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Link

mental health and intellectual disability...

coordinator's message...

Welcome to the first edition of the CHW School-Link Newsletter for 2011.

What a catastrophic year it has been so far with floods, cyclones, fires and earthquakes creating devastation in our region. They say adversity brings people together and these natural disasters have transpired a great community spirit. I was reminded of the extended role that schools play in the community- providing shelter, water/food and emotional support to those affected. This highlights the capacity for health promoting schools as outlined by the World Health Organisation. CHW is currently utilising this health promoting schools approach by collaborating with ADHC and four SSPs in NSW to trial Stepping Stones, a Triple P parenting program to reduce problem behaviour in children with disabilities. You can read more about this from Dr. Phil Ray (pg 6).

These recent natural disasters have also reminded me of the slow emotional recovery from trauma. Many children with intellectual disabilities experience trauma in its many forms. The Child Safety Commissioner of the State Victorian Government has created a good resource for teachers on trauma and what approach teachers can take in the classroom entitled Calmer Classrooms.

Other features in this edition include an insight into behavioural phenotypes by our CHW School-Link leader and developmental psychiatrist Dr David Dossetor, after attending a recent conference in Italy. Other highlights include a look at the antipsychotic drug risperidone (pg 11) and a rare glimpse inside CHW Hall Ward- a child and adolescent psychiatric unit (pg 14). Our regular training section will help you plan your professional development calendar and I must make a special mention of our joint School-Link conference on MH+ID *Learning and Growing Together* on 27 May 2011.

We are establishing an interagency editorial committee in order to improve our content across the education, disability and health sectors. If you have any feedback or contributions for future editions please email schoollink@chw.edu.au.

Happy reading!

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

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Learn more about School-Link and the Children's Hospital at Westmead project on page 16 or visit www.schoollink.chw.edu.au



a note from David Dossetor...



Behavioural Phenotypes: A Window into the Mechanisms of the Mind

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

The emotional and behavioural problems of young people with intellectual disabilities have regularly been overlooked as just part of their intellectual disability, what has been termed 'diagnostic overshadowing'. Not only is recognising and treating their psychological and social maladaptive problems of critical importance to their wellbeing and quality of life, but understanding these problems provides light on the processes of the early development and mechanisms of the mind. Amongst the causes of disability are genetic conditions and many of these genetic conditions have characteristic patterns of behaviours. Particularly as we are able to discover and define genetic abnormalities, so we are able to illustrate that certain genes or their problems are biologically linked to specific behaviours.

Behavioural phenotypes are defined as characteristic motor, cognitive, linguistic and social abnormalities which may or may not constitute a psychiatric disorder which are consistently associated with a biological disorder (Flint, 1996). It may apply to syndromes where a genetic aetiology has not been defined. The term was coined by William Nyhan in 1964, from the Greek word Phainein- to show. A list of some of the best known behavioural phenotypes is listed on page 5*.

In most instances the manifestations of the mind are seen as unrelated to the functioning of the brain, what Descartes call dualism. At some level most people accept that conscious processes have a biological basis. Genetic conditions with specific behavioural phenotypes provide the best models for examining and understanding the biological basis of mental function and behaviour.

There are approximately 7,50 known genetic abnormalities, and in my clinical practice I come across 2-3 new genetic conditions a year and many have characteristic behavioural phenotypes. Each condition gives clinical researchers an opportunity to look at what underlies certain behaviours by finding differences of brain structure and functional processes associations with that genetic abnormality. With the genetic revolution of the last decade the science is developing rapidly, even though it is based in most cases on fairly rare conditions or populations of children and adults. For example Copy Number Variants (CNVs) are repeater sequences in the human genome which can now be detected by DNA chips, which are identifying a whole new lot of genetic disorders. One paper last year reported on 22 new such conditions (Viseer et al, J Med Genetic 47, 2010). Both 7% of Autism and of Schizophrenia are associated with CNVs.

The Society for the Study of Behavioural Phenotypes is a small international multidisciplinary group of clinicians and researchers that meet every year. Last October I attended the annual meeting in Pavia, a renaissance town 30km south of Milan, that, in its heyday, boasted 100 brick towers as a sign of affluence. The Meeting was held in the beautiful old library of the 800 year old University and Medical School. It was in Pavia that Camille Golgi in 1875 developed the Golgi silver nitrate stain which first enabled the visualisation of brain neurones and dendrites, the connections between cells. We saw his Nobel Prize, awarded in 1906 for this achievement, and his original ink drawings of neurones. James Harris, Professor of Psychiatry and Paediatrics at Johns Hopkins, Baltimore, confirmed the importance of his achievement as, even **with today's technology, his stain is still** the best way of viewing whole neurones, and abnormalities of dendritic structure and connectivity is now the most common

biological association of intellectual disability, whether this is Downs Syndrome, Fragile X, Neurofibromatosis 1, Tubero Sclerosis, Williams Syndrome, Phenylketonuria or Lesch Nyhan Syndrome. For example Lesch Nyhan Syndrome, which is manifest by over production of Uric acid, intellectual disability, movement disorders and self injurious behaviour (SIB) including chewing of lips and fingers, has a reduction of presynaptic dopamine transfer with reduced long dendrites and dendritic spines. There is also reduction of caudate nucleus volume and the hypoxanthine-guanine phosphoribosyltransferase (gene missing, necessary for production of generation of purine nucleotides and adenosine-5'-triphosphate (ATP), a multifunctional nucleotide which stores energy in cells. This is one example how a behavioural phenotype can lead to understanding structure and function of the brain.

Chris Oliver Professor of Psychology of the Cerebra Centre, Birmingham University UK, has used behavioural phenotypes to illustrate different levels of structure and function that influence behaviour. He expanded the causal traditional framework of behaviour of impairments, disabilities and handicaps to:

- i) **The physical phenotype** (Impairments) Including: genetics, intracellular chemistry, cellular connectivity and functionality, connections between different regions of the brain, and physical health,
- ii) **The cognitive endophenotype** (Disabilities) Including cognitive capacity, communication skills, neuropsychology, theory of mind, executive function skills, patterns of behaviour eg of attention and gesture, and
- iii) **The behavioural phenotypes** (Handicaps with environmental interaction) Including the quality and match of environment, the influence of services systems and the wider political, economic and policy environment in which services and the individuals they serve exist.

Oliver and other speakers then illustrated this with findings from behavioural phenotypes. **Cornelia de Lange's Syndrome** (CdL) suffers extreme SIB. This behavioural phenotype illustrates the problem of understanding pain in the absence of a capacity to explain. 80% suffer gastro oesophageal reflux and treatment with omeprazole which reduces the effects of the gastric acid helps in many cases. Other SIB can be related to middle ear disease found in 94% and hearing loss found in 80%, ophthalmology problems

with ptosis, myopia and retinal detachment or dental problems, leading to head bashing, and dropping on to their knees **with Perthes's Disease of the hip**, along with other orthopaedic problems. 25% also have renal problems with vesical ureteric reflux, and renal function decline. This behavioural phenotype illustrates the importance of searching for the unseen medical problem in those with limited communication problems. It is evident that this can apply in any case of someone with

The psychiatry of intellectual disability is exciting and novel and it has potential to influence our understanding of the mechanisms of the mind in special populations

distress and limited communication, yet there is a real paucity of the empirical literature on the effects of physical ill health on behavioural problems. One report quoted that 50% of children with Autism had gastro oesophageal reflux.

There is a mild version of CdL now recognised on a scale score of symptoms. They usually have greater problems of expressive language, often with no verbal skills, yet can even be of normal intelligence. 40% of CdL show features of selective mutism. If asked a question they show increased fidgeting. Is this a factor in the increase in impulsivity and hyperactivity with increased age? They also show increasing social emotional problems or Autistic Spectrum Disorders (ASD) (30%) with time although they have less stereotypic features and more social and communication features on the ADOS (Autistic Diagnostic Observation Schedule). Those with CdL also use more gestures than other groups in terms of gestures per 100 words and Chris Oliver illustrated the differences in gestural communication which they use,

and how the gesture of self revealing palms is absent when theory of mind is missing. It is suggested that problems with communication leads to anxiety that leads to challenging behaviour. We were exposed to a lovely demonstration of Augmentative and Alternative Communication (AAC) using reading to enable the development of communication and a decline of SIB.

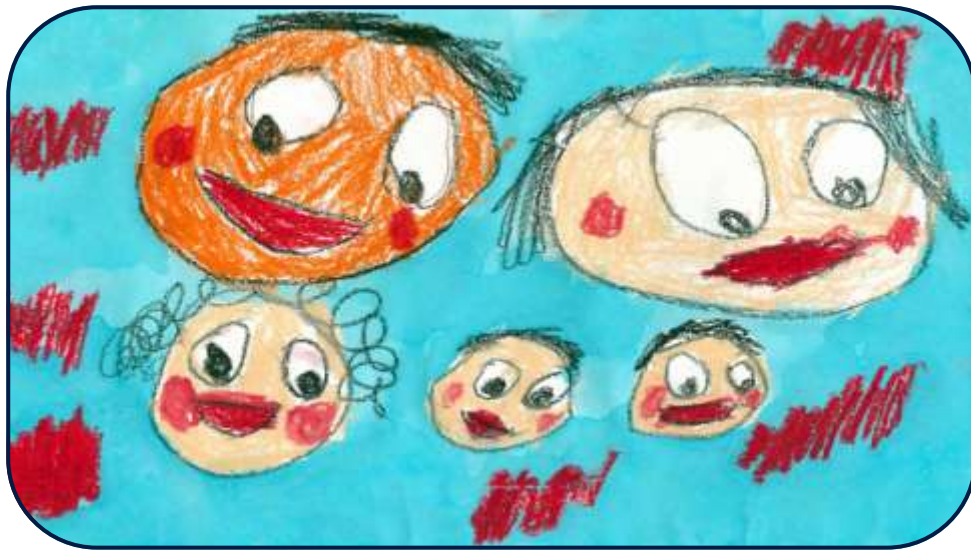
CdL has several genes identified, the main one is found in 50% of cases and is called NIBPL (deletion of chromosome 5p13.2). The theory is that the various genes are involved in the expression of Cohesin which is an enhancer for various genes and involved in linking chromatids in mitosis and involved in many tissues and the linking of cells together as illustrated in the characteristic problems of limb, bone and nerve growth. Synaptic development goes through growth, pruning and maintenance. It is the pruning at **4 years of age that doesn't occur** in CdL leading to ID and ASD features. This too is a model of how pruning of neurones and dendrites may provide a model for understanding other cases of ASD and ID.

Jo Moss has looked at the patterns of repetitive/stereotypic behaviour using the Geddes Compulsive Behaviour Checklist across various syndromes. This demonstrates that although many different syndromes have significant autistic features, there are discrete and definite differences which are recognisably part of the syndrome characteristics, but what specific implications do they carry? CdL show increased ordering, completeness, cleaning, checking and grooming than expected for ASD. Smith Magenis Syndrome have repetitive behaviours/obsessions about people, familiar or strangers (as well as extreme impulsiveness). In particular, Prader Willi has a characteristic pattern of increased repetition of questioning, routine and hoarding. The adherence to routine is related to problems they have with

attention shifting and visuo-spatial tests, which when stressed, increases anxiety, **and risk of aggression. Oliver's team** have shown that Functional Magnetic Resonance imaging in Prader Willi has increased frontal activity in attentional shift, whereas as in the controls it is more parietal, suggesting that in Prader Willi when attentional shift capacity is tested, they need to use a compensatory mechanism in the frontal lobes which reduces their cognitive reserves. This was illustrated with a card sorting test where if the rules of sorting are increased to more than one category, they make greater mistakes and get angry. This problem was associated **with increased scores on the 'Brief'**, a measure of Executive Function, compared for example with Downs Syndrome. Similarly, those allowed to develop greater routines are more aggressive with change. This neuropsychological observation can lead to behavioural vulnerability in transition eg from school to post school options. An intervention using a visual/card warning of change of routine has been helpful to reduce levels of aggression. How often do we think about the problems of attention shift might lie behind resistance to change or aggression?

How Autism has a negative effect on family interaction and attachment is well described. **Angelman's Syndrome (the happy puppet syndrome, chromosome 15 q11-q13)** illustrates the opposite behaviour/environment interaction: Those with **Angelman's have increased sociability, classically described as having "a happy disposition with inappropriate outbursts of laughter"**. It is observed that they are more likely to initiate social contact and this has an effect making the carer smile and keep on smiling! Thus illustrating an effect of a gene acting on the relationship environment, leading to a mutual positive affect.





Terje Naerland from Norway proposed an interesting psychological phenomenon in **ASD**. He identified ‘**focus related performance problems**’ in **10% of ASD and 50% of Down’s Syndrome with autism and Tuberose Sclerosis with autism**. If a carer draws attention to their performance of an action it inhibits them and can even lead to the loss of skills. They learn by incidental learning such as copying others. Performance is smooth if unobserved but they stop if observed. So many interventions routinely used are by design at risk of impairing performance or compliance because they focus on the desired behaviour such as through the use of over-learning, use of praise and even the use of token economies. This highlights that no approach is universally good for everybody; even showing rewards and social approval can be harmful.

The study of behavioural phenotypes is also leading to innovation in medical treatments. Some remain experimental such as the use of deep brain stimulation by electrode implantation in Lesch Nynhan Syndrome. James Harris described how deep brain stimulation through the introduction of electrodes precisely into the basal ganglia of the brain was ethically approved to improve dystonia but was also found to reduce SIB incidentally. The study was able to show, using proton magnetic resonance spectroscopy, basal ganglia dopamine neurotransmitter deficits of 60% in putamen and caudate, and the electrical brain stimulation increased dopamine action in meso cortical and frontal lobe neuronal projections. There is some suggestion that in the mainstream population low basal ganglia dopamine levels is associated with emotional dysregulation.

Petrus de Vries, a child psychiatrist from Cambridge has studied the neuropsychology of attention in the Tuberose Sclerosis Complex (TSC). He found that even adults of normal intelligence with TSC have spe-

cific problems in dual tasking, for example when visual selective and auditory sustained attention tasks were combined in a cross-modal dual task. His work has drawn attention to a developmental sequence of attentional skills, and the importance of neuromolecular protein TSC1-2 protein which affects higher cognitive functioning separate to functional deficits from the anatomical changes of TSC tubers in the brain. Rapamycin is an immunosuppressant medication used in transplantation, eg of kidneys, to reduce the risk organ rejection. In animal models of TSC Rapamycin has been found to shrink tumours and improve memory, possibly through effects on the hippocampus where changes in electrical activity are found, reducing the long term potentiation. Thus Rapamycin is being explored in human trials and is reducing levels of an **abnormal neuroprotein ‘mTOR’ (target of rapamycin)**, improving cognitive functioning and even causing TSC tubers and tumours to shrink.

Possibly the development of greatest impact and controversy is the mGlu 5 antagonist trials in Fragile X led by Randi Hagerman at UC Davis Medical Centre, Boston. Fragile X which is the most common cause of intellectual disability and autism is due to an increase in trinucleotide CGG repeats in the X chromosome. In most healthy individuals, the number of nucleic acid CGG repeats are fewer than 40. When the repeats are over 200, this causes methylation and deactivation of the FMR1 (fragile X mental retardation 1) gene which codes for the fragile X mental retardation protein (FMRP) and FMRP is thought to downgrade the development of synaptic connections between nerve cells in the brain and cell-to-cell synaptic communication. The synaptic connections between nerve cells change and adapt over time in response to experience which is important for learning and memory. Without adequate FMRP, an RNA-binding

protein, severe learning deficits or mental retardation can develop, along with physical phenotypic abnormalities seen in fragile X syndrome. The functions of FMRP in different domains is still relatively unknown. One hypothesis is that many symptoms are caused by unchecked activation of mGluR5, a metabotropic glutamate receptor, which was found in a 2007 mouse model study to contribute significantly to the pathogenesis of the disease; suggesting that mGluR5 blockers could be used to treat fragile X syndrome.

There are a number of mGluR5 blockers drugs available including lithium, used in bipolar disorder, Minocycline, an antibiotic, an experimental drug STX107 and Baclofen, used for relaxing muscle tone. There is particular interest in the racemic form of Baclofen, Arbaclofen, which is 10 times more effective than the levo form, that is the right handed version of the molecule, versus the mirror image or left handed version. Hagerman has found 70% improvements including in sociability in a randomised controlled trial of Fragile X. There are delays in the release of this treatment due to a drug patent legal battle on whether the racemic molecule constitutes a novel drug. Similar effects are also reported in a proportion of people **with autism. It can’t be long before specific Fragile X treatment clinics start up!**

This brief conference report illustrates how exciting and novel the psychiatry of intellectual disability is, and how it has potential to influence our understanding of the mechanisms of the mind in special populations and I suspect in mainstream populations. If this introduction interests you, or you have observations on behavioural phenotypes that you would like to share, then please make sure you join us at this years meeting of the Society of the Study of Behavioural Phenotypes, which is to be held in Brisbane 5-7th October 2011 hosted by Dr Honey Heussler; further details at: www.ssbp.co.uk/ssbp.

Relevant Reading:

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- Dykens, E. M., & Hodapp, R. M. (2001). Research in mental retardation: Toward an etiologic approach. The Journal of Child Psychology and Psychiatry and Allied Disciplines, 42(1), 49-71.*
- Flint J. 1996. Annotation: Behavioural Phenotypes: a window onto the biology of behaviour. Journal of Child Psychology and Psychiatry 37(4):355-367.*
- Harris J, 1995 Developmental Neuropsychiatry. Vol II, Ch 10: 251-304.*
- O’Brien G, Yule W. 1995. Behavioural Phenotypes. Mac Keith Press: San Diego*

*Best Known Behavioural Phenotypes

Fragile X

Most common form of inherited ID, responsible for 30% X-linked ID. Fragile site @ Xq27.3 The number of CGG nucleotide repeater sequences and more than 320 is proportional to the level of intellectual disability. ADHD in 75%; PDD like symptoms; self injurious behaviour biting hand; picking skin when excited; hand flapping; Communication problems.

Prader Willi

Characteristic physical appearance, extreme overeating & obesity, short stature, hypogonadism, mild ID (IQ 30-85), skin picking, obsessive behaviours, temper tantrums, sleep abnormalities. 1/10,000. Deletion in paternal chr 15q11-13, or maternal disomy or translocation or mutation of an imprinting centre (<5%). Previous reports of increased rates of affective or bipolar psychoses.

The rarer genetic cause of Prader Willi Syndrome, of maternal uniparental disomy of chromosome 15 in adults suggests it may be the highest risk of schizophrenia in any population (Dykens, 2001).

Velo Cardio Facial Syndrome

Deletion of 22q11, characteristic dysmorphism, cleft lip and or palate, learning disability,

Behaviour in childhood: Simple Phobia 22.6% Anxiety Disorders 17% Eneuresis 14% Major Depression 12% & Others. Psychiatric disorder found in adult populations to have a prevalence of :- 42% major psychiatric disorder, including 30% psychosis, and 24% schizophrenia, (with stronger positive symptoms and weaker negative symptoms than is normally seen)

Smith Magenis Syndrome

Deletion of chromosome 17p11.2, 1/25,000. Short, characteristic facies, neurological features etc.

Intellectual Disability, ADHD 90%, aggression, autism, self injurious behaviour, inverted sleep and circadian melatonin cycle, obsessions, anxiety, specific learning problems, self hugging etc

Tuberous Sclerosis

Autosomal Dominant, triad of adenoma sebaceum, fits and Intellectual Disability (less than 30% have classic triad) (38% have average IQ); with hyperactivity & social impairment. TS Complex as involves all tissues; 80% have fits. 70%

have behaviour disturbances incl: 36% autism, asperger's, and social impairment; many have infantile spasm assoc. 35% ADHD, 35% obsessive/ritualistic behaviour. 60% sleep problems, 1/3 Self injurious behaviour.

2 groups: tubers in temporal lobe associated with ASD, intellectual disability related to total mass of brain tubers.

Cornelia de Langes Syndrome

Characteristic appearance, short, abnormal growth eg of limbs, self injurious behaviour.

Angelman's Syndrome, the happy puppet syndrome

Deletion of same part of chr. 15q11-13 as Prader Willi but from maternal gene.

Sotos Syndrome or Cerebral Gigantism

Syndrome specific symptoms and signs
Hyperphagia of Prader Willi, "Cry of the cat" of 5p Syndrome and Self-hugging in Smith Magenis Syndrome (Dykens, 2001).

Symptoms over represented in syndromes

Some symptoms are over-represented in several conditions such as: -

- Overactivity and inattention seen in **Fragile X and William's Syndrome**
- Self injurious behaviour is seen in different syndromes: -
- Extreme lip and finger biting in Lesch Nyhan Syndrome. The specificity of SIB in Lesch Nyhan Syndrome raises the suspicion of abnormalities of purine or dopamine function in this pattern of SIB.
- Hand biting in Fragile X
- Skin picking in Prader Willi Syndrome.
- Head banging, nail biting and gauging, and insertion of objects in orifices in Smith Magenis Syndrome.
- Anxiety disorders seen in William's Syndrome present with different subtypes of anxiety disorder.
- Major sleep disturbance and catnaps in Smith Magenis Syndrome is related to an inverted melatonin circadian cycle
- Autistic spectrum disorder, intellectual disability and motor incoordination in **Joubert's Syndrome: cerebellar (vermal) agenesis.**

The behavioural phenotype can lead to the genetic diagnosis and the chromosomal abnormality will often only be suspected on clinical grounds, and not always the other way round. ●



facts and figures...

Interesting Facts to Know!

After 66 years, The Spastic Centre has been re-named the Cerebral Palsy Alliance but they still provide outstanding services to families and people with Cerebral Palsy.
-SMH 9th February 2011

\$16.1 million has been provided for Home and Community Care (HACC) services across NSW. The program will now total more than \$625 million.
- Federal Minister for Health and Aging and NSW Minister for Aging and Disability Services 27th January 2011

The NSW Ombudsman recently completed **a review of the implementation of ADHC's Aboriginal Policy framework and Consultation Strategy.** Visit www.ombo.nsw.gov.au to read the Report on improving service delivery to Aboriginal people with a Disability including 11 recommendations.

NSW Government has introduced legislation that will help people with disabilities cast a secret ballot in state elections using a new online and telephone voting system. iVoting is expected to be in place for the 2011 state election.
Visit www.elections.nsw.gov.au

April is Autism Month and the 2nd of April is World Autism Day as declared by the United Nations. Visit www.worldautismawarenessday.org to register your event and download some resources. Be part of the big day!

meeting Dr. Phil Ray...



*Dr. Phil Ray, Clinical Psychologist
Department of Psychological Medicine
The Children's Hospital at Westmead*

I would like to take this opportunity to introduce myself to the School-Link audience. My name is Dr Phil Ray and I am a Clinical Psychologist, with additional qualifications in Neuropsychology, working in the Developmental Disability Team at CHW which is led by Dr David Dossetor, Associate Professor and Child Psychiatrist.

I started with the team in May 2010 after working for nearly six years in Developmental Disability in the UK. My previous role in the UK involved developing and providing a Pae-

diatric Neuropsychology service which included the assessment, diagnosis and treatment of children with a range of acquired neurological and neurodevelopmental conditions including brain injury, epilepsy, autism, ADHD, metabolic and genetic disorders.

Since immigrating to Australia in April 2010 my role here at CHW is very similar to my previous post, utilising both my academic, clinical and research experience with this fascinating and complex population. Of particular interest in my current role is investigating, by both clinical and neuropsychological methods, the interplay between this **population's psychological, cognitive and neurological difficulties, and how these aspects influence each child's individual profile** of strengths and difficulties.

Specific to School-Link I am Project Leader for the Group Stepping Stones Triple P (Group SSTP) project. Stepping Stones Triple P is part of the Triple P parenting and family intervention program adapted for parents of pre-adolescent children aged up to 12 years who have a developmental disability. Group SSTP is delivered to parents over the course of 9 weeks.

This exciting project will involve evaluation of Group SSTP when it is delivered in four Schools for Specific Purposes (SSPs) within the Metro North region. This is unique as it is a conjoint project across Ageing, Disability

and Home Care (ADHC), NSW Department of Human Services (Metro North and Statewide Behaviour Intervention Service; SBIS), **Children's Hospital at Westmead (CHW)**, and Department of Education & Training (DET).

It is a general finding that parental competence and confidence is the most effective intervention for enhancing the mental wellbeing of children and in turn other members of the family. SSTP is a relatively new program to enable parental awareness specifically designed for the additional and complex problems that befall children with an intellectual disability. Data will be collected and analysed in the form of pre and post intervention measures from the parents looking at areas such as child behaviour, parenting style, stress, and family relationship difficulties. This will provide detailed information on the difficulties that parents face before the group and the effectiveness of the intervention once the group is finished. This presents an opportunity for the stakeholders to further the evidence base for Group SSTP regarding the reliability and effectiveness of the program.

In my role as Research Leader I am involved in both the logistical, academic, and statistical aspects of the project and I also serve as a point of contact for the schools if there are any queries regarding the running of the groups or the collecting of the data.

The groups start in February and will likely run **until April/May. So from the looks of it I'm going to have a busy 2011!** ●

new intellectual disability network...



The Agency for Clinical Innovation (ACI) was established in January 2010 as a board-

governed statutory health corporation in direct response to the recommendations of the Garling Inquiry into Acute Care Services in NSW Public Hospitals.

The ACI works with clinicians and the community to rapidly develop and implement new ways of caring for patients which are evidence-based and best practice. Reporting to the NSW Minister for Health and Director General of the NSW Department of Health, the ACI has set up and supports statewide clinician-led networks which bring together doctors, nurses, allied health professionals, managers, scientists, researchers and consumers across NSW. Its networks harness the clinical and practical knowledge of people working in the NSW health system and consumers accessing care.

In 2007, after an extensive consultation process, the Service Framework to improve health care for people with intellectual disabilities was developed by the NSW Department of Health and Department of Ageing, Disability and Home Care in collaboration with a number of key stakeholders. The Service Framework aims to reduce health inequalities for children, adolescents and adults with intellectual disability and

is based on a tiered model of care.

In 2009, the NSW Department of Health engaged KPMG to conduct an independent economic appraisal of the framework which formed the basis for the business case to the NSW Government to establish specialised services for people with intellectual disability and a centre for clinical leadership, research and education, including a clinical network. In the 2010/11 Budget, \$0.5M was allocated to the NSW Department of Health to improve health care for people with an intellectual disability. The allocation was approved to pilot a specialised clinical service for people with an intellectual disability, support the establishment of an ACI Clinical Network and to conduct an evaluation of both initiatives.

In December 2010 an ACI Network Manager, Maxine Andersson, was appointed. Maxine is a Registered Nurse and Social Worker with over ten years experience in the intellectual disability sector, predominantly with the home and community care industries. Les White, NSW Chief Paediatrician, has been appointed Chair and will lead the steering group. On 21 January 2011 a public forum was held at the Northern Sydney Education and Conference Centre, at which clinicians, consumers, carers and interested professionals from government and non-government organisations were invited to join the new Network.

Establishment of the ACI Intellectual Disability Network is based on the Determinations of Functions of the ACI and on the recommendations outlined in the Service Framework. The ultimate goal is to improve primary and secondary health care services for people with intellectual disability by promoting clinical leadership, research and education.

The Network will:

- Lead the way to ensure that people with intellectual disabilities in our community receive fair and equitable access to health services throughout NSW
- Provide expert advice and clinical leadership to the NSW Department of Health on matters relating to patient care, models of care, education, research and other related areas.
- Build workforce capacity to facilitate the inclusion of people with intellectual disabilities in mainstream health services.
- Increase the capacity for continuous service improvement.

If you are interested in becoming involved with the Network, please contact Maxine Andersson on the number below.

Contact: Maxine Andersson
Ph: (02) 8644 2194 Fax: (02) 8644 2148
maxine.andersson@aci.health.nsw.gov.au ●

upcoming training...

Intellectual Disability:

Joyful learning: Engaging all students in the inclusive classroom by Dr. Paula Kluth and *Family Advocacy*. This is a practical workshop for parents and educational professionals of students with developmental disability. 3rd-4th March 2011. Ryde Leagues Club. 9.30-3.30. Visit www.family-advocacy.com or contact 9869 0866. Prices range from \$20- \$200.

School-Link Conference. Mental Health and Intellectual Disability: Learning and Growing Together. 27th May 2011. Liverpool Catholic Club. Registrations open March 14th, visit www.schoolink.chw.edu.au/conference

Autism Spectrum Disorder:

Aspect BIS parent and professional workshops aim to build capacity in families, schools and other services whilst developing consistency across settings. 3 day workshop is run over 6 weeks. Penrith. 22nd Feb, 8th and 22nd March. Free for families, \$90 for professionals. Contact bis@autismspectrum.org.au or 88781804

ASD Workshop 1 by Minds and Hearts (specialist ASD clinic). Speakers include Professor Tony Atwood and Dr Michelle Garnett. 12th April Sydney. 9.00-4.30pm. \$550. Contact michelleg@mindsandhearts.net or 07 3844 9466.

Redbank House lecture series. **Complex Case Formulation and Practice Challenges in Multi-element Intervention** by Lisa Fahey, Friday 4th March. 1:30-2:30pm. **Autism Spectrum Disorders: An update for practitioners** by Dr Anne Chalfant. Friday May 6th, 1:30-2:30pm. Lecture theatre 1, Education block Westmead Hospital. Free. Enquiries Kerry or Chloe 9845 6577. Videoconferencing available with two weeks prior notice by emailing chloe_macdonald@wsahs.nsw.gov.au. The Lecture series occurs the first Friday of every month.

Diana Henry Australian Tour. Hands-on workshops about children's struggle with sensory processing. Visit www.lifeskills4kids.com.au to find out more or contact 6536 5308.

Disability:

Rockability is a special musical event. Bowral Memorial Hall, Bendooley St Bowral. Saturday 2nd April 2011, 2pm-6pm. \$5. Contact Sharon 48622644.

People with Disability training calendar includes *Disability Awareness* 10th March Newcastle, 28th April Sutherland, 1st June Sydney \$300. *Responding to Abuse and Neglect* 9th March 2011 Newcastle, 15th March 2011 Sydney, 27th April 2011 Sutherland, \$300. *Responding to Sexual Assault* 1-2 March 2011 Sutherland, 29-30 March 2011 Newcastle, 4-5 May Sydney \$650. www.pwd.org.au/archive/10/July2010-June2011.pdf

Vocabulary is Vital; Empowering Children and Adolescents with Learning Difficulties through Vocabulary Enrichment presented by Julia Starling and Annette Guterres. 29th March 10am, Parramatta. Contact 9806 9960 or visit www ldc.org.au

Home and Community Care Service Workshops in collaboration with STARTTS present a workshop that includes information about trauma survivors and their carers- ageing and disability as part of an information day. Contact STARTTS HACC training officer on 9794 1900.

A Vision Bigger than your Vision presented by *Dr Paula Kluth* is a practical workshop about setting goals and imagining possibilities for people with developmental disabilities. 5th March 2011. Parramatta. 9:00-2:30pm. Ranges from \$10-\$60. Contact 9869 7753 and register by 24th February.

Stronger Together community information sessions offered around the state for people with a disability, their families, carers and service providers. Various times and locations. Visit www.dadhc.nsw.gov.au

Other:

Carers NSW conference 2011. Changing Society, Changing Needs, Thursday 17th and Friday 18th of March. Brighton-Le-Sands, Sydney. Visit www.carersnsw.asn.au or contact 9280 4744.

Introductory Psychopharmacology, Tuesday 8th March 2011. Presented by Ian McGregor. Obtain specialised knowledge of key psychotropic medications. Sydney. \$300. Advanced Psychopharmacology, 10th May 2011. \$300. Email mentalhealth.trainig@wesleymission.org.au or contact Suzanne Wood 8922 9083.

AIS Special Schools Conference 2011: Planning for Success- Effective Processes in Inclusive Schools. 23rd and 24th June 2011. 9.00am- 3.30pm. Epping. \$330 for non AIS NSW members. Visit www.aisnsw.edu.au to register.

Challenging Behaviour:

Aspect Recipe for Success assists families to better understand and manage the challenging behaviour of their children in the home. 3 day course. Hornsby 31st May 1st and 2nd June 2011, Ballina 27th, 28th and 29th June 2011, Newcastle 26th, 27th and 28th July 2011, Goulburn 23rd, 24th and 25th August 2011, Tweed Heads 19th, 20th and 21st September, Cooma 1st, 2nd and 3rd November 2011, CALD TBA. Register online at www.autismspectrum.org.au or contact 6628 3660.

Making it Work: Implementing the Planning Process. This course examines the process involved in planning for students with learning difficulties, disabilities and challenging behaviours. 15th March 2011. East Wagga Wagga. 9.00-3.30pm. \$165. Register at www.aisnsw.edu.au.

Mental Health:

CHW Youth Health Forums by the *Centre for Advancement of Adolescent Health. E-Health: Connecting with Young People.* 16th March 2011. \$25 Mental Health and Young People, 8th June 2011, TBA. At Risk Young People, 31st August 2011, TBA. Visit www.caah.chw.edu.au/events/#forum for more details or contact Ken Yap on 9845 3338/0631

Mental Health Connect is essential training for those working with people with mental health issues. 4-5th of April Sydney, 16-17th March Orange, 3-4th May Newcastle, 2-3rd August Lismore, 21-22nd November Queanbeyan. Contact 9555 8388 ext 106 or email training@mhcc.org.au. This organisation will run courses in rural and remote regions by request.

Search more mental health courses at www.psychology.org.au

lamineate, cut-out and keep street safety cards...

These picture cards are from www.dotolearn.com and are not for commercial use. They can be used with students with or without the words written below! Enjoy! Share your similar resources with us; email schoollink@chw.edu.au



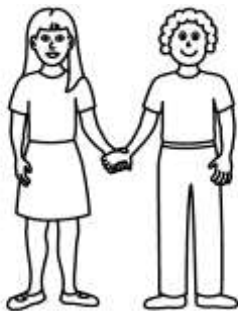
crossing



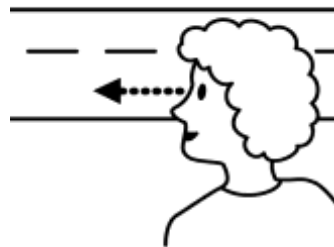
don't cross



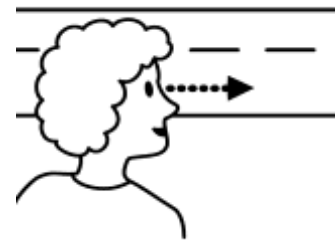
don't walk between cars



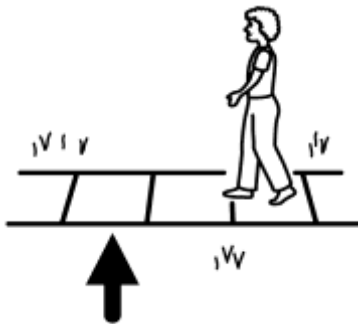
hold hands



look left



look right



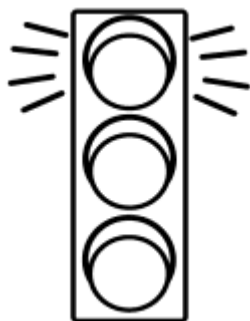
footpath



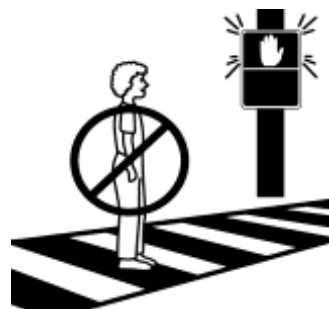
stop at street



stay in yard



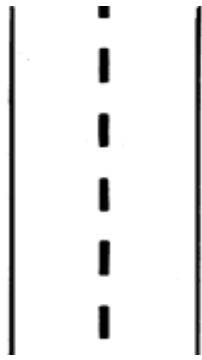
street light



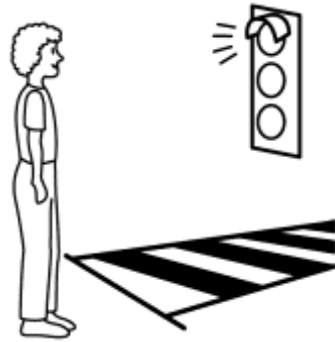
don't stop in street



driveway



street



wait for light



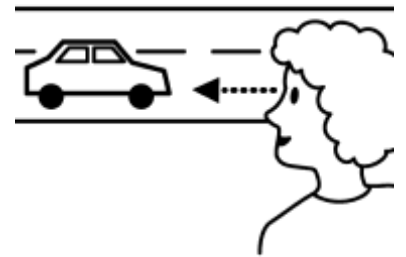
wait for walk sign



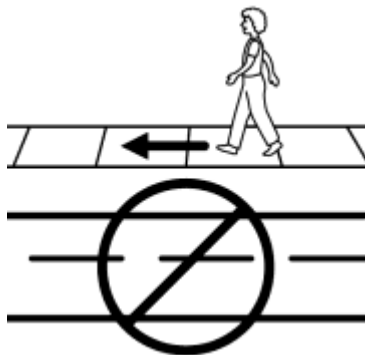
don't walk/walk



stop sign



watch for cars



walk on footpath



no crossing



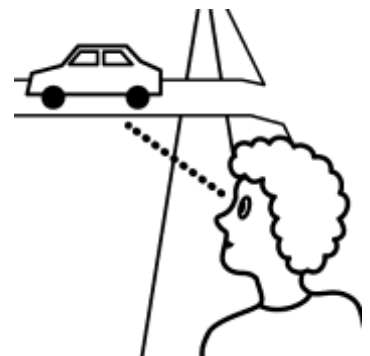
school crossing



pedestrian crossing



walk at walk sign



watch driveway

reading list...

ABS (Australian Bureau of Statistics). (2010). Disability, Ageing and Carers: Australia. Release number 4430.0. Accessed www.abs.gov.au Last updated 15th December 2010.

Latest statistics about disability, ageing and carers in Australia. Differentiates by restriction level.

Forster, S., Gray, K.M., Taffe, J., Einfeld, S.L. and Tonge, B.J. (2011). Behavioural and Emotional Problems in People with Severe and Profound Intellectual Disability. *Journal of Intellectual Disability Research*. Vol 55, Iss 2, Pp. 190-198.

Investigates the differences between severe and profound intellectual disability in the area of emotional and behavioural difficulties. Utilises the Developmental Behaviour Checklist.

Matson, J.L. and Shoemaker, M.E. (2011). Psychopathology and Intellectual Disability. *Current Opinion in Psychiatry*. Vol 24. Provides an update on recent trends and developments in the study of psychopathology in persons with intellectual disability. This is a North American paper that summarises assessment, treatment and challenging behaviours.

McConkey, R. and Collins, S. (2010). The Role of Support Staff in Promoting the Social Inclusion of Persons with an Intellectual Disability. *Journal of Intellectual Disability Research*. Vol 54, Iss 8, Pp. 691-700.

Compares individualised housing options and other options and their role in social inclusion of this population. Care tasks had a higher priority than social inclusion tasks.

Miller, C., Nguyen, N., and NCVER (National Centre for Vocational Education Research). (2008). *Who's Supporting Us? TAFE Staff Perspectives on Supporting Students with Mental Illness*. NCVER. Accessed www.ncver.edu.au/publications/1834.html

This report discusses the role of the professionals working with students with mental illness. It includes issues about learning with mental illness, support of these students, support of staff and the importance of mental health promotion.

Pragnell, S.J. (2009). Behavioural Interventions for Self-Injurious Behaviour: A Review of Recent Events (1998-2008). *British Journal of Learning Disabilities*. Vol 38, Pp. 259-270.

Discusses Self-Injurious Behaviour and people with severe learning disability and studies over ten years. Also touches on implications for research and clinical practice.

Preece, D. (2009). Obtaining the Views of Children and Young People with Autism Spectrum Disorders about their Experience of Daily Life and Social Care Support. *British Journal of Learning Disabilities*. Vol 38, Pp. 10-20.

An interesting article from the children's point-of-view about Social Care including children living at home and those in short term care.

resources...

- The Child Safety Commissioner of the State Victorian Government has created a good resource for teachers on trauma called Calmer Classrooms. Visit, http://www.ocsc.vic.gov.au/downloads/calmer_classrooms.pdf
- www.e-bility.com. This site offers easy access to a wide range of information, resources, services and products of interest to people with disability, their families and carers, health professionals and service providers in the disability sector.
- Making the Move: Information for families of children with a disability making the move from primary to secondary school. This information booklet is published by Human Services, Ageing, Disability and Home Care. To download, visit www.adhc.nsw.gov.au
- Autism and Aspergers Support Group Inc – Sydney. This group was formed in 1998 by a group of parents and carers of individuals with ASD. The group includes support group meetings, organised events and activities, social groups and a monthly newsletter. Visit www.autismsupport.org.au for more information and to become a member. There are two groups – Hawkesbury 0425 380 575 or Inner West 0425 380 574. They are also on Facebook and twitter.
- Tourette Syndrome Association of Australia has an education awareness program where they offer every school

in Australia a free DVD titled 'What is Tourette Syndrome?' contact info@tourette.org.au or call 02 9382 3726 to order your copy. Visit their website www.tourette.org.au for more resources and information about this syndrome.

- *NSW Suicide Prevention Strategy for 2010-2015: A whole of Government Strategy Promoting a whole of Community Approach*. This document was recently published by NSW Health. You can access the document and its implementation plan at www.health.nsw.gov.au/pubs/2010/suicide_ps.html.
- Early Days is an Australia-wide series of workshops for mothers, fathers and other family carers of children aged 6 years or younger who have recently been diagnosed with an autism spectrum disorder or are going through the assessment and diagnosis process. Workshops are available face to face, over the telephone or online. They are also available in five community languages. Visit www.earlydays.net.au or contact 1800 334 155.
- PlayConnect Playgroups help families with children with Autism Spectrum Disorders. These groups offer opportunities for ASD children to connect and share experiences. Contact 1800 171 882 or visit www.playgroupaustralia.com.au for more information.

the medicine cabinet: Risperidone...

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

George Liangas
Child and Adolescent Psychiatrist.

Risperidone and other atypical antipsychotics

Generic Name: Risperidone
Brand Names: *Risperdal, Ozidal, Resdone, Rispa, Rixadone*

Risperidone is an *atypical antipsychotic* medication. Its primary use is in the treatment of psychotic illnesses such as schizophrenia. It also possesses mood stabilising and relaxant properties, and hence it is used in a variety of other situations, including aggression. Other medications in the atypical antipsychotic medication class include olanzapine (Zyprexa), quetiapine (Seroquel), amisulpride (Solian), aripiprazole (Abilify), ziprazidone (Zeldox), paliperidone (Invega) and clozapine (Clopine, Clozaril). They differ somewhat in the way they work and their side effect profile. They are called *atypical* because they are newer and much different to the original antipsychotics such as haloperidol (Serenace) and chlorpromazine (Largactil), which are nowadays less commonly used.

Risperidone, and to a lesser extent the other antipsychotics may be used in children with intellectual disability for the following reasons:

1) Children with intellectual disability are more likely to have psychotic symptoms (eg. hearing voices or feeling perse-

cut) than other children. Rates of psychosis are less clearly known in children, but in adults, 3% of those with intellectual disability have a psychotic disorder, compared to 1% in the general population. Rates are likely to be less in children. Risperidone and other antipsychotic agents act directly on the brain to decrease psychotic symptoms.

2) Some children with intellectual disability and autistic disorders have troublesome symptoms such as aggression,

‘Teachers and other non-medical professionals can assist in the assessment and management of aggressive behaviour ‘

self-injury, explosiveness, overactivity, irritability and poor sleep. In some cases, **the child’s aggression may be related to their temperament or anxiety.** In other cases, especially in children with communication problems, aggression can be the means by which they communicate their wants, distress or worries (much like a crying baby). Some syndromes such as the Smith-Magenis syndrome are specifically related to aggression, and this is believed to be related to neurochemical abnormalities in the brain. Risperidone has been thought to manage these symptoms by decreasing **the body’s arousal.**

Risperidone comes in various forms, including a tablet, quicklet (a tablet that dissolves in the mouth) and liquid. The long-acting injectable form is not often used in this population. The oral forms are usually given once or twice per day, in the

morning and/or at night. The most common side effects of risperidone are weight gain and sedation. Less common side effects include dry tongue, a tremor, restlessness, and in pubertal females, menstrual irregularities. The side effects of the other atypical antipsychotics are similar, with weight gain and sedation being particular problems for some.

The use of atypical antipsychotics to manage aggressive behaviour in children with intellectual disability is a controversial area. Most clinicians would agree that in cases where the aggression is driven by psychotic or bipolar mood symptoms, prescribing these agents is entirely appropriate. In the other cases mentioned, the indication for medication is less clear. Most children with intellectual disability suffer other mental health problems such as ADHD, anxiety, depression and changes of mood which may indicate the use of other medications before considering an atypical antipsychotic.

In all fairness, in many of these children it is very difficult to ascertain what is driving the aggressive behaviour. Often it is a combination of factors. Hence, it is imperative for medical and other professionals looking after children on antipsychotic medications to look for contributors to aggressive behaviours, such as:

- Pain or other medical problems;
- Changes in medication;
- Changes in their environment, such as a change in carer or residence;
- Bullying by peers; or
- Stressors in the home environment.

Hence, use of these medications in these children should be accompanied by use of behavioural interventions and a supportive, nurturing environment. These may include:

- Modifying the environment to help make it feel safer;
- Applying consistent parenting/caring strategies so that the child feels more contained, whilst being encouraged to use more adaptive ways to express distress.

Teachers and other non-medical professionals can assist in the assessment and management of aggressive behaviour by looking out for contributors of aggression or distress, and by being part of the team that implements the behavioural interventions. Regular communication and thoughtful planning involving all agencies is hence imperative to optimally treat aggressive behaviour. The considered use of risperidone or related agents can be a useful adjunct in these cases.



shared care family support program...

REOPENED AND TAKING REFERRALS NOW

Shared Care Family Support (SCFS) is an ADHC funded pilot program in the Metro North Region, managed by Interaction Disability Services. The program, which was set up in 2007, closed for a short period this year, however has now reopened.

SCFS provides tailored support to families with children aged 6 to 15 years with an intellectual disability, challenging behaviours, high to very high support needs, who live at home and who are at risk of family breakdown.

A team of trained staff, including key workers, the Program Manager and Clinicians, work in partnership with children and their families/carers, to identify support needs and develop a plan to increase the capacity of the family as a whole. SCFS staff work closely with the family to provide a sustainable intervention whilst collaborating with other agencies and professionals working with that family.

The program provides a mixture of centre based and in home support and adopts a strong family centred approach to service delivery. SCFS aims to strengthen the skills and ability of families to respond to the changing needs of the child as they grow, and to build resilience through clinical intervention and case management.

Clinical Intervention:

- Behavioural assessment and intervention
- Assessment of attachment and separation issues and the emotional support needs of children
- Assessment and evaluation of family functioning and well being, as well as individual quality of life (pre and post measures)
- Family based intervention, including short term/crisis counselling and extension of services to siblings
- Carer training and support
- Psychometric assessment and mental health assessment and intervention
- Individual and/or group training

Case Management & Family Support:

- Comprehensive needs assessments
- Service Planning
- Implementation of Family Support Plans
- Navigation of support services, implementation and monitoring of support plans
- Advocacy & Support
- Planned Exit and Service handover to ADHC

SCFS also offers brokerage funding that can be used by each family to access specialist support, services, or equipment to meet the support needs of the child in accordance with family goals.

SCFS operates out of a residential facility located in the Castle Hill area, providing

support for up to 4 children at any one time. The facility supports the placement of compatible or priority groups (e.g. siblings, age groups) to ensure that individual needs are met. Each child has their own bedroom to help them feel a sense of security, safety and self-identity.

SCFS does not operate during school hours over the school term but does operate during school holidays. It is expected that children will continue attending school and transport to and from SCFS/school can be negotiated on an individual basis.

The program runs for a period of up to 12 months, commencing with centre based care and then progressing to a combination of centre based and in home support, before finishing with in home support only. Service delivery at the centre is very flexible and other arrangements for service delivery can be accommodated if overnight stays are not possible for the child.

Referrals are being taken **now** and can be made to ADHC Intake and Referral. For any further information about SCFS, please contact Program Manager, Lauren Neeves on 1300 668 123, or via email:

lneeves@interactiondisability.com .

Written by Lauren Neeves

SCFS Program Manager

17 February 2010 ●

Kidsmatter...

KidsMatter Primary provides a comprehensive framework for mental health promotion, prevention and early intervention for primary school aged children. The initiative promotes a whole **school approach to children's mental health** including those children experiencing mental health difficulties. This involves promoting partnerships amongst the people who have a **significant influence on children's lives** – parents, carers, families, all school staff, health and community services and the broader community.

In 2006-2008, KidsMatter Primary was successfully piloted in 101 schools across Australia. A comprehensive evaluation of KidsMatter Primary was conducted by Flinders University of South Australia. Findings showed that KidsMatter had a positive

impact on schools, children, parents and carers.

Whilst KidsMatter Primary adopts a whole school approach to support the mental health and wellbeing of all children; further analyses of the evaluation data was recently conducted, at the request of the South Australian Minister for Education, to understand the impact of KidsMatter on students with a disability. Approximately 11% of the total South Australian sample (N=494) had an identified disability with communication disabilities such as Autism Spectrum Disorder, the most common.

It was found that students with one or more disabilities had a higher chance of experiencing mental health difficulties than students without a disability.

The findings also suggest that KidsMatter Primary had a positive effect on students with a disability by strengthening their wellbeing and reducing mental health difficulties. The report is available on the KidsMatter website: www.kidsmatter.edu.au/evaluation/.

Under the "Taking Action to Tackle suicide" package, the Australian Government is significantly increasing funding for the initiative until 2014. This means that KidsMatter Primary now has the opportunity to support significantly more schools in working towards improving the mental health and wellbeing outcomes of their students.

More information is available on the website: www.kidsmatter.edu.au. ●

seminar review...

ARACY Access Grid Seminar:

Developing Indicators for Health and Wellbeing of Children and Youth with Disabilities.

Gwynnyth Llewellyn
24 November 2010

*Review by Jodie Caruana
School-Link Coordinator
The Children's Hospital at Westmead.*

An enlightening seminar was hosted by ARACY (Australian Research Alliance for Children and Youth) at Sydney University last November. Gwynnyth Llewellyn, Professor and Dean, Faculty of Health Sciences, University of Sydney presented on Developing indicators for health and wellbeing of children and youth with disabilities.

Professor Llewellyn noted that in 2003 there were 1 in 12 children (317,900) aged 14 and under in Australia who had a disability with about half of these children needing additional assistance with self

Dynamics in Australia (HILDA) for young people 15-24.

Professor Llewellyn discussed the results and the finding that disabled children and youth were significantly disadvantaged compared to their peers on the majority of indicators. Of particular relevance to School-Link were the health and safety indicators. Children with disabilities were more likely to have significant emotional or behavioural difficulties (OR: 3.38-3.84) and young people with disabilities were more likely to have poor mental health (OR=2.83) and be at very high risk of having a common psychiatric disorder (OR=4.39).

The second approach Professor Llewellyn outlined used two United Nations Conventions, the Convention on the Rights of a Child (CRC) and The Convention on the Rights of Persons with Disabilities (CRPD) as a basis for 23 indicators. Results highlighted that in using this approach there was an absence of consideration of fundamental individual rights, including experiences of equality, for example the ability to access appropriate health support.

'Collation of accurate health and wellbeing indicators of children and young people with intellectual disabilities is integral to ensure that policy makers provide the right services for this group.'

care, mobility and/or communication.

While a major research piece conducted by ARACY 2008 Report Card Australians, compared the well-being of young people in Australia with that of young people in other high income countries, Professor Llewellyn stated that it did not examine whether or not there were differences in health and wellbeing between children aged under 14 who had a disability.

To offset this non-representation two approaches were taken. A Disability Report Card was created using the same age-range (0-24 years), domains and, where possible, indicators used in the ARACY Report Card. This was achieved by using two data sources: 1)The 2005/6 wave of the Longitudinal Study of Australian Children (LSAC) for children at age 2/3 and 6/7 and 2)The 2007 Wave of the annual survey of Household Income and Labour

Professor Llewellyn concluded that the collation of accurate health and wellbeing indicators of children and young people with intellectual disabilities were integral to ensure that policy makers could provide the right services for this group. This can be achieved through collaboration across all sectors to identify potential data sources.

For further reading a literature review entitled *Indicators of Health and Well-being for Children and Young People with Disabilities: Mapping the Terrain and Proposing a Human Rights Approach* is available on the ARACY website:

http://www.aracy.org.au/publicationDocuments/Indicators_of_Health_and_Wellbeing_Literature_Review.pdf? ●



EBSST update...

Emotion-based Social Skills Training is a research-based program for young people with Autism and Asperger's Syndrome, their parents and teachers. Training of 64 DET school counsellors around NSW is now complete with EBSST being delivered to almost 400 students, their parents and teachers around NSW in 2010-2011.

Preliminary evaluation results of EBSST delivery will be available at the end of 2011. Emotion-based Social Skills Facilitator Training is now available for all clinicians through the Children's Hospital at Westmead.

Contact Phuong or Rebecca on 9845 2005 or www.ebsst.com.au for further details on EBSST Facilitator Training. ●

staying in: a day in the Hall Ward inpatient unit...

Zoe Quick
Clinical Psychologist, Hall Ward
The Children's Hospital at Westmead

The idea of staying in hospital, particularly in a psychiatric unit can be pretty **daunting (even as an adult)**. So here's to sharing some information that should make it all seem a little less scary!

Firstly, we are here to help. The vast majority of the patients that stay on our ward are voluntary. That means they have agreed to come in of their own accord. In fact, in special circumstances, some patients come back more than once.

Second, the ward is designed for children and adolescents! We even have our own school classroom which only the **Hall Ward patients attend. That means there's** a maximum of eight in the class. So patients need not worry about missing out on too much school work or about being overwhelmed by attending a large school. We also have a games room with a Wii, a large screen TV and a Playstation. But just like home, the patients only really get **to use these "toys" in free time when all** the work is done.

Every day we have a pretty similar routine. We know that simple and consistent routines can be very beneficial for children and adolescents generally. When going through difficult times with mental health issues these are particularly important and can offer a sense of calm and structure.

We have a great team of nurses who have a good knowledge and understanding of both mental health and paediatrics. Nurses get the patients up, help with breakfast in the dining area then get them ready for school (including any medications, observations and bloods required). Just like at home, patients are expected to shower and keep their rooms clean before heading off to school. Some patients have single rooms and some share. It really depends on ages and the mix on the ward.

Our school day is shorter than most and runs between nine and two. Class work **comes from each child's home school** so that kids can keep up with important work. The Hall Ward classroom also runs some of its own activities like craft and cooking. Just after morning tea the patients also have physio. We run physio for a couple of reasons. First, because our ward is small and is a locked unit (to en-

sure patient safety) it is nice to have some time out and a chance to let off some energy. Second, and more importantly, physio recognises the role of exercise in both our physical and mental health. Daily exercise is important for all of us!

After school we usually run a group. Patients are expected to attend groups as part of their therapeutic treatment. Some groups are psychoeducational. On Hall Ward these groups are typically based on special treatment approaches. Frequently we focus on Distress Tolerance and Mindfulness strategies. Other groups include leisure activities (designed to encourage good socialisation/peer skills), art and craft and therapeutic music groups. Therapeutic music groups are a particular favourite among the patients and are often also run on Saturdays!

After group it's time to relax and see Mum and Dad. Visitors are allowed on the ward between four and eight in the evening. We encourage all parents to visit their children regularly (if possible daily), as we see **the family as key to a child's recovery** and mental health and wellbeing. Some patients might have visitors on the ward while others may go out for dinner or even go home overnight if they and their families feel up to it.

At some point during the day each of the patients are likely to have some individual

time with one of our Doctors and/or Allied Health Staff. We have one Consultant Psychiatrist, currently Dr Lucy Chapman, and two Junior Doctors (a Registrar and a Resident). We also have a Social Worker, a Clinical Psychologist and an Occupational Therapist. Who the child sees and **how regularly will depend on each child's** individual needs, their care plan and where they are at in their treatment. Families are also expected to come in for regular meetings so that they can work

'We have a great team of nurses who have a good knowledge and understanding of both mental health and paediatrics'

together with the team to support their child for ongoing improvement. Some meetings may also involve the local Child and Adolescent Mental Health Service (CAMHS) who will be involved to support the child and their family once they leave the ward.

Then at eight-thirty it is time to head for bed. This might seem early, but these can feel like long days especially for patients who are unwell and working hard on getting better. A good rest is important to be able to help us prepare and face the next day. As any of us will know, lack of sleep equates to bad moods and poor coping and we are working against that!

And that's about it really. We take a wide range of kids with multiple illnesses and disabilities (however, all patients must be medically stable). We try to get patients **out as quickly as possible (and in fact it's** illegal for us to keep a child in if they can be treated in a less restrictive manner) so our average stay is usually about two to three weeks. Some might stay longer; some might stay shorter but remember, like I said first, **WE ARE HERE TO HELP.**

Please note admission to the ward requires a comprehensive mental health assessment within the 24 hours prior to admission. Parents, children, teachers and school counsellors should seek medical consultation with their GP or Community Mental Health Services as their first point of call. If you or your family are expecting an upcoming inpatient visit please phone the ward to organise more information and discuss the option of coming to see the unit. ●



reviews...



Book Review:

House Rules- Jodi Picoult

When a teenage boy with Asperger's is arrested for murder, his family face a daunting task to prove his innocence. Jacob Hunt is a teenage boy with Asperger's Syndrome. He's hopeless at reading social cues or expressing himself to others, and like many children with AS, Jacob has an obsessive focus on one subject - in his case, forensic analysis. He's always showing up at crime scenes, thanks to the police scanner he keeps in his room, and telling the cops what they need to do - and he's usually right. But then one day his tutor is found dead, and the police come to question him. Reluctance to make eye contact, stimulatory tics and twitches, inappropriate gestures - all these can look a lot like guilt - and suddenly, Jacob finds himself accused of murder. House Rules looks at what it means to be different in our society, and at the extremes of love and loyalty members of a family have to call upon to help each other overcome impossible circumstances.

Website Review:

Global Disability and Health Care Services is a leader in Health and Disability Recruitment. As well as offering work to suit individual needs this website also offers a link to a large online newsletter. The Global Gazette Disability and Ageing is an up-to-date service for all professionals working in the disability, Ageing and nursing fields. The gazette and website will keep you informed about any news or media releases in this field. They also include updates to policies, information on new books and give access to directories, newsletters and organisations. There are over 16500 subscribers, so get in the know! Look under education at

www.globalcarestaff.com

Organisation Review:

ARACY; the Australian Research Alliance for Children and Youth is a national non-profit organisation working to create better futures for Australia's children and young people. ARACY builds and supports collaborations of researchers, policy makers and practitioners across disciplines. ARACY hosts several events throughout the year, conferences and training with membership available to receive newsfeeds and newsletters. Visit their website for more information, current campaigns, access to their research network, publications and resources, discussion forums and much more.

www.aracy.org.au

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



ServiceLink is a comprehensive online directory of human services across NSW available free of charge to members of HSNet. The directory provides organisational and service information across a variety of sectors including health, welfare, community services, education, disability, aged care, legal and housing. ServiceLink aims to help front-line human services workers quickly and efficiently find information about the services available to assist their clients.

The information in ServiceLink is tailored specifically to the needs of service providers. Each record contains detailed information about organisations and their services, including:

- contact details
- intake, eligibility, referral and service setting information for each service provided

- maps and geographical coverage
- accessibility, parking and transport details
- opening hours

Members can search ServiceLink by keyword or with advanced filtering options such as service setting, target age groups, ethnicity or regional coverage. Services can also be found by browsing service types, life events or issues.

The aim is to help front-line human services workers quickly and efficiently find information about the services available to assist clients. You can Search by keywords or Browse by topics. The information in ServiceLink is tailored specifically to the needs of service providers.

ServiceLink is supported by an interactive online tutorial, available at the top right hand side of any ServiceLink page or from the Home page. The tutorial covers the use of the directory as well as making and receiving electronic referrals.

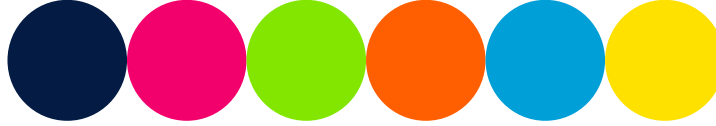
eReferrals

The eReferral component of ServiceLink allows members to make electronic inter-agency referrals. Enabled agencies can securely refer clients to other agencies and track the progress of their referrals.

Before members can make referrals, the HSNet team works with the network of organisations involved to establish referral protocols to define the process for sending and receiving referrals in that network. Workshops and training are available to establish and support the organisations in referral networks.

If you are interested in setting up an eReferral network, please contact HSNet at hsnet@hsnet.nsw.gov.au or on (02) 9228 4200. Please read the fact sheets on Developing an electronic referral network and Statement of Agreement for eReferrals

For more information visit www.servicelink.hsnet.nsw.gov.au



What is School-Link?

The NSW School-Link Initiative is a collaboration with NSW Health and the NSW Department of Education and Training (DET) that has been addressing mental health in schools since 1999.

The Children's Hospital at Westmead (CHW) has recognised the potential to further develop the existing School-Link Initiative by focusing on students with an intellectual disability.

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

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

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

in the news...

Building Better Lives

Monash University, 25th January 2011

Young Australians with an acquired brain injury are more disconnected from their communities when living in aged care nursing homes than group homes according to new research published by Monash University and Di Winkler -- Director of Building Better Lives. The study compared 128 people with acquired brain injury (ABI) living in 'group homes' in the community with 61 young people with ABI living in nursing homes. The study found that the two groups had a similar level of disability. However, compared to those in nursing homes, the people living in group homes went outside more often, participated more often in community-based leisure activities and visited friends and family more often. The productivity commission is due to make recommendations regarding a national disability insurance scheme in July 2011. For further findings visit www.buildingbetterlives.org.au

NSW Council for Intellectual Disability (NSW CID)

NSW CID www.nswcid.org.au

NSW Health has awarded \$415,000 recurrent to South East Sydney Illawarra Area Health Service to set up a new intellectual disability health service. This comes from the budget allocation in the current NSW budget and is a valuable step towards a state-wide network of intellectual disability health services. NSW CID and supporters are urging the government for more funding to services that are on the eligibility list.

Better Start for Children with Disability (Better Start) Initiative

FaHCSIA 31st January 2011

The Better Start for Children with Disability (Better Start) initiative aims to assist eligible children with developmental disabilities to access funding for early treatment, diagnostic and management services. From 1 July 2011, eligible children diagnosed with a sight or hearing impairment, Down syndrome, cerebral palsy or Fragile X syndrome will have access to funding and Medicare rebates under the initiative. The initiative includes the following components: 1) children under the age of six can register for access to funding for early intervention services and treatments and 2) Medicare rebates for the development of a treatment and management plan for eligible children under the age of 13.

Subscribe to our E-list!

Visit our website and fill in your details at

www.schoollink.chw.edu.au

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

School-Link Conference

Mental Health and Intellectual Disability

Learning and Growing Together

May 27th, Liverpool Catholic Club. Registrations open March 14th, visit www.schoollink.chw.edu.au/conference

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

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

contact us...

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