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# mental health and intellectual disability...

*Link*

## coordinator's message...

Welcome to the first issue of our newsletter for 2012. This marks our third volume and seventh issue since 2010. CHW School-Link has been preoccupied with numbers lately. The end of 2011 was an opportunity to reflect on the three years since our inception and record our achievements in a mid-term report. So here are a few of our achievements since 2009:

- 1 scoping report, 1 website and 1 joint School-Link conference
- 2 school counsellor supervision pilots and 2 babies (Hebah's girl, my boy!)
- 3 schools participated in our 2011 Stepping Stones Triple P Pilot
- 4 School-Link employees, Jodie, Hebah, Alison and Helen
- 5 hundred e-list subscribers
- 6 thousand exposures to our awareness raising of children and adolescents with MH+ID.

We will be posting the report on our website shortly. Many thanks to our collaborative partners at DEC and ADHC whom make our work possible and enjoyable.

It is with great pleasure that we will no longer need to write a midterm report as the School-Link Program across New South Wales has been granted ongoing funding by Mental Health and Drug and Alcohol Office and commitment from our partners. We will of course be writing reports to capture our progress with a name change.

In this issue we are reminded of the critical role that families and peers play in the lives of all children, and ever so of children and adolescents with an intellectual disability. Dr David Dossetor from the children's hospital at Westmead writes about this in his feature article where he describes how poor peer relationships is the best single predictor of mental health as an adult. We are very excited to be publishing a short story "Sometimes Miracles Work" from Vivian Tran, who received a special award from The Children's Hospital at Westmead for her entry into the young writers Transcribe 2011 competition. Her story describes her journey as a sibling of a boy diagnosed with Autism. Barbara Fleming from DEC writes about a Siblings Australia resource and how she has used this in her school with parents.

Kim Eisler from Justice Health writes about their School-Link Initiative and why school matters to young people in contact with the criminal justice system. Judy Longworth from The Children's Hospital at Westmead discusses obesity and how medications can affect weight.

My school-link colleague and editor Hebah Saleh has listed the latest invaluable resources, reading lists, reviews, and training which should keep you busy until our next edition. ●

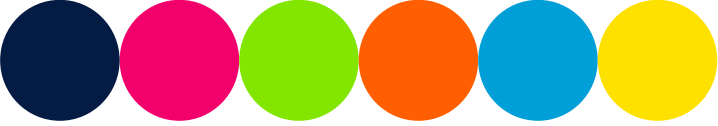
Happy Reading!

Jodie Caruana, School-Link Coordinator, [jodie.caruana@health.nsw.gov.au](mailto:jodie.caruana@health.nsw.gov.au)

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



## a note from David Dossetor...



### Mental Health Problems: Disorders of Social Development caused by Maladaptation's of 'Theory of Mind'? A Developmental Psychiatry View.

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

#### Introduction

This article describes a way of reconceptualising mental health disorders and illnesses, based on observations from working in children and intellectual disability and autism. It proposes that by approaches to understanding the way the mind develops in childhood, without detracting from current scientific knowledge, we can re-frame adult mental health problems as maladaptive processes of the social development of the human brain, mind and spirit.

#### Measuring the modern mental health epidemic

Mental Disorders are the growing health epidemic of the modern world. Across the developing world as well as the developed, the burden of health is due more to conditions that cause disability than due to 'years of life lost' (measured in Disability Adjusted Life Years {DALYs}) (Gore et al, 2011). The top ten causes for those 10-24 years are: (% of DALYs accounted): 1. depression (8.2); 2. unintentional injuries (accidents) (5.4); 3. schizophrenia (4.1); 4. bipolar disorder (3.8); 5. violence (3.5); 6. alcohol use (3.0); 7. HIV/AIDS (3.0); 8. self-inflicted injury (2.8); 9. tuberculosis (2.6); 10. lower respiratory tract infections (2.6).

In Africa the top ten list includes for girls abortion (3.7) and maternal sepsis (2.7) and for boys aged 20-24 war (2.7)! Neuro-psychiatric disorders are the main cause (45%) of years lost to disability in all countries. Unintentional injuries (eg RTAs) are second (12%), except in the Americas where it is self-injury and violence.

This list of health problems does not reflect the priority of focus of the health system. Of this list, the infectious diseases of HIV, tuberculosis and respiratory infections reflect the traditional activity of the health system and account for 8.1% of health burden. Depression, schizophrenia, bipolar disorder are considered mental health problems accounting for 16% of the burden of health, but accidents, violence, self inflicted injury and alcohol use which is the second biggest group (13.7%) are more likely to be seen as social problems. Public health considers prevention of accidents, and excessive alcohol use as recognised and considered in addiction medicine services; violence is dealt with by the justice system and self-injury by acute response services.

#### Different concepts of mental health and mental illness.

Currently the diagnostic and statistical manual for mental health disorders (DSM-IV) is undergoing a revision which illustrates that our definition of mental health disorders is evolving. Child mental health includes the above social disorders in their definition of psychiatric disorder: (ie any disorder of emotion or behaviour that causes addition handicap or impairment to self or carer) and is derived from an epidemiological approach to child wellbeing. Adult mental health has a more

strictly limited illness model, derived from its origins of studying mental disorder in asylums and emphasises the biological vulnerability of those who end up being unable to fend for themselves. One reason for the dominance of the adult definition is that mental health disorders are still stigmatised and substantially under funded compared with physical health services and mental health services which have to be highly restrictive in service provision. Ultimately in a capitalist system, it seems the cost to the economic efficiency of our society will become a primary driver for considering and redefining mental health disorders.

The developmental psychiatry of children and adolescents with and without intellectual disability contributes to the conceptual framework for understanding mental disorders. In childhood, poor peer relationships is the best single predictor of mental health problems as an adult. This is the measure of a school-aged person's ability to make new attachments to age related peers. Traditionally, the two main problems are those kids with internalising problems which make them too anxious to get close to others, and those with externalising problems where their antisocial skills lead other children to reject them. Extremes in both deviations have long term risk of adult mental health problems. It is evident that the establishment of maladaptive emotions or behaviour reflects or affects the adaptive skills necessary for the development of new age-related attachments. The emphasis on developing mental health services for youth may reflect the time of onset of the major mental health disorders, but the genesis of this burden of adult mental health problems is likely to be due to a failure to intervene in the extreme maladjustment in childhood (Ferguson, 2009).

The third childhood group is those who have the developmental delay problems



of Autism and/or intellectual disability which impairs the development of the skills for making peer relationships. In this framework, child mental health disorders can be divided into *General Disorders of Social Development* where the problems appear to be secondary to other emotional/behaviour problems and *Specific Disorders of Social Development* in which problems of social development are the result of problems of biological development. Indeed, the American committee developing the 5<sup>th</sup> Edition of the Diagnostic and Statistical Manual (DSM) is debating whether Specific Disorders of Social Development would be a more socially acceptable, if not more appropriate term for the Autistic Spectrum Disorders (Susan Swedo: personal communication).

### Neurobiology versus emotional stress in mental illness

In the last decade, mental health research has focused on the biological vulnerability that underlies mental illness, with the dramatic growth of genetics, neurobiology, neuro-imaging and psychopharmacology. These are exciting developments towards our understanding of the human predicament, but the current emphasis on neurobiological research is at risk of neglecting the importance of relationships and the emotional environment. It is worth recalling that the genetic risk of schizophrenia is as great as that for tuberculosis. Indeed, genetic vulnerability plays a large part in a lot of physical health conditions, including tuberculosis. Although the tubercular microbacterium is readily identifiable, and genetics influences vulnerability, a number of environmental factors also influence outcome, such as nutrition and housing. In schizophrenia there are methodological limitations to the reliability of identifying and intervening in the quality of relationships and other emotional stresses (Dossetor, 2011). Nonetheless these factors are central to understanding mental health and illness. For example, although schizophrenia has a similar incidence in all cultures, the recovery and relapse rate is predicted by the quality of relationship with the next of kin. The rates of recovery in rural India are better than those in urban India which are in turn better than the urban developed world and reflect the **quality of relationship or rates of 'high expressed emotion' in the next of kin** (Bhugra & McKenzie, 2003). The influence of **'expressed emotion' on outcome** is greater than the effect of medication. Research has shown that the presence of **'expressed emotion' has a similar detrimental influence on the progress of all mental health disorders** (Hooley, 2007).

### Autism and Schizophrenia

Autism used to be called childhood schizophrenia, until the age difference of the course autism and schizophrenia were described by Kolvin (1971). However, the debate on how often schizophrenia occurs in autism has highlighted how similar they are phenomenologically and the lack of a reliable discrimination. They both have thought disorder (delusions) and they both have problems identifying influence as coming from inside their mind versus outside their mind (hallucinations). They also both lack emotional recognition. These features are present from early childhood in autism whereas in schizophrenia they are of later onset (Starling & Dossetor, 2009). The genetics research shows significant overlap of the genetic risk and neurobiological research indicates similarities of under-connectivity of the "social brain": superior temporal sulcus, amygdala, orbital frontal cortex and fusiform gyrus (Pelphrey et al, 2011). Both patient populations have very low self esteem and they both lack a capacity **to see things from someone else's perspective** (insight). They are fundamentally disconnected in their sense of otherness which is the fundamental quality of **'theory of mind'**. **Increasingly, schizophrenia** is described as a developmental disorder, and the main early predictor is problems of social relationships, indicative of a predisposition of problems of social reciprocity.

### Theory of Mind and human connectedness

Theory of mind is the ability to attribute mental states: beliefs, intents, desires, pretending, knowledge, to oneself and others and to understand that others have beliefs, desires and intentions that are different from one's own. Theory of mind can be seen as the quality that is central to being human and part of cognitive development and related to skills of empathy. Theory of mind is a theory insofar as the mind is not directly observable (Baron Cohen, 1991). The philosophical and scientific assumption is that others have a mind which is intuitively attributed **through the awareness of one's own mind**. However, it is experimentally testable as demonstrated in the development of 3 year old skills of appreciating false belief **in another (eg tested by Sally's Marbles paradigm)** and leads on to the ability to attribute knowledge and mental states to others. An infant's understanding of attention in others is a social skill found as early as 7 to 9 months of age, and is necessary for joint attention which is a "critical precursor" to the development of theory of mind (Baron-Cohen, 1991). Such "proto-declarative pointing" to appreciate

the directed attention and interests of another, imitative experience and understanding of others' intentions may be the underlying motive behind all human communication but develops in complexity over many years with social and other experience.

It is the development of theory of mind that is specifically delayed in development in autism and as described above is lost in acute schizophrenia. The development of theory of mind has also been recognised in traditional literature as the development of the human spirit, which is prized as the essential quality of humankind (Watts, 2011). Thus the development of theory of mind, the sense of otherness in normal childhood development, which correlates with a capacity for social reciprocity and skills to play with another, is seen in the years between 18 and 36 months. It is the start of the skills of shared thinking and imagination. In this developmental stage, the focus of mental interest and energy shifts from a preoccupation with primary processing of sensory stimuli to a dominance of awareness of the internal world of the mind and imagination in relation to a social and relationship world. The related skills in social attribution, second and third order theory of mind, which leads on to the skills of collaboration versus the competition of bluff and counterbluff, are further studied in the skills of social intelligence and game theory. These are the attempts to measure the cognitive skills which underlie educational, economic, social and cultural development. Game theorists describe community leaders working in sixth order theory of mind (Hargreaves Heap & Varoufakis, 1995).

### Maladaptation of theory of mind and mental health problems

Research into cognitive ecology adds to this picture. In this context, people with anxiety and depressive disorders have maladaptive thinking processes which perpetuate their mental disorder and associated social impairment. Such measurement and description can also be seen as maladaptions of the development of the theory of mind and understanding of human social connectedness. Cognitive Behaviour Therapy enables the patient to use scientific method to challenge these maladaptive assumptions of mind. Bipolar Disorder also has acute loss of emotional recognition in the same way is described in schizophrenia. Accordingly, maladaptions of theory of mind provide a unifying concept that underlies all mental health problems. They all have common elements of stress impacting via the social brain. They represent problems of our

understanding of otherness and connectedness with other people.

### The social power of professional healers

Cross cultural studies of mental health healing, despite large disparities of approaches and allocated clinical consultation time in the different cultures of China versus Canada, show similar sorts of outcome (Kirkmayer, 2006). One significant therapeutic contribution is the validation of the sick and disabled role for the mentally unwell patient in their family and social context. This enlists a change of social status requiring emotional and practical support during their period of recovery and possibly extended convalescence. This change of role no doubt has an effect on the quality of relationships and even impacts on the 'expressed emotion' of the next of kin. The Fort Bragg Studies of child mental health services showed something similar. Child mental health services have a huge effect on diminishing mental health symptomatology, but the academically prestigious service was not significantly better than the standard community based service. Further, most of these childhood mental health disorders continued to improve over a 9 month period (Bickman, 2000). On standard measures, their scores of social and emotional dysfunction regressed towards the mean. This may suggest that even in issues of mental health, with support, children become more adaptive and become more like the mainstream population.

Part of the role of the therapist is to use his **healer/doctor authority to shift a family's** approach through a medical understanding of the mental disorder. This involves validating the illness process, maladaptive emotional stress and damage to their theory of mind, which in turn affects their functional connectedness especially with their primary relationships. The patient receives a sick role, and attention given to stress factors which thereby enables supportive recovery processes to these mental emotional deviancies, often with the aid of medications to lower one or other of the arousal systems. This in turn allows a complex supportive social recovery process leading to the recovery of their theory of mind, sense of otherness and social connectedness whereby they can resume their social roles. For mental disorders, these processes often take months and sometimes years, especially for the severe mental illnesses, whereas the social expectation of physical illnesses is that they are generally recover in days to weeks.

### Development and health of the mind: biology and environment

It is the study of the delay in the development of the mind as seen in those with Autistic Spectrum Disorders and Intellectual Disability that provides the opportunity for scientifically understanding the developmental sequences and developmental nature of the growth of the human mind and our social connectedness.

We all too readily assume that it is a fundamental quality of being human to have a spirit. While that potential may be part of being human, clearly its development can be delayed, or harmed at different stages in life. The studies in the infant **show how awareness of the infant's own** feelings and theory of mind only develop by the matching and reinforcing of behaviour and moods by a caring parent (Sleed & Fonagy, 2010). That is to say, by identifying and matching mental states in a sympathetic parent/carer a child develops awareness of their own mind.

The importance of early childhood environment is well established for mental health disorders. For example, the empirical evidence shows the best prevention of mental health problems in children and young adults is dependent on improving the quality of parenting for both emotional and disruptive behaviour problems. There is a growing area of research describing how a lack of emotional attunement seen in disordered parenting and attachment disorders distorts the process of emotional recognition and response. This is thought to be the mechanism behind what **is called a lack in 'mentalisation skills'** described in some disturbed and poorly functioning personality disordered teenagers. Accordingly, lack of early parent-child attunement leads to a young person developing long standing problems of relationships and emotional/behavioral regulation through a disordered theory of mind. Developing therapeutic skills to help these young people whose early experience has damaged their social and emotional potential is a worthy challenge (Bateman & Fonagy, 2008).

The measurement of social connectedness and understanding in adulthood is deemed part of social and economic science and as such is complex and disputed. However, growing evidence on the social environment of schools indicates that it has a major impact on the mental health and wellbeing of their students both through the development of intellectual skills and their social and emotional literacy. There is also growing appreciation on the influence of the culture of peer relationships and its influence on mental

health, this includes school features that enable a sense of belonging and protection from bullying.

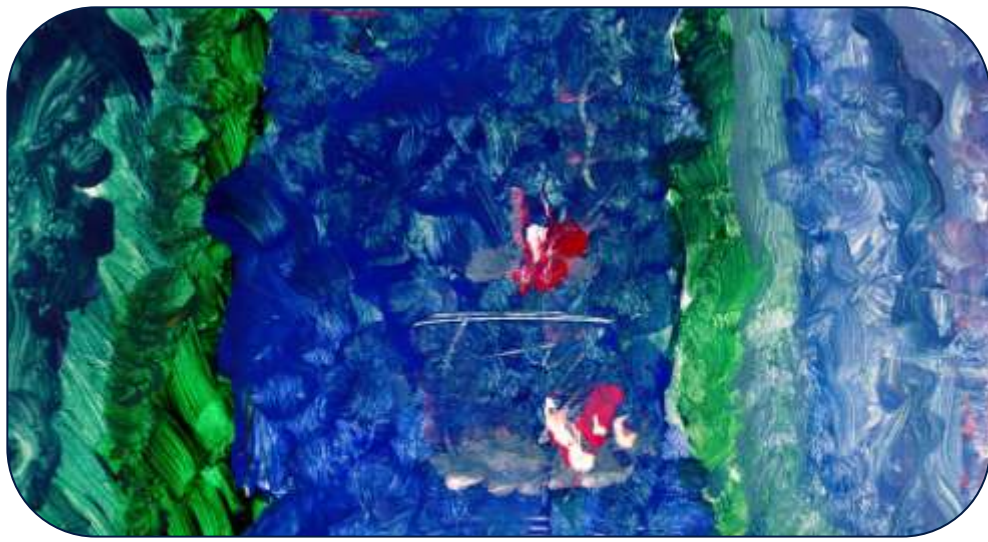
The idea of environmental impact on the wellbeing of theory of mind makes some sense of why a range of broader measures such as unemployment, housing, and social capital have a big impact on a **community's mental health. Relative inequity** in the western world is becoming a primary driver of the mental health and social problem epidemic. Wilkinson and Pickett (2006) ascribe this growing issue to the problems of human trust in less equitable societies that affects both the rich and the poor.

### Conclusion

In writing this article, I do not want to diminish the importance of medical and psychological research to help understand and help mental disorders and illnesses. Indeed as the world is becoming a more competitive and economically disparate place, skills to treat and prevent mental breakdown and build resilience, for example as measured by community rates of personal flourishing (Seligman, 2011), become more important. With the growing **emphasis on "positive psychology"** the approaches for preventing and treating mental health problems have increasing overlaps of teaching skills of personal cognitive, emotional and social understanding and effectiveness. Our own research on teaching emotional literacy skills through a specialised program for ASD finds developing emotion and social skills leads to improved social communication and relationships and improved mental health (Ratcliffe et al, 2012).

The developmental qualities of the mind **and the ways the mind's capacities are** damaged under stress and recover with therapeutic process is insufficiently appreciated in specialist mental health services. Recognising a societal communality of mind can support ethical and humane approaches to both mental illness and mental health.

The importance of a unifying concept of mental health and ill health is to make all responsible adults in our society and, especially parents and others that work with children, more aware of how they can contribute to the prevention, promotion and **treatment of other's mental health. The** promotion of mental health, the prevention of mental health problems and the treatment and recovery of social and mental health problems are all affected by relationships and other stresses and can be helped by supporting the recovery and growth of the skills of the human spirit



and our sense of connectedness in all its manifestations. This will apply to struggling with obesity in a youngster, the anxiety and tantrums in a young person with Autistic Spectrum Disorder, the disruptive or self-injurious behaviour in a teenager, the violence and substance abuse of a homeless young adult, or the recovery process of someone who has become alienated by schizophrenia.

The priority of mental health services may be to deal with those acutely affected by psychosis, or who need protection because of a loss of their ability to keep themselves safe. However as a society we all share responsibility for caring for the disaffected, alienated and dispossessed and how our society attempts to support or obstruct their re-integration. The development of such a linking concept is part of the empowering process of the modern world: understanding the way we are all connected. In Australia there has long been a call to have a ministry of children, so that both state and federal governments consider the impact of all policies to the future of wellbeing of children and our future population. They **don't vote, they are vulnerable to the behaviour of adults and societal change** and on many measures are doing progressively less well, despite our times of affluence (Stanley et al, 2005). Promoting their wellbeing is critical to the future of this country. If we are to take seriously the future mental wellbeing and therefore health of our population, the political leadership of the country also needs to put similar processes in place for all those with chronically disabling conditions including mental health. Such a framework helps us understand the links of healthy lifestyles and health giving society to improve mental health, as recently established in a new ministry by the NSW government. Can such good intentions complemented with the building of adequate

specialised mental health services change the course of the epidemic of mental health and social problems in Australia? ●

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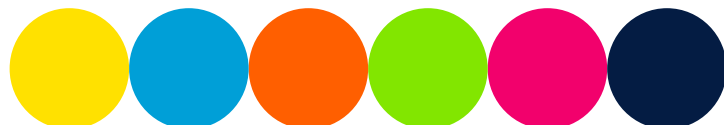
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# Fragile X ..

Adapted from the Fragile X Association of Australia Website [www.fragilex.org.au](http://www.fragilex.org.au). Accessed 11th January 2012

Fragile X Syndrome is the most common cause of inherited intellectual disability and the most common known genetic cause of autism. It is a condition which can have impact on individuals and families in various ways and degrees of severity. Fragile X is found in all races and at all socio-economic levels. Latest statistics indicate 1 in 3600 males and 1 in 4000- 6000 females are affected and that approximately 1 in 260 females are carriers. Every week in Australia one child is born who is fully affected and twelve children are born who are carriers.

The name of the syndrome comes from its location on the X chromosome. Under particular laboratory conditions, the bottom of the long arm of this chromosome can appear broken or fragile. It has been estimated that, worldwide, 50% of people affected by fragile X have not been correctly diagnosed. Diagnosis of Fragile X is achieved through DNA tests. There is currently no cure for Fragile X. However, special therapies, methods of teaching and medication all provide real benefit to people with the syndrome and help them perform the best they can.

## Behaviour

It is important to understand the behavioural and emotional effects of the syndrome, as they can be as significant as developmental delays. Because people with fragile X syndrome look much the same as others, their behaviour problems can be misinterpreted.

Almost all people with the syndrome have trouble self-regulating their behaviour. This shows up in problems such as:

- Attention deficit disorders and hyperactivity – which can impair learning
- Repetitive behaviours
- Late toilet training
- Disturbed sleep
- The inability to control emotions
- Lack of control of emotional behaviour can result in tantrums or other emotional outbursts.

Both males and females:

- Find concentration difficult.

- They may be quite severely hyperactive and impulsive.
- They may have fixed interests in objects and
- They can strongly dislike any change in routine.

Some behaviours, most obvious with males, is similar to autism. For instance,

- Children can refuse to be touched or held.
- There can be difficulty with making eye contact.
- Hand flapping is often found, which becomes more vigorous when the person is anxious or excited.
- Some people bite their hands or chew their clothing. This can be a way to calm themselves.

Females with fragile X:

- May be shy and moody
- Lack social skills
- May avoid social contact
- They can suffer from depression and severe anxiety.
- Refusing to talk in certain situations (selective mutism) can be exhibited.

Despite the behavioural challenges outlined, people with fragile X often enjoy being social, have pleasant personalities and a good sense of humour.

## Development

Intellectual disability is the most significant characteristic of those with Fragile X. Most males and approximately two thirds of females exhibit some intellectual disability. This is usually accompanied by poor fine and gross motor skills. The range of learning problems is wide. Some are affected by minor developmental delays. At the other end of the scale there can be severe intellectual disability. Most affected males fall somewhere in the middle. Males typically appear more severely affected than females. However, parents and educators are often surprised at their achievements.

Females appear less affected. However, they may experience difficulty with math and tend to suffer from a range of anxiety disorders including social anxiety.

## Weaknesses

- Short-term memory
- Auditory-only processing
- Abstract concepts
- Sequencing, praxis and

planning

- Fine and gross motor
- Perceptual, visual motor
- Social, language, semantic-pragmatic
- Attention and initiation

## Strengths

- Learn visually e.g. pictures, computers
- Whole word, number and pattern recognition, 'gestalt' learning
- Long term and incidental memory
- Concrete, relevant tasks
- Strong imitation skills, drama
- Good functional life skills
- Friendly, good sense of humour

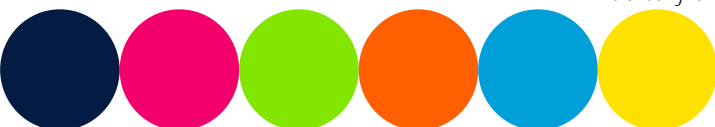
## Appearance

There are some of the physical features common to many, but not all, people with Fragile X syndrome. Even if present, the degree of visible effect varies from person to person. The features are more common in males than in females and are seen in approximately 50% of individuals

- The ears may be prominent.
- There may be a high forehead and/or long jaw, making the face look long, although this is often not apparent until puberty.
- Eye & vision impairments may cause a squint or turn in the eye which may only be apparent when the eye is stressed, for example in strong sunlight.
- Eyelids can tend to puffiness
- **The chest may have a "hollow" look**
- There may be a single palmar crease
- Flat feet (pes planus) may be evident
- A high arched mouth palate may be present
- Low muscle tone and hyper-extensible joints can cause awkwardness of movement and a "double jointed" look
- Large testicles (may be evident after puberty)
- The skin can be especially smooth and soft.
- Growth patterns indicate that children with Fragile X, especially males, are of average height or tall while young, but tend to be average once they are adults. These features are more common in males than in females and are seen in approximately 50% of individuals.

## Genetics

A change in a gene is called a mutation. Some mutations have no effect, but others, such as in the FMR-1 gene, cause changes in the structure or function of our bodies.





In front of the FMR-1 gene is the DNA sequence 'CGG'. This sequence is normally repeated between 6 and 50 times. In some people, this sequence is repeated between 50 to 200 times and is called a premutation, which generally causes few or no symptoms of fragile X syndrome.

In a woman with the premutation, the size can expand to over 200 repeats when that X chromosome is passed on in her egg. This is called a full mutation. In the full mutation, the gene for FMR-1 switches off and no protein is produced. Fragile X syndrome is the result. The expansion does not occur from males to their children. Males with the fragile X gene will pass that X chromosome without a change to all of their daughters.

### Medical Issues

People affected by Fragile X syndrome have a normal life expectancy. They do not suffer from major medical problems because of the syndrome and thus are generally healthy. However, there are some medical factors which may be more common in those with fragile X syndrome.

#### Common Medical Issues:

- Problems with connective tissue can lead to flat feet and low muscle tone.
- Eyelids that tend to puffiness and chests with a 'hollow' look are features which probably also relate to this problem.
- The joints are often extremely flexible and may be subject to dislocation.
- Hernias are sometimes present.
- Children, especially boys, are particularly prone to ear infections (otitis media). It is very important that every occurrence of ear infection is treated quickly, as problems in speech and language can be increased if there is even a slight temporary hearing loss.
- Eye problems can include squint (strabismus), long sightedness and visual perceptual problems.
- About one in four people with fragile X have epilepsy which can be generalised

or focal (grand mal, petit mal or absences, or complex partial seizures). Seizures usually begin in childhood or adolescence and are not frequent, often being outgrown before adulthood.

- A few people have heart valve problems (mitral valve prolapse), which may show up in late adolescence to early adulthood. Hence annual medical review is recommended.
- Many boys develop enlarged testicles (macroorchidism) after puberty, but this does not seem to pose any medical problems.
- Women with the premutation can have premature menopause. In extreme cases this can occur in the early twenties.
- FXTAS: Some male carriers, very often grandfathers of children with Fragile X Syndrome, may suffer from FXTAS (Fragile X-associated tremor/ataxia syndrome). This is a neurological disorder which can cause progressively worsening tremors as well as balance and coordination problems, cognitive and psychological changes.

### Sensory Issues

People with fragile X have difficulty in sorting out and screening all the messages that come through their senses. They are extremely hypersensitive to their environment. The problems they have in sorting sensory information are called 'sensory integration deficits'. These characteristics can increase learning and behavioural problems, as all sensations are received in an extreme form. They may have a negative response to situations that seem normal to others. Such situations include reactions to unfamiliar or strong smells, refusing to wear tight clothing, or clothing made of a rough fabric and being extra sensitive to bright or flashing lights. They are often disturbed in areas of high ambient noise, such as shopping centres and other crowded locations.

People with fragile X may not be able to communicate what is upsetting them. It is important for carers to know about this sensory integration problem. This response to sensory overstimulation has been called 'sensory defensiveness'. Individual programs, usually involving commonsense ways of organising and reducing environmental stimulation, can be planned to lessen the reaction. For instance, noise which is sensed as too loud, lighting which seems too bright and hypersensitivity to certain types of clothing can all be changed.

Occupational therapy with a sensory integration focus can lessen a person's sensory defensiveness.

### Speech

Most males exhibit delayed speech as children and poor command of spoken language. Some are inhibited when they do begin to speak.

#### Common speech characteristics:

- The rhythm of speech may be uneven or be fixed in a chant-like pattern.
- The automatic use of known phrases is common.
- Speech can be very fast and others may find it difficult to understand.
- Males with fragile X often continually repeat words and phrases (perseveration).
- Echoing the words of others (echolalia) is another problem.
- Males can speak constantly and inappropriately about a single topic.
- There are often problems in the use of expressive language, that is, in conveying thoughts to others.

On the positive side, vocabulary can be within the normal range. Some children verbally imitate others extremely well; this can become a helpful learning tool. Speech and language pathologists can assist in encouraging people to communi-

cate, and in improving the speech of older children and adults. For non-verbal individuals, augmentative communication systems, such as visual aids and signing, may be introduced. As with all helping techniques, the earlier the therapy begins the better.

## Education

Education is available for people with Fragile X at all stages of their development, from pre-school to the end of high school. Post-secondary education is an option for some. Children with developmental delay can be helped with early intervention even before a diagnosis is made. The earlier that this intervention can be included into the child's learning pattern, the better the results later on.

### Teaching Recommendations:

- Establishing structured routines
- Making careful preparation for changes
- The use of calming techniques and the elimination of distractions.
- **Being able to see 'the whole picture'** of what is going to happen, for example knowing in advance the full schedule for the day's schooling.
- Placing them with good role models in the classroom, wherever possible, as they are excellent imitators.

Pre-school and school teachers should be encouraged to work with the particular strengths of those with Fragile X.

### Strengths:

- They generally have very good long-term memories.
- They tend to learn visually. Use of pictures

can be very helpful, and illustrated social stories can assist with behaviour.

- A particular strength of many students with fragile X is their computer skills.

## Therapy

### Sensory Issues

Sensory problems are common particularly in boys affected by Fragile X. An excess of stimuli coming in through the senses can cause stress, anxiety and problems with concentration and behaviour. This sensory defensiveness can, in turn, result in a lowering in performance in other areas of development and learning. There are many strategies that can be used to alleviate such sensory challenges. Occupational therapists with sensory integration knowledge can work with the child and advise parents and carers of methods they can use themselves on an ongoing basis.

Sensory integration involves the ways we process and make sense of information coming in through each of our 5 senses. People with Fragile X, especially males, may be hypersensitive to sounds and noises, smells and tastes may be too strong for them, touch too intense and visual stimuli too much for them to process efficiently. In some cases the opposite may be true: they are hyposensitive and not getting enough stimuli.

A number of calming techniques can be used to reduce anxiety, to improve concentration and learning, to prevent inappropriate behaviour and enable the child to get used to his surroundings. Methods include massage, skin brushing, deep pressure, wearing weighted vests, the use

of equipment such as swings, mini trampolines and therapy balls and specially made objects to chew on.

Reducing strong stimuli that causes distress or preparing children in advance are other techniques that can be used. For example: removing fluorescent flickering lights, keeping noise levels down, using earplugs, giving the child a break or time out can reduce their stress. Explaining in advance in a way they understand can help prepare them; the use of homemade photo books is often recommended. Physical activity can improve sensory integration skills by giving a child practice. ●

You can learn more about Fragile X on the Fragile X Association of Australia Website. Visit [www.fragilex.org.au](http://www.fragilex.org.au)

You will find information about

- Clinics, Testing, Treatment and Counseling around Australia
- Resources
- Support for families
- Links to more information about Fragile X and related issues
- Membership
- Fundraising
- Forums



## resources...

- **The Nest** is a national plan for child and youth wellbeing by the Australian Research Alliance for Children and Youth. The Nest will involve an evidence review, national public consultation and a national action plan. You can find out more [www.thenestproject.org.au](http://www.thenestproject.org.au).
- **Book in Hand** is an Australian bookseller that focuses on books and resources for the ASD community. You can sign up to their e-list at [www.bookinhand.com.au](http://www.bookinhand.com.au).
- A new web resource for indigenous social and emotional wellbeing workers is now available on the **Australian Indigenous Health/foNet** website. The web resource provides free online access to Indigenous publications, resources and mental health screening and assessment tools. Visit [www.healthinfonyet.edu.edu.au](http://www.healthinfonyet.edu.edu.au) for more resources.
- The **Intellectual Disability Rights Service** has a great tool on their website which is a step by step guide to making a section 32 Application for a person with intellectual disability. Go to [www.idrs.org.au](http://www.idrs.org.au) and download the guide.
- **ABC Ramp Up** is a website on disability media. This site is where you will find ABC stories, interviews and videos on the subject on disability. You can visit the website at [www.abc.net.au/rampup](http://www.abc.net.au/rampup) or keep connected by RSS feed, following on Facebook or twitter @ABCRampUp.
- Visit [www.child-encyclopaedia.com/en-ca/home.html](http://www.child-encyclopaedia.com/en-ca/home.html) for an online child encyclopaedia of early childhood development. The encyclopaedia is free and has over 47 topics related to the psychosocial development of the child.
- **Network Autism** is a place where professionals can come together, share good practice and achieve better outcomes. Visit [www.autism.org.uk/networkautism](http://www.autism.org.uk/networkautism)
- The School Counselling Workforce in NSW Government schools and the literature review: Meeting the psychological and emotional wellbeing of children and young people: models of effective practice are available on the webpage <http://www.det.nsw.edu.au/about-us/statistics-and-research/public-reviews-and-enquiries/school-counselling-services-review>



# wwild-svp...

WWILD –SVP Association Inc is a not-for-profit organisation based in Brisbane, Queensland that works with people with intellectual disabilities who have experienced or are at risk of experiencing sexual violence or have been criminally victimised. They were funded by the Queensland Department of Justice and Attorney General to develop a resource to assist mainstream services to build their capacity to support people with intellectual disability who have been victims of crime or exploitation. Their **resource kit called 'How to Hear Me'** contains a book and accompanying DVD and is designed to augment the existing expertise of counsellors and other professionals and allow them to adapt their current practice to meet the needs of a wider and more diverse client base.

It is the view of WWILD-SVP that all counsellors have a professional responsibility to increase their competence in working with this broad group of clients, as they would with any other group of service users. In the past, people with intellectual disability have been portrayed as lacking the cognitive ability and insight to engage meaningfully in counselling. This, along with the lack of confidence that counsellors often express about working with this client group, has often led to people with intellectual disability being excluded from mainstream or generalist counselling services.

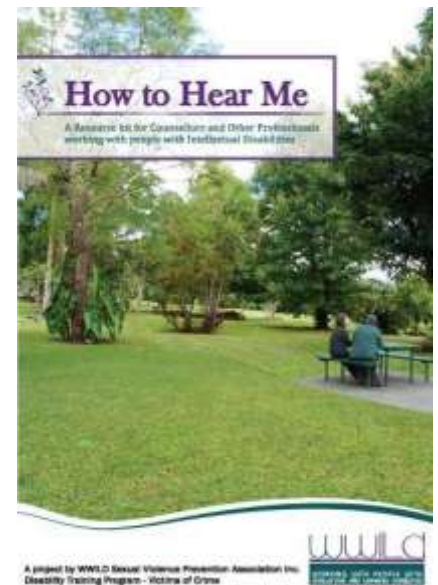
Counselling services that cater to the specific needs of people with an intellectual disability are rare. Thankfully, we are **becoming more aware of people's emotional and psychological needs** and there are an ever increasing number of mainstream counsellors seeking to work with this **client group. The 'How to Hear Me' resource kit** was developed to build the capacity of mainstream services to provide quality support and therapeutic interventions for this group whose needs are still largely misunderstood and under-recognised.

Fundamental to the purpose of this resource is the knowledge that people with intellectual disability in Australia are over-represented in nearly every area of disadvantage, for a wide range of complex individual, social and systemic reasons. For the same complex reasons, people with intellectual disability are significantly more vulnerable to becoming victims of crime than other members of the population and therefore more likely to experience trauma and require therapeutic counselling and support. We have given considerable space to discussing the **'lived experience' of this disadvantage** in the first half of the book to support professionals to better understand this complexity.

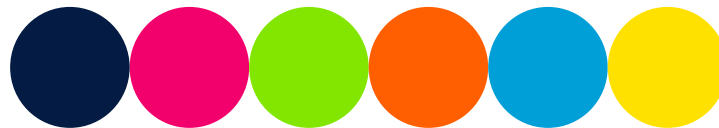
The book provides information to enhance understanding and practice skills in the counselling context when working with people with intellectual disability, includ-

ing barriers to communication, useful therapeutic approaches, important considerations for practice and tips for legal professionals. The accompanying DVD provides a short explanation and demonstration of four individual counselling techniques that might be usefully applied in counselling practice with people who experience intellectual disability. It aims to contribute to the conversation about how this group can be better served and supported within our community, particularly within the mainstream counselling setting. ●

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Web: [www.wwild.org](http://www.wwild.org)  
email: [info@wwild.org](mailto:info@wwild.org)



## reading list...



Cramm, J.M. and Nieboer, A.P. (2012). Longitudinal study of parents' impact on Quality of Life of children and young adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. Vol 25, Pp.20-28.

A nice literature review to start that confirms that emotional, social and situational variables can change Quality of Life among children with intellectual disability.

Cottis, T. (2009). *Intellectual disability, trauma and psychotherapy*. Routledge, London.

I am still only part way through but I thought this would be interesting to add to the list as a way of understanding the practical issues of participating in therapy for people with intellectual disability. Also of interest is the developing of secure attachments.

Emerson, E. and Einfeld, S. (2011). *Challenging Behaviour*; 3rd edition. Cambridge university press. New York.

A handy book that describes everything a beginner might want to know; with more detail for the practiced clinician. This book is really a handbook as it describes the social context, epidemiology, biology, behaviours and pharmacotherapy. It also acknowledges assessment, intervention and the challenges ahead. If you are bored on a Sunday choose an article from the 48 page reference list to read.

McKenzie, K. and Megson, P. (2012). Screening for intellectual disability in children: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*. Vol 25, Pp.80-87.

We have received many questions about assessment and screening. This article is a sufficient literature review with a nice reference list.

Rillotta, F., Kirby, N., Shearer, J. and Nettelbeck, T. (2012). Family quality of life of Australian families with a member with an intellectual/developmental disability. *Journal of Intellectual Disability Research*. Vol 56, Iss 1, Pp. 71-86.

This issue of the journal of intellectual disability research focuses on quality of life of people with intellectual disability. There are several articles based around the world; this one is close to home.

# conference review; translating genetics to phenotype...

**Translating Genetics to Phenotype: the Society for the Study for Behavioural Phenotypes Research Symposium, Brisbane Oct 2011**

Associate Professor David Dossetor

This was an intimate meeting of 70 international clinicians in the Riverside Centre designed by Harry Seidler, overlooking the Brisbane river. Drinks at the Powerhouse was especially memorable, where Bill Shorten Federal Minister for Finance, sponsor of the National Disability Insurance Scheme, opened a photographic exhibition by an eminent American fashion photographer Rick Guidotti. Rick presented work to challenge the stigma of people with genetic disorders and disability, capturing moments of their joy and beauty in photographs and thereby *celebrating diversity*. Intellectual diversity in bringing science to our understanding of the mind best describes this stimulating meeting organised by Honey Heussler **Paediatrician at the Mater Children's Hospital**.

The last decade has seen so much invested in genetics research. **'Gene Wide Association Studies'** may have identified numerous genes of interest, but together they explain very little, such as 1% of the causes of schizophrenia or autism. Prof John Mattick, Director of the Centre of the Centre for the Molecular Biology and Technology at the University of Queensland said the human genome project has failed to unlock the function of the brain. All the **'silent' DNA in our chromosomes is involved in the coding of small 'non coding'** RNA molecules which are involved in regulatory feedback systems. There are 180,000 exons where the active DNA areas creates functional proteins (1% of the genome), but we are starting to discover that the rest of the genome is there for a purpose. Exploring the functional

roles of these previously unrecognised RNAs has made understanding the regulation of the brain so much more complicated. Professor Frank Bowling a biochemist and Director of Inherited Metabolic Diseases at the Mater Children's Hospital described how individuals with every neurotransmitter/biochemical metabolic disorder have been described. Some of these are found in certain genetic phenotypes, such as abnormalities of the glutamate transporter system found in 5/6 families with OCD; Tourettes is a presentation of histamine decarboxylase deficiency. But genetic diseases do not represent dysfunction of a single gene, but a disruption of a function from several genes (disease polymorphism) and no single biochemical mechanism is the cause of a mental illness. Mental illness must be the consequence of parallel processes coming together to create such disorders. The gene revolution has led to amazing complexity in understanding intracellular metabolic pathways and some of the differences in function in different cells and different brain locations, what is called epigenomes. The European Union has just invested 30 Million Euros in 41 institutions studying this variation of epigenomes. The current technical challenge requires a new discipline of **"informatics" ie high powered computer analysis** to unravel the patterns in 2 terabytes of information from identifying different proteins and other chemicals through mass spectrometry in a single experiment.

This level of complexity creates scientific uncertainty and a significant error margin. Prof James Harris, Neuropsychiatrist from Harvard illustrated this with his talk on Oxytocin. Oxytocin is currently the fad explanation for a whole range of situations and can be bought by salesmen in the internet in the hope of making their victims socially compliant. Oxytocin certainly contributes to sociability and social cohesion of the prairie vole and a dose at a develop-

mentally sensitive time leads to consistent long term pairing. There are several types of oxytocin receptor. Increased methylation of oxytocin gene leads to reduced activity with increased fear and reduced trust. Oxytocin administration has led to short term reduced repetitive behaviour in Prader Willi Syndrome, increased eye gaze in Williams Syndrome, reduced eye gaze aversion in Fragile X Syndrome, it may help self injurious behaviour in Lesch Nyhan Syndrome and there are now 7 current studies on its use in autism and 8 in schizophrenia!

There is no doubt that the animal models of genetic conditions are an important part of the process of unravelling biological and neurotransmitter systems in certain conditions. Prof Bruce Tonge gave an elegant presentation on the extreme male brain theory of autism, as promoted by Simon **Baron Cohen, with a 'knock out' mouse** deficient in estrogen aromatase, which leads to increased formation of testosterone. These Spiny Arko mice have increased sexual activity, increased ritualistic grooming behaviour rubbing hair off their face, increased running, cerebellar problems with variability of stride length and toes turned in (also found in autism), reduced social interaction and increased withdrawal, reduced (ultra sonic) communication, bigger brains and increased abnormal purkinje cells in the cerebellum. Darren Hocking made a case for using gait analysis for studying these sorts of coordination problems in Autism and other behavioural phenotypes as a core clinical feature.

Mouse models of Fragile X have identified a number of complex biochemical and neurotransmitter details of this disorder. The number of repeats (copy number variants) on the X chromosomes correlates to increase in the FMR1 RNA which inhibits the production of FMRP and other proteins, and affects many regulatory mRNAs and in turn synaptic formation and plasticity. There is



enhanced metabotropic glutamate receptor 5 activity leading to long term depression in the hippocampus. Glutamate is the final common pathway of neurone energy metabolism. Anti oxidants reduce these effects and smoking increases them. Randi Hagerman, Director of UC Davis MIND Institute, summarised the science and the forays into treatment with mGluR5 antagonists which is a form of targeted treatment to reverse these abnormalities. Fenobam, RO491723, AFQ 056, Racemic Baclofen (Arbaclofen) and STX209 are all mGluR5 antagonists and a number of international phase 3 drug trials are under way. In randomised cross over trials, Arbaclofen reduces aggression and anxiety, increases language. Those under 8 years do better especially with enhanced education but the effects are not large compared to placebo, emphasising the importance of early intervention. Aminocycline can tighten up floppy muscle tone and has also been look at in Autism. Lithium down regulates these mRNAs. GABAa and glutamate imbalance are also found in both Downs Syndrome and Autism and GABAa down regulation is being studied with Ganaxolone a neurosteroid, used in Infantile Spasms, and Allopregalone which has been used in PTSD, as they are found to be neuroprotective and stimulate neurogenesis. Winari reported on the use of small doses of sertraline in children 12-50 months age with Fragile X and found improved receptive and expressive language. Sertraline affects increased neurogenesis and brain neurotrophic factor.

Petrus de Vries, child psychiatrist from Cambridge, presented on Tuberose Sclerosis. TSC is caused by two different genes; TSCI is at chromosome 9p34 and TSCII at 16p13.3. There are differences in patterns of severity for example in IQ between TSCI and II genes, although considerable overlap. Drosophila fly research identifies that TSCI and II protein inhibits intracellular signalling, upregulating the mTOR (mammalian target of Rapamycin) leading to dysregulation and proliferation of cell growth. Rapamycin is an antibiotic found in a streptococcus on Easter Island. Rapamycin can significantly shrink subependymal giant cell astrocytomas, angiomyolipomas and the hamartomas in many difference tissues. Petrus has been working on identifying the neuropsychological deficits in those with TSC and finding deficits such as reduced attentional skills, becoming easily stressed by demands and lack of patience in those with the gene but not obviously affected. Phase II Rapamycin studies have shown improved memory and in now licensed as Envolimus.

Helen Leonard from the Telethon Institute in Perth presented on the differences of severity and symptom pattern in Retts Syndrome according to which of the different genetic deletions is involved. She has published clinical guidelines for management of their scoliosis. Retts Syndrome suffer apneustic breathing when they seem to forget to breath. This is a feature that leads to placement on a respirator and is a cause of death. Robert Delamont, a neurologist, has done a study on Buspirone, a 5HT1a agonist, and shown improved breathing patterns.

Prof Mark Bellegrave of the Queensland Brain Institute and the school of psychology presented on ADHD attentional studies suggesting that ADHD was equivalent to a parietal lobe deficit which causes left '**visual neglect**' or **lack of attentional responsiveness** in the left space (as found in stroke victims), whereas normals have a left sided attention preference. This is related to reduced right sided cerebral, cerebellar and caudate nucleus size, reduced right sided activity on functional MRI and the up regulation of the dopamine transporter gene (one of the genes implicated in ADHD).

What is clear is that identification of biological correlates requires good definition of behavioural phenotypes and psychiatric syndromes and symptoms. Lucy Wilde from the Cerebra Institute in Birmingham, UK, presented on the impulsivity and lack of inhibition in Smith Magenis Syndrome on a number of neuropsychometric tests compared with Downs Syndrome. These features correlated to lack of emotional regulation in SMS and may involve the amygdala and frontal cortical processes. These studies suggest that different symptoms of ADHD such as impulsivity and concentration may have different biological **mechanisms. These 'hot' executive function skills** may respond to biofeedback.

**Greg O'Brien mentioned that Modafranil** has been used to promote wakefulness in SMS. Phil Ray from our department presented on specific executive function deficits in Autism in cognitive flexibility, complex planning and self monitoring.

Chris Oliver Director of the Cerebra Institute presented on the phenomenology of 1p36 syndrome which has self injurious behaviour, profound intellectual disability and autism. They have early feeding difficulties followed by increased appetite and obesity. Their eating problems proved to be less severe than the eating problems in Prader Willi Syndrome who are distinguished by a tendency to hoard food, but will accept a delay in food gratification.

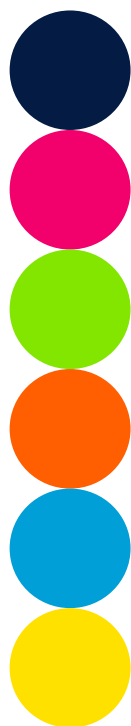
**Angelman's Syndrome in contrast will eat inedible objects.**

Beth Williams reported on the evaluation of computer learned affect recognition in autism using the Transporters Program where trains are the vehicle of affect expression. Although the kids did better on the computer skills, this did not generalise to any clinical improvement, emphasizing that such programs do not lead to improvement without teaching the implementation of the social pragmatics.

Alexander von Gontard reported on the high rates of elimination disorders in Prader Willi Syndrome of both bowel and bladder, day and night time in children and in adults, totalling 30%. These are often ignored but need investigation sometimes with a sonograph, pelvic floor EMG, and fluid studies in order to properly classified. They are then readily treatable.

Prof Tomy de Ravel from the Centre for Human Genetics in Leuven drew attention to the growing minefield of ethic issues in genetics. Whose information is it and for what purpose?

Prof Tony Holland, psychiatrist in intellectual disability, Cambridge UK, summarised the conference in the Tom Oppe Lecture presenting on the evolving nature of research in intellectual disability. While inborn errors of metabolism and twins genetic studies have contributed to a boom in research, what has had more influence on people with intellectual disability is legislative and social changes with recognition of their rights for example to marry, access to education and normalisation in community living. People with intellectual disability still lack access to health care as demonstrated by the reports in premature death. None the less the dramatic increase in longevity has revealed different problems including the early presentation of dementia. The clinician is attuned to the range of experience and presentation and incorporates what scientific information can be used in the complex process of formulation the understanding of a problem and an individualised approach to intervention. We are along way from standardised approaches to helping people with intellectual disability, but clinical expertise based on scientific method, despite growing scientific complexity, provides real opportunity for improving their health and mental health care. ●



# Justice health School-Link initiative: supporting young offenders get back on track through education..



Kim Eisler  
Justice Health School-Link Project Officer

Justice Health Forensic Mental Health Network (JHFMHN) provides health care to adults and young people in contact with the criminal justice system, both in custody and in the community, and those within the NSW forensic mental health system. Even though our patients have come into contact with the criminal justice system, the vast majority spend only a short period of time in our custody and thus it is vital that they also receive support from mainstream services in the community.

JHFMHN is committed to working with other Government Departments and Non Government Organisations to reduce the stigma of young people in contact with the criminal justice system, to improve their health and consequently reduce criminal recidivism.

In 2009 JHFMHN received funding to establish its own School-Link Initiative in recognition of the complicated and demanding needs of the young people who find themselves in contact with, or at risk of coming into contact with, the criminal justice system. It has a unique role providing state-wide support to clients with highly complex and challenging problems.

The JHFMHN School-Link Initiative aims to:

- Raise awareness of the health and well-being needs of young people who come in contact with the criminal justice system
- Raise awareness of the protective function that education and vocational endeavours can have for mental health and well-being of young people
- Facilitate understanding of the circumstances that influence a young person's successful engagement with education

- Support young people associated with, or in danger of being associated with, the criminal justice system to optimise access and engagement with health and education services

## Facts and figures : young people in custody

Each year close to 5,000 young people are admitted into custody, approximately 450 young people are in custody on any given day. Most young detainees spend short periods of less than a week in detention. Almost half are in remand awaiting sentencing, and this is especially true for female detainees.

A comprehensive survey of the health of young people in custody was completed in 2009 (Indig et al, 2011). The data collected substantiates evidence found in many other studies - that those young people who come in contact with the criminal justice system face a range of social, economic, health and personal problems. (Wilson & Tully, 2009). These young people are often from the most disadvantaged sections of society and have confronted a range of difficulties, often from birth.

There is an array of physical health problems that confront juveniles in detention, including obesity, dental health issues and speech and hearing problems (Wilson & Tully 2009). Other research confirms that **young offenders' performance on all language and social skills measures is significantly worse than non-offenders.** (Snow and Powell, 2008).

Young detainees report high rates of childhood abuse and neglect. Over a quarter reported being placed in out of home care before the age of 16, and 43% of those young people had been placed in care before they were aged 10 years. Over one in four said that they lived with someone with a physical, mental or emotional problem that impacted on their daily life. Almost half reported one or both of their parents had ever been in prison.

Young people who come in contact with the criminal justice system frequently have high rates of mental health problems, 87% of detainees were diagnosed with at least one psychological disorder. Young women in detention are significantly more

inclined to report high psychological distress, including more self-harming and suicidal behaviour.

Drug and alcohol abuse is common, many of the young people participate in binge drinking and experience impaired control of their drinking. Nearly all young people reported having smoked tobacco and using illicit drugs. Cannabis is the most common drug used, particularly among Aboriginal young people, followed by ecstasy.

Overall, 77% of young people in custody had an IQ score below 89, that is, in the low average or lower range. One third of those surveyed had an IQ score which placed them in the borderline or extremely low intellectual disability range.

On the whole young detainees are born in Australia (89%) with almost all of them speaking English at home. Aboriginal young people are disproportionately over-represented comprising approximately 50% of detainees, despite making up only 4% of the general adolescent community.

## Why school matters

For young people in custody the average age of leaving school was 14.4 years, with the median age being 15 years. Only 38% of young people in detention reported going to school in the six months prior to custody, 88% had been suspended from school at least once. Two thirds had been suspended three times or more. Nearly half had been excluded from school and 41% had attended a special class or special school

Young people, who experience a multitude of risk factors across personal, family and social contexts, will have an increased likelihood of engaging in criminal activity. For those who are missing the protective factors of a steady education, good health and a supportive nurturing environment these risks are all the more concerning. (Wilson & Tully, 2009)

Research in Australia and internationally consistently shows that successful engagement and completion of education can be protective for mental health, physical health, future socio-economic status and employment as well as contact with the justice system. (Sander, 2010; Geib et al 2011)

Early school-leavers are more likely to experience:

- Poorer mental and physical health
- Higher unemployment rates

- Lower incomes and lifetime accumulated wealth
- Higher rates of crime and
- **LESS engagement in “active citizenship” (Lamb & Rice, 2008)**

A high proportion of young people in the criminal justice system have experienced disengagement from school and poor academic achievement. The inter-connection between early behaviour problems and academic difficulties are well documented. (Geib et al 2011; Sprott et al 2005)

### JHFMHN - Adolescent Community Programs

As well as providing services to young people in custody, JHFMHN is engaged in a range of services which both improve the health outcomes of young people whilst reducing criminal recidivism and risky behaviours:

### Justice Health Adolescent Court and Community Team (JH-ACCT)

The JH-ACCT is a multi disciplinary team of clinicians who have extensive child and adolescent mental health experience and risk management skills to enable them to identify and assess risks posed by young people to themselves and others. The JH-ACCT provide two services, the Court Diversion and Liaison Services and the Community Consultation Liaison Service

### JH-ACCT Court Diversion and Liaison Services

JH-ACCT clinicians attend Bidura, Parramatta, Campbelltown, Port Kembla, Sutherland, Wyong and Woy Woy, Bourke, Wagga Wagga, Bourke and Dubbo courts. They divert young people with emerging and established mental health and/or drug and alcohol problems from the criminal justice system into appropriate treatment in the community – when it is appropriate to do so.

When a young person is referred to the service the JH-ACCT clinician carry out a brief assessment and a mental health report indicating the feasibility of diversion into community health treatment or any other options that may be applicable is provided to the Magistrate.

### JH-ACCT Community Consultation Liaison Service (CCLS)

The CCLS provides comprehensive forensic mental health and risk assessments to support other government agencies in the management of young people with challenging behaviours. The CCLS sup-

ports the ability of community services to engage, manage and retain these young people in treatment. Referrals can be made from any government agency however the young person does need to be connected to a Child and Adolescent Mental Health Service treating Team.

### Youth Drug and Alcohol Court (YDAC) Program

The Youth Drug and Alcohol Court (YDAC) program is a multi-agency initiative led by Juvenile Justice. It uses a combination of judicial and therapeutic interventions to **reduce or manage young people’s drug and/or alcohol use and related criminal activity.**

### Community Integration Team (CIT)

The CIT is a Justice Health initiative to aid the successful reintegration of young people from custody into the community with significant mental health and/or problematic drug and alcohol issues

CIT goals:

- Coordinate integrated, ongoing care for young people prior to and during the critical post release period
- Link young people to appropriate specialist and generalist community services
- Provide young people and their families/carers with information in regard to effective health management.
- Reduce the number of young people re entering custody as a result of mental health and/or drug and alcohol related offending behaviour
- Assessment and develop individual case summary/management plans and refer to appropriate community services
- Engage in joint brief case management Juvenile Justice (JJ) and other government and non government departments, to achieve the individual case management goals of the young person.

The CIT operates at Kempsey, Bourke, Newcastle, Broken Hill, Grafton, Penrith, Fairfield, Gosford, Wagga Wagga, Dubbo, Fairfield and Sydney Metropolitan. ●

For more information on the Justice Health School-Link Initiative and Justice Health Services please contact :  
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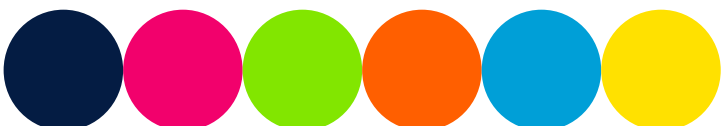
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# Transcribe 2011: young writers competition participant wins the special award of the children's hospital at Westmead School-Link initiative...

The Transcultural Mental Health Centre launched its 8<sup>th</sup> TranSCRIBE Young Writers Competition with its 2011 partners the NSW Centre for the Advancement of **Adolescent Health at The Children's Hospital at Westmead**, Schizophrenia Fellowship (NSW) and the Black Dog Institute. A biennial event, the competition is open to all young people aged 12 – 24yrs across NSW and focuses on the importance of mental well being for young people within the context of diverse societies. Each competition has a new theme and in 2011 this was *Half Way Home*. The 2011 entries again displayed the remarkable writing talents of the competition entrants and their deep understanding around issues of resilience, mental health and cultural diversity within the Australian context.

Since 1998, TranSCRIBE has attracted more than 2300 young writers from over 300 schools and educational facilities across NSW. This year multiple entries were received from 77 educational facilities across the 3 age categories.

As part of the initiative TMHC publishes the winning stories from each category in the TranSCRIBE Young Writers Competition Booklet. The booklets have widespread appeal and have been used as additional source materials in subjects such as English, PDHPE and society and culture classes in secondary schools and as a resource in therapeutic settings.

The *Half Way Home* winning stories booklet was published and distributed to over 700 schools and educational facilities across the state. The booklet was

launched by The Honourable Kevin Humphries, MP Minister for Mental Health, Minister for Healthy Lifestyles, Minister for Western NSW who also presented the winners with their certificates at an award ceremony at the Sydney Convention and Exhibition Centre on the 10th of November as part of the **Youth Health 2011: It's Totally Important!** Conference. Minister **Humphries officially opened up the night's** proceedings stating that the competition is of great significance as it challenges young writers to think about the effects of mental health and cultural diversity on families and young people living in Australia.

Additionally, The Children's Hospital at Westmead School-Link Initiative is also proud to present one of the 2011 TranSCRIBE entrants, Vivian Tran, aged fourteen, with a special award for her story entitled 'Sometimes Miracles Work'.

**Vivian's entry highlighted the mental health** issues of young people with Autism and Intellectual Disability. In recognition of her effort, Vivian will receive a pack from The Children's Hospital at Westmead School-Link Initiative.

The School-Link Initiative has been funded to address the mental health needs of children and adolescents with an intellectual disability. Activities in the Initiative focus on 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 for students with an intellectual disability. You can read more about the Initiative at [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au) or browse resources and publications.

If you would like to obtain a copy of the TranSCRIBE11 booklet *Half Way Home* for your school library, service or organisation visit the TMHC website: [www.dhi.gov.au/tmhc](http://www.dhi.gov.au/tmhc). Alternatively for hard copies contact TMHC on 9840 3800 or via email: [tmhc@swahs.health.nsw.gov.au](mailto:tmhc@swahs.health.nsw.gov.au). Please note previous competition booklets are also available for download from the TMHC website.

For more information about the 2013 TranSCRIBE Young Writers Competition, please contact: Michele Sapucci on (02) 9840 3909 or [Michele.Sapucci@swahs.health.nsw.gov.au](mailto:Michele.Sapucci@swahs.health.nsw.gov.au).

## Halfway Home



# Sometimes Miracles Work

By Vivian Tran

At the age of four, I lived in an old blue house next to a park and a semi-busy street. I was the type of child who didn't take naps, or eat food from the preschool. I was the type of kid who got lonely easily. Television, at the time, affected me greatly. I would see pretty houses bigger and cleaner than mine, parents who got along better, and lastly, siblings. What I saw on television, I wanted too. But of all that I had seen on television, I wanted a sister the most.

Both of my parents did not have much time to play with me. I had to wake up at six in the morning to say 'goodbye' to my mother. My father came home hours after my bedtime. I was babysat by my grandma, the one on my mother's side. As nice and as loving as she was, she wasn't a friend. Not a kid who could play with me.

As a child barely past the age of a toddler, I did not know the dynamics of childbirth, or of raising children. Therefore, I had no idea how long it would take for my playmate to grow to an age where she or he could actually play with me. But it didn't matter. Television taught me that babies were cute and likable anyway.

Around mid-year, I was told that soon, I was going to be a big sister. I was happy. I was God-praising happy. The next few months, I would help out a bit. Not causing as much trouble, not seeking as much attention and behaving well enough when

my mother had to go to the hospital.

When she came back, I had a new baby sister. An adorable baby sister. I didn't even mind that she was taking most of the attention. I even helped take care of her, and I got to name her, too. Emily. A pretty name for a pretty girl.

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**“She told me that my sister was better off than some autistic children, since she had and used her emotions and could learn...”**

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When she was about one year old, we found it strange that she didn't make a lot of progress in anything. It took her months longer than other babies to crawl, and she hadn't ever uttered a single word.

At the age of three, she was diagnosed with autism. I was told that my sister would be different. She would not interact with other humans normally; she would not talk like we did, and she would not understand like we did. I was about eight at the time, and had no idea a disorder like that existed. Then, a startling revelation found its way to me. She wouldn't be able to play with me. I was very selfish, like most children at that age. It did not occur to me that it would be hard to take care of my sister.

I would soon find out. At first, taking care of my sister was fun. I never had a proper baby doll, so it was new to me. But, all

good things don't last. I would soon tire of it. Repetition made things boring.

Taking care of an autistic child took time. Time my mother didn't have. She had to quit her job, leaving my father once again the main breadwinner.

During year two, I was going to take ballet lessons. Just what every little girl wanted. Just what I wanted. The first lesson was fun, and so was the second. Just before the third lesson, however I fell sick and couldn't go. My mother was too busy with my sister to drive me to the fourth lesson. And that would be the end of the story. The little free time my mother had before was then taken up by my sister. My mother and I tried to convince myself that ballet lessons weren't important. They weren't fulfilling at all. They weren't that fun. But, they were. Even now, I almost wish I didn't stop.

By my year three, we had moved to an old yellow house on a very busy road, which gave me the creeps. The only perk was the swimming pool in the backyard. I liked swimming, but my sister loved it. I was decent, being able to float and do some of the basics. Over two summers, I had gained the ability to swim better than most kids I knew. Over two summers, my sister had gained the ability to walk into the shallow end and to use a floaty. In the end, she received a lot more praise than I did. Being the little brat I was, jealousy was inevitable.

I understood. She needed more love and more attention than I did. She needed to be looked after more closely, and more carefully. Furthermore, I had to help. I understood that it was fair. But it didn't mean I had to like it. Despite that, I always thought my sister was adorable. She would've been prettier if she wasn't autistic. She never let us brush her teeth, despite keeping a collection of toothbrushes numbering over sixty. She had terrible hair, and we had to keep it neatly trimmed since she hated long hair. Her typical outfits consisted of a t-shirt and pants, always refusing to wear skirts and dresses.

My appearance contrasted with hers. My nose was flatter, my skin tanner, my teeth clean, and my hair long. Somehow, I looked ugly. No one point of my appearance made me ugly, but to look at me as a whole, I wasn't pretty. The only 'pretty' thing about me was my eyes, which I shared with my sister.

I thought that I would be compared to my sister in looks, and somehow, academic results too. Despite earning an average B minus in class, I was not happy with my marks. My father wasn't happy with my



marks. But to be completely honest, he **didn't really care either. My mother didn't** mention much of it in passing, but would often comment on how smart my sister **would've been if she wasn't autistic.**

Despite probably being a completely innocent, prideful comment, it had an effect on me. It started leading me to thinking- **what if my parent's expectations in me** were doubled because my sister would not be able to achieve what I could? What if I disappointed them?

With that thought under my belt, I worked harder. And it was *hard*. **I didn't get anywhere.** That aspect of my school life left me disappointed in myself. To make matters worse, something else had started stirring up. I had once noticed white vans **in my sister's school driveway. The curious child I was, I had promptly asked my mother what they were for.** She told that they were used to drive some of the children to and from school. That left me a bit confused. If my sister could be driven to school by my mum, how come the other **parents couldn't drive their children to school?**

Knowing that I was probably thinking about something like that, she started to explain to me that not all parents had enough time to drive their children to school. Some had to work harder to earn enough money to take care of their child, **because they might've split from their partners, and might've been taking care of their child themselves.**

## siblings australia...

I recently received a review copy of a new DVD produced by Siblings Australia. This organisation runs an informative website ranging from info for siblings of children and young people with a disability, to books and other resources. They have also produced a kit to assist with running some activities for siblings groups.

Having viewed the DVD I felt it was a balanced approach – looking at the development of strengths – resilience, empathy, responsibility in siblings, as well as a frank discussion of some of the concerns of these children and young people. The format was one of a combination of talking heads – teenage siblings, parents/ caregivers and professionals drawn together by a celebrity narrator. As well as looking at issues for siblings the DVD explores sources of support within the family, outside the family, and professional supports. It provides very useful information about supporting siblings and taking care of carers.

Sometimes, partners would squabble about whose fault it was- whose genetics **might've passed the disorder, who might've dropped the kid on its head when it was younger, and so on.**

My parents themselves never got on very well in the first place. It was the typical arranged marriage. They would have their wedding, try to get along, squabble and argue some more.

**My sister's condition probably made matters worse.** By my year five, my parents had officially separated. By grade six, on **Valentine's Day, they had divorced. I didn't** know whether or not to be happy or sad. **I might've been sad because I probably** would never have a nice, normal family or happy because my mother was finally free of my father.

With my father failing to meet his child support payments, my mother had to work even harder to support us all. I had to help out to look after my sister. Being a **babysitter for her wasn't so bad. I bonded a bit** more with her, playing with her and comforting her when she became upset. But it **meant I didn't have that much time to do** what I wanted to.

Since my mother was always busy, we **couldn't spend much time together. But** when we did, we talked. She told me curious things. We talked about how lucky my sister was to be a girl, because boys with autism were often worse off than girls and **how lucky we were that my mother wasn't**

I showed the DVD at a recent parents meeting at a School for Specific Purposes, and it was very well received. I only showed some sections as one challenge of working in our area is the very high number of different languages and cultural backgrounds among our parents – currently some 29 language groups are represented. The DVD is in English, and some speakers are a little difficult to understand even when this is your first language. Nonetheless the discussion generated was excellent and really got people thinking. Some parents of older young people with a disability expressed regret that these issues were not talked about so freely when their other children were younger – so it is clearly a very much needed support.

I would be very interested in collaborating with anyone else who might be interested, to run a pilot sibling support group using the materials from Siblings Australia. I imagine this could pose some logistical

**weak-willed, otherwise she might've ended** up with depression like many other women with autistic children. She told me that my sister was better off than some autistic children, since she had and used her emotions and could learn.

One day, when she had a day off, I was allowed to go to the movies with my best friend. She was astonished to learn that that time was my first time going to see a movie in a cinema. However, already knowing of my situation, she understood. **We went to see 'The miracle worker',** a movie based on a play based on the life of Helen Keller, who was deaf and blind, and consequently, mute. I watched the fits Helen threw and sympathised with her teacher, Annie Sullivan. I watched as Helen grew in understanding, slowly and winced at her frustration.

Then, at the climax, I watched Helen identify and understand her first word- water. It was like a key to the gate of knowledge. With one word, she changed her whole life. It was a miracle.

I was left breathless after the movie. A glimmer of hope shined in me. If Helen could do it, then my sister had a chance as well. My mother did say she could learn. Maybe, just maybe.

**"What happened to Helen, anyway?"** I asked my friend. She looked at me, and **then answered, "She earned a Bachelor of Arts degree and became an author. Why?"** I smiled. **"Nothing, don't worry."**

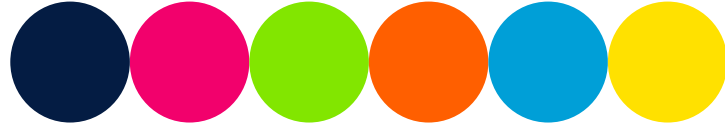
My sister had a chance to have a future because sometimes, miracles work. ●

issues – but would like to give it a go. From my experience of running parent support groups at school with Relationships Australia, I feel this to be an appropriate and much needed extension. If anyone else has already used these materials I would love to hear from you!!

Parents were keen to take away a brief handout, and check out the website, and if appropriate encourage siblings to explore it for themselves. Aging Disability and Home Care also have material for siblings on their website. Overall a much needed resource and I would encourage readers to explore the Siblings Australia website for yourself, **if you haven't already found it** [www.siblingsaustralia.org.au](http://www.siblingsaustralia.org.au).

Barbara Fleming  
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## Intellectual Disability:

*University of New South Wales Public Lecture: **Future directions for intellectual disability services** by Prof Jan Walmsley. 28th March, 4.30-5.30pm. Room 119, John Goodell Building UNSW, Kensington. Register online at <http://education.arts.unsw.edu.au/public-lecture-series/> other sessions include **People with Intellectual disabilities conduction research.***

The 47th annual conference for **Australasian Society for Intellectual Disability: Research to Practice.** 7-9th November, Wellington New Zealand. Visit [www.asid-2012.org.nz](http://www.asid-2012.org.nz).

## Challenging Behaviour:

**Toddler clinic workshops** as an introduction to Parent Child Interaction Therapy Model by *Karitane* for children with challenging behaviours. 4th June and 3rd September 2012. Carramar. \$175. Contact 9794 2348 or [enquirieskfc@sswahs.nsw.gov.au](mailto:enquirieskfc@sswahs.nsw.gov.au) for more information. You can pay online at <http://karitane.com.au/ProfessionalsEventsRegistration.php>

## Autism Spectrum Disorder:

**Autism and Aspergers Seminar:** Tony Attwood and Temple Grandin presented by *Autism and Aspergers Support Group.* 26-27th April. Richmond. \$230. Contact 0417 269 945 or [www.autismsupport.org.au](http://www.autismsupport.org.au).

*Autism Spectrum Australia* presents a series of workshops including **Forensic Implications of Autism Spectrum Disorders.** 2nd May. \$330. Frenchs Forest. For enquiries contact Vicki Gibbs on 8977 8331 or visit [www.autismspectrum.org.au](http://www.autismspectrum.org.au) for more workshops and events.

## Disability:

**The Why and How of School Inclusion.** *Family Advocacy* present Dr Bob Jackson. Newcastle March 13th, Ryde March 14th, Hurstville March 15th, Wollongong March 16th. 9.00am-2.30pm. Contact 9869 0866 or email [workshops@family-advocacy.com](mailto:workshops@family-advocacy.com). \$60 for professionals, \$10 for persons with a disability.

*Australian Network on Disability* national conference; **Raising the Bar.** 1th May 2012. Sydney. \$795. visit [www.and.org.au/pages/registration.html](http://www.and.org.au/pages/registration.html)

*Strengthening Disability Advocacy Conference.* **Disability advocacy and the legal system; you be the judge.** 26-27th March. Melbourne. \$400. visit [www.youbethejudge.eventbrite.com](http://www.youbethejudge.eventbrite.com) for more information and to register.

## Other:

**Inclusive learning technologies conference 2012** presented by *Spectronics.* 22nd-25th May 2012. Gold Coast. Maximum \$895. visit [www.spectronicsinoz.com/conference/2012](http://www.spectronicsinoz.com/conference/2012).

**Education and Mental Health: We can do it together.** *School-Link Greater Western Area Health Service.* 23rd and 24th of April. Orange. \$180. Contact Cathie Matthews on 6360 8000 or [cathie.matthews@gwahs.health.nsw.gov.au](mailto:cathie.matthews@gwahs.health.nsw.gov.au)

Cordeaux street talks by Sydney *South West Area Health Service School-Link* presents **Justice Health- Snapshot of young people with complex needs.** 20th March, Carramar. 27th March, Campbelltown. 1.30-3.00pm. Free. Register to [Viviane.benjamin@sswahs.nsw.gov.au](mailto:Viviane.benjamin@sswahs.nsw.gov.au) or 9616 4251.

## Mental Health:

*Gunawirra* (an organisation of aboriginal and non aboriginal workers) presents four sessions; **Drug and Alcohol Abuse.** 23rd February; **Domestic Violence.** 27th April; **Trauma in Infancy and Early Childhood.** 29th June; **Trauma.** 29th August. \$80per session or \$250 for series. Burwood. Contact [ntracey@bigpond.net.au](mailto:ntracey@bigpond.net.au) or 02 9427 2028.

**Australian Positive Psychology and Wellbeing Conference** hosted by the Australian Institute of Business Wellbeing, Sydney Business School, University of Wollongong. 22-25 March. Sydney and Wollongong. \$1095. visit [www.uow.edu.au/sbs/positive2012/aboutconference/index.html](http://www.uow.edu.au/sbs/positive2012/aboutconference/index.html)

**Child Development and Mental Health: Linking the two sides of the same coin.** *Infant child adolescent mental health service research and clinical practice.* 23rd April, Liverpool. \$100. Contact 9616 4205 or email [angela.rebolledo@sswahs.nsw.gov.au](mailto:angela.rebolledo@sswahs.nsw.gov.au).

**Attachment Theory: Theory and Practice** by the *Institute of Family Practice.* 14th and 15th of May 2012. Parramatta. \$440. Contact [info@ifp.nsw.edu.au](mailto:info@ifp.nsw.edu.au) or 8830 0755.

*Mental Health Professionals Network* presents a free online webinar; **Perinatal Mental Health; working together, working better.** 19th March, 6.45-8.00pm. Visit [www.mhpn.org.au](http://www.mhpn.org.au) for more information and to register your interest. Previous webinars available for viewing.

Expression of interest for free **Suicide Awareness Workshops** by the *rural support program.* Currently being planned for Berrigen, Corowa, Oaklands, Walbundrie and Holbrook. Contact Di Pritchard on 6051 7703 or [di.pritchard@dpi.nsw.gov.au](mailto:di.pritchard@dpi.nsw.gov.au)

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

# the medicine cabinet: Obesity– Problem of Number and Size...

Judy Longworth  
Senior Clinical Pharmacist  
Psychological Medicine  
The Children's Hospital at Westmead

Childhood obesity is one of the most serious public health challenges of the 21st century.<sup>1</sup> Excess body weight is the sixth most important risk factor contributing to the overall burden of disease worldwide. Obesity is a preventable disease and the incidence of obesity has doubled since 1980<sup>2</sup>. Nearly 43 million children under the age of five were overweight in 2010 with majority in developing countries. In 1995, 19-23% of Australian children and adolescents were overweight or obese. Between 1985 and 1995 the prevalence of being overweight in this age group had almost doubled and that of obesity had more than tripled<sup>3</sup>.

The cause of obesity is multifactorial but results in the main from a chronic imbalance between energy intake and energy expenditure<sup>9</sup>. The widely held belief is that inactivity leads to fatness, and this is reflected in a series of public health initiatives aimed at making children active. One study in UK has shown that fatter children are less active and this might be due to physiological and psychological explanations<sup>9</sup>. This then has implications for how one addresses the obesity epidemic as there needs to be a multifactorial approach encompassing both physiological and psychological supports and with children it cannot be done in isolation but with the family unit.

Epidemiological studies have suggested that metabolic programming is one of the contributing factors to the aetiology of obesity as well as concurrent increase in related chronic illnesses<sup>6</sup>. One hypothesis for this is over nutrition is the delivery of nutrients in excess of the needs required for normal growth, development and metabolism<sup>6</sup>.

Given all this it is also important to note that medications can also have significant effect on a patient's weight by affecting some of the brain neurotransmitters and receptors sites and thus affect how the body responds to food when taking the medication. Those medications that block the histamine 1 receptors (H<sub>1</sub>) are known to cause weight gain but the exact mechanism is not fully elucidated. Other receptors involved include the serotonin receptor 5HT<sub>2C</sub> so when both 5HT<sub>2C</sub> and H<sub>1</sub> are blocked at the same time patients can experience weight gain<sup>7</sup>.

## Medications can affect weight

### Putting weight on

**Atypical antipsychotics** and conventional **antipsychotics** that have most potent antagonist actions on both H<sub>1</sub> and 5HT<sub>2C</sub> receptors have shown the greatest weight gain in adults<sup>7</sup>. Correll suggests that the gain might be even greater in children<sup>11</sup>. This weight gain and associated abnormalities in lipid and glucose metabolism and following association to diabetes, dyslipidemia, and hypertension and leading risk factor for future cardiovascular morbidity and mortality. Although there have not been significant long term studies of these medications in paediatrics let alone the disability population from the adult data, it can be assumed that there will be an increased risk of cardiometabolic syndrome and future cardiovascular morbidity and mortality<sup>11</sup>.

More and more are using antipsychotics and there is a known link in the adult populations between the use of antipsychotics especially amongst the schizophrenic population and increase in type II diabetes. This risk increases with the number of individual drugs prescribed but also differs considerably between medications<sup>8</sup>.

Associated weight gain from adult studies<sup>12</sup>

medication	Weight gain
chlorpromazine	+++
haloperidol	+
Amisulpride	+
Aripiprazole	+
asenapine	+
clozapine	+++
olanzapine	+++
paliperidone	+
Quetiapine	+
risperidone	+
ziprasidone	-

**Mood stabilisers** this includes sodium valproate, carbamazepine, and lithium have all been shown to cause weight increase but the mechanisms of action for this adverse effect has again not be elucidated. **But it has been shown in Correll's meta-analysis** that the combination of mood stabilisers and antipsychotics that the ad-

ditive effects of the combination are greater than when the individual medications are combined<sup>11</sup>.

Lithium is associated with weight gain and in adults is a significant contributor to poor medication adherence. This is because **lithium can increase body's thirst and the increase in weight could be correlated with increase in high caloric drinks used to quench the thirst**. Lithium also increases insulin secretion and thus increases adipose tissue leading to increased BMI (body mass index)<sup>12</sup>.

**Tricyclic antidepressants** such as amitriptyline, clomipramine, and imipramine, these all have effects on histamine receptors H<sub>1</sub> and thus have effects on weight gain. Carbohydrate craving has been reported with tricyclics and this contributes significantly to weight gain<sup>12</sup>.

### Weight neutral – can put weight on or off

When one is depressed, one of the symptoms can be increased or reduced appetite and it has been shown in clinical trial initially **selective serotonin reuptake inhibitors** (SSRIs) increased metabolic rate, suppressed appetite and increased basal body temperature. Over time though the initial weight loss wears off, there can be gradual weight gain thus making SSRIs weight neutral<sup>12</sup>.

### Can lose weight

**Psychostimulants** such as methylphenidate and dexamphetamine have been reported to cause weight loss; a clinical trial showed more marked weight loss in heavier children with methylphenidate. For a long time psychostimulants had the reputation of causing growth delay but this has been disproven in long term studies.

**Topiramate** is an antiepileptic has been shown to cause weight loss and at one time it was considered as adjuvant therapy for patients who have gained considerable weight but clinical trials have not been successful and serious adverse effects have also been noted,

There are other medications that have been used to cause weight loss and this includes fenfluramine and sibutramine, both of which have been removed from the Australian market. There are studies using the antidiabetic drug metformin in obese children who have developed type 2 diabetes with modest reduction in weight and blood glucose control but as with all medi-

cation there are adverse effects and these include an excess of lactic acid in the body which can cause pain and discomfort.

So when excessive weight gain is attributed to medication is noted then there tends to be a medication change to a more weight neutral medication. But changes in eating habits and exercise can also help in the effectiveness of any weight loss programme

### Summary of non medication approaches:

- increase consumption of fruit and vegetables, as well as legumes, whole grains and nuts;
- limit energy intake from total fats and shift fat consumption away from saturated fats to unsaturated fats;
- limit the intake of sugars; and be physically active - accumulate at least 60 minutes of regular, moderate- to vigorous-intensity activity each day that is developmentally appropriate.

In recent study on Arizona showed that Autistic children have statistically significant differences in their metabolic and nutritional status when compared to non sibling match neurotypical controls<sup>4</sup>. This study showed that the autistic group had decreased biomarkers which include vitamins leading to increased oxidative stress, reduced capacity for energy transport and elimination of waste products. This can be expressed as variations in severity of autism. So healthy eating covering all the food groups is important but can be difficult with autistic children let alone with the added burden of medication increasing the carbohydrate craving. Switching options offered from high to low GI products can also help.

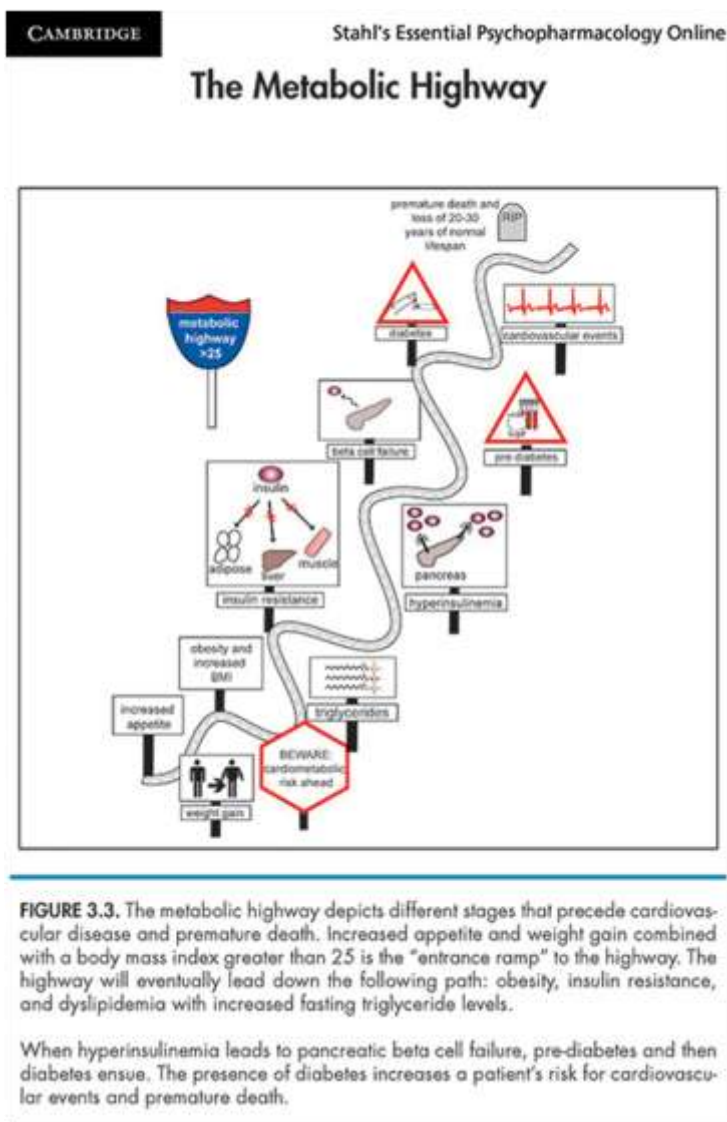
### Summary

Obesity is increasingly prevalent in childhood and adolescence. Family doctors are well placed to manage this problem. Effective management of obesity in this age group will include:

- having a family-focused approach, especially with pre-adolescent patients
- setting small, achievable goals for behaviour change
- targeting sedentary behaviour
- helping families and young people to make healthier food choices
- providing ongoing support as families and young people make sustainable lifestyle changes<sup>3</sup>. ●

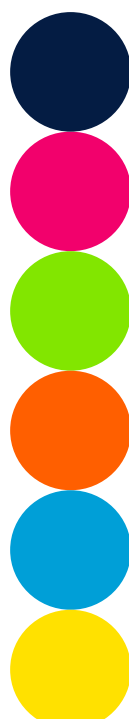
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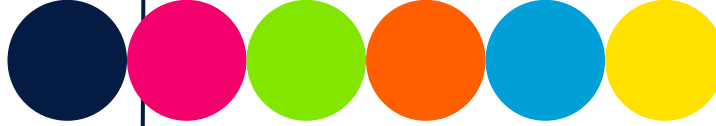
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**FIGURE 3.3.** The metabolic highway depicts different stages that precede cardiovascular disease and premature death. Increased appetite and weight gain combined with a body mass index greater than 25 is the "entrance ramp" to the highway. The highway will eventually lead down the following path: obesity, insulin resistance, and dyslipidemia with increased fasting triglyceride levels.

When hyperinsulinemia leads to pancreatic beta cell failure, pre-diabetes and then diabetes ensue. The presence of diabetes increases a patient's risk for cardiovascular events and premature death.





## reviews...



### Book Review:

#### Mental Health Aspects of Autism and Asperger Syndrome- Mohammad Ghaziuddin

This book alerts parents and professionals alike to the occurrence of common emotional and psychological problems in Autism Spectrum Disorders (ASD) such as schizophrenia, anxiety, violence, depression, tics etc. and discusses the detection and treatment of psychiatric problems. This book gives a great overview of Autism and Aspergers syndrome with historical backgrounds, prevalence, causes and information about interventions.

Although the language is advanced in some areas, the conditions described in this book are those that the author has most commonly seen in autistic children and adults. There are some great case studies paired with the individual chapters which is very informative and gives you a nice overview of each disorder. Although a little complicated, it is a great book to use as a handbook of sorts.



### Website Review:

[www.physicalasanything.com.au](http://www.physicalasanything.com.au)

This new website contains both medical and educational information on more than 50 medical, developmental and psychological conditions. There are videos, online resources and information to help parents, carers, teachers and healthcare professionals to support students. Importantly, it also describes the educational implications of each condition.

The information for schools includes implications of the condition within the school setting, what classroom support is needed, future planning issues, teaching and learning and other key points. It is an extremely detailed resource that is a help in day-to-day questions about children and adolescents at school and home with any one of these conditions. It additionally focuses on future planning. The website is endorsed by NSW Department of Education and NSW Health.



### Organisation Review:

NSW Institute of Psychiatry  
[www.iop.nsw.edu.au](http://www.iop.nsw.edu.au)

The New South Wales Institute of Psychiatry (NSWIOP) is a major provider of continuing professional education in mental health in Australia. The Institute provides training for health care professionals, psychiatrists-in-training, consumers and staff of non-government organisations, general practitioners and the public. NSWIOP offers a variety of courses and ongoing professional development including multidisciplinary education about perinatal and infant mental health, child and adolescent mental health, adult mental health, older persons mental health and family therapy. Courses range from workshops to masters degrees and research fellowships.

The institute offers mental health related **DVD's and other publications**. You can download their online professional development calendar that offers an array of courses throughout the year.

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

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

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

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