionalisation and specialist tertiary supports.

Is there anything else you want to add to this?
I think more than ever, there will be a need for mainstream clinical services to be across disability issues and so some of the work that we have started in relation to the psychiatry fellowships and ensuring that we are able to target psychiatry registrars and enhance their training to ensure they're well equipped to work with people with a disability. I think that's really, really important and we can't lose sight of this. Not only being focused on just disability professionals, but we need to ensure that there is a greater range of professionals that have a good understanding and awareness of disability issues.

And you could take that down to another level which is not only disability awareness but also awareness of issues around culturally and linguistically diverse communities, working with indigenous communities. You know we ask a lot of our professionals but we need to have that broad skills set.

One of the other things which I think is a bit of a highlight is in March this year I was invited to go to Denmark to give a series of lectures to one of the universities in Copenhagen about supporting people with complex support needs and so I went and did that. But for me, it was really exciting because this directorate was recognised as having some really important expertise in the disability sector and so to be asked to go to Denmark to provide that information was really, really, really exciting. We now have formal links with a number of universities in terms of research but also student placements and one of the outcomes of that university visit was they would like to establish with us a formal student placement agreement.

Will there be someone to support NGO's?
We're not clear yet, presumably that will be the responsibility of NDIS, NDIA. The Ombudsman may have some monitoring role into the future. A centre of excellence if it gets off the ground may have a role there as well.

I wonder if something like this has happened before and what the outcome was for the state?
Well they have done similar work in the UK but it's not been an "all or nothing" so the UK has gone down the path of moving quite significant parts of government services within the NHS and local health authorities. There have been a number of reviews where, in the UK, the government is looking at how to take back some responsibility for some services. So there have been a number of high profile incidents in the criminal justice system where people were released and dreadful incidents occurred and so there were questions asked about the validity and the appropriateness of the monitoring and the review. So I think there are some processes in place to look at how government takes back some of those functions.

The beautiful artworks in this journal are taken from the participants of the **Operation Art project** at the Children's Hospital at Westmead. You can find out more at https://www.artsunit.nsw.edu.au/visual-arts/operation-art-2014

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