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mental health and intellectual and developmental disability...

Link

coordinator's message...

Welcome to the first edition of the school link newsletter for 2013,

The CHW School-Link Steering Committee has broadened our focus to include developmental disabilities in addition to our intellectual disability focus. This will enable us to provide our readers with more articles and resources than ever before. In line with our new focus, a small team of staff at the CHW was able to initiate *Autism and Friends at The Movies* earlier this month, see article below. Happy reading and please send us any material or ideas for future editions.

AUTISM AND FRIENDS AT THE MOVIESFIRST SCREENING

On Saturday 6th April, in celebration of Autism awareness month, the first *Autism and Friends at the Movies* screening took place at Event Cinemas Castle Hill, with 65 people attending. Autism friendly cinema screenings take place regularly in the United Kingdom and have been running in Event Cinemas in Queensland. This screening was a first for New South Wales, creating an environment that reduces the chance of adverse reactions to high sensory stimulus such as sudden loud noises and darkness.

The movie *Wreck it Ralph* remained the same but the environmental conditions were modified - the lights were left on low, the sound was turned down and it was okay for children to get out of their seat and move around if they needed to. This event provided an opportunity for families of children with Autism, an intellectual or developmental disability, or other sensory needs to finally enjoy a cinema experience just as many other families take for granted.

Families were very appreciative of the opportunity to attend the event and highlighted that it was great to be able to be themselves without others judging. Event Cinemas hosted a morning tea to raise money for the hospital and Bandaged Bear helped greet the children and passers by. We look forward to planning the next event. ●



Jodie Caruana,
School-Link Coordinator

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Learn more about School-Link and the Children's Hospital at Westmead project on www.schoolink.chw.edu.au



a note from David Dossetor...



Better Health Services for People with Intellectual Disability in NSW: The Agency of Clinical Innovation Disability Network.

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.

This article describes the health needs for people with intellectual disability in Australia, and describes the developments in NSW to establish a health framework for better health services for people with intellectual disability. Brief comparison is made to the initiatives to tackle the health disadvantage of this population in the UK.

The context and the evidence of health need in people with intellectual disability

There are approximately 200,000 people in Australia whose main disabling condition is intellectual and developmental disorders, and in NSW there are 65,000 or 0.9% of the population and this corresponds with surveys which report 1% of population need assistance with basic daily living activities: self-care, mobility, and verbal communication. Such people require lifelong support and assistance, and the levels of support have been defined as intermittent, limited or high/pervasive support needs. In NSW of those of adult age it has been "guestimated" that 0.2% or 15,000, with intellectual disability also have complex health needs, but this could be an underestimate.

There is good evidence that people with intellectual disability are disadvantaged in their health status compared with a mainstream population. People with intellectual disability are characterised by communication difficulties, poor understanding of their everyday and special health needs and poor procedures for the delivery of health services. They have poorer outcomes and have more difficulty in obtaining the necessary health services (NSW Health: Service Framework to improve the health care of people with intellectual disability, 2012). Whereas the mean life expectancy of men and women in the general population is 78.7 and 83.5 years respectively, for people with mild, moderate and severe intellectual disability mean life expectancy are 74, 67 and 58 years (Bittles et al, 2000). This data derives from Western Australia, which is the only state to have an intellectual disability register, which is a key tool to evaluate the health needs and outcomes.

Although there have been substantial increases in life expectancy across the spectrum of intellectual disability, health services are ill prepared for the special health needs of this growing ageing population. Further the NSW Ombudsman (McKenzie K, Reviewing the deaths of people with disability in care, 2011. www.ombo.nsw.gov.au) has reported on the number of deaths of people with intellectual disability in boarding houses, accommodation provided by Non-Government Organisations and by NSW Disability Services, often from readily preventable and treatable problems such as recurrent respiratory infection and aspiration pneumonia in the context of swallowing problems. Also reported were the co-existing chronic health problems including incontinence, dysphagia (swallowing or drinking problems), epilepsy, constipation, weight concerns, gastro oesophageal reflux and helico bacteria infection, osteoporosis, diabetes, hypertension and asthma. Most had other disabilities such as physical disability (eg Cerebral Palsy) sensory impairment (almost half, mainly sight impairment) and psychiatric disability (almost a quarter, mainly psychosis). Most also required a substitute decision-maker or person responsible for providing consent to mental or dental treatment on their behalf.

Contemporary research indicates that people with intellectual disability experience a high prevalence of significant med-

ical and mental health problems as well as conditions often being unrecognised, misdiagnosed and poorly managed (Lennox & Kerr, 1997). For example Helen Beange the NSW medical practitioner and advocate found higher rates of medical disorders in an unselected or random sample of people with ID aged 20-50 living in North Shore of Sydney (Beange et al, 1995) (see table). Only 15% had been seen as patients, 10% had visited the Health Promotion Clinic for people with intellectual disability at Royal North Shore Hospital, and 5% had presented because of symptoms. Despite a mean of 5.4 health problems per patient, when interviewed 65% reported no symptoms and 24% of carers said there were no problems.

Accordingly, even those without recognised problems still need a thorough health check-up. People with intellectual disability across all ages are at greater risk of developing mental illness: 40% of children require treatment of mental health problems and as many as 50% of adults and 60% of older people with intellectual disability. Studies show that people with mild and borderline intellectual disability are vastly over-represented in the criminal justice system (35%) and have high rates of alcohol and drug problems (Kenny, 2006).

Table of Rates Medical Disorders	
Medical Disorder	Rate in %
Dental	86
Ocular	68
Dietry	57
Neurological	53
(Incl Epilepsy)	29
Skin	96
ENT	40
(inc deafness)	25
Orthopaedic	35
Endocrine	29
Cardiovascular	24
Psychiatric	24
Gastrointestinal	17
Haemopoetic	12
Iatrogenic	11
Renal	11
Respiratory	10

Table of Summary of Health Impairments	
Type of Problem	Mean #/person
Major Problems	2.5
Minor Problems	2.9
Total Problems	5.4
Not previously diagnosed	2.3
Not adequately managed	2.7
Specialist care needed	4.0

(Beange *et al*, 1995)

Note: *Iatrogenic means problems caused by medical intervention

**A major problem was a health problem that significantly added to health handicap or performance.

As life span is increasing the disease patterns and risk factors for diseases are increasing with increasing rates of cancer, coronary heart disease, diabetes, thyroid disease, arthritis, falls, and early dementia. In addition, people with intellectual disability do not use preventative health care and health promotion programs to the same extent as the general population?. Many of the causes of intellectual disability are also complex with associated problems. 25% of people presenting to health clinics are taking psychotropic medications for behaviour and psychiatric disturbances, often several at a time.

Family carers are the major contributors to the care and support of people with intellectual disability, so their health is as important as for those dependent on them. Yet this population of carers have marked increased limiting health problems compared to the general population, such as depression (4 times more common), back problems and stress related illnesses. Numerous surveys have found that both general practitioners and other specialists lack confidence in meeting the health needs of people with intellectual disability and believe current training is inadequate (Cook & Lennox, 2000). This also applies to undergraduate medical and allied health training or post graduate training for doctors and nurses (Lennox & Diggins, 1999).

The NSW Health initiative to develop a framework for better health for people with intellectual disability

How was the framework developed?

The deinstitutionalisation and the demedicalisation of the care of people with intellectual disability in the 80s, left a government led service that was inadequate for the support of people with intellectual disability in the community, and a lack of investment in a specialist health system to support them (Parmenter, 1988). Further, there has been a lack of collaboration between the two underfunded services. In this context NSW Department of Health and ADHC commissioned a draft service framework to improve the health care for people with intellectual disability in 2007 and in 2009 I was a member of the advisory group to consider various options to improve health services. This in turn led to the Consultancy report by **KPMG for NSW Health: "Analysis of costs and benefits of specialised intellectual disability health services and enhanced clinical leadership"** (See Below).

NSW Health introduced a Service Framework of 5 tiers:

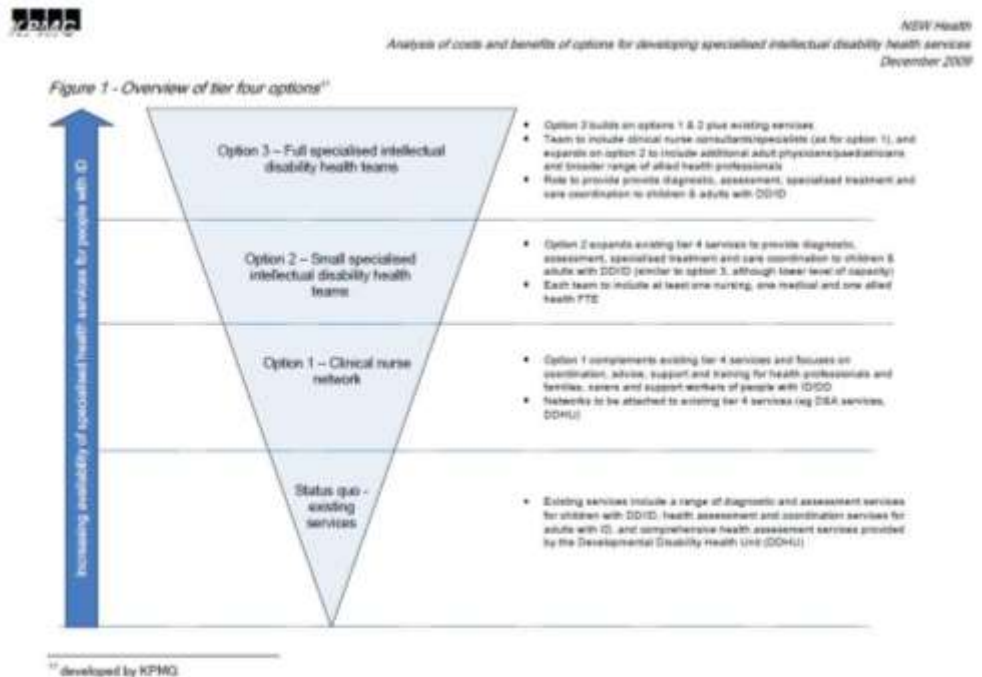
- Tier 1.** Strategic health policy and population health;
- Tier 2.** Primary health and community health care;
- Tier 3.** Acute health care services;
- Tier 4.** Specialised intellectual disability

estimated cost of a sample of clinical cases that illustrated the additional cost incurred through inadequate or inefficient health and mental health provision for those with complex and special needs. They estimated the costs that might be saved through the provision of multidisciplinary expertise, particularly from saving lengthy hospitalisation or through maintaining care in the family as opposed to long term community care, not to mention the improved health and quality of life which was not costed. They also looked at costing different specialist service models to improve tier 4 specialised health services:

Three options for enhancing tier 4 were costed to provide a service throughout the state:

1. A Clinical Nurse Network:
 - a. one CNC per area health service: \$1.364M.
 - b. one CNC/CNS per 450,000 population: \$4.575M.
2. Small intellectual disability teams: \$14.488M.
3. Full intellectual disability health teams: \$37.146M.

It was felt that having specialist services



health services which provide specialised assessment, intervention and treatment for people with intellectual disability and complex health needs and facilities development of the health systems capacity to meet the needs of people with intellectual disability generally;

Tier 5. State-wide clinical leadership, research, education and training.

in some area health services that provided outreach to others was unacceptable, but that was before this number was increased by breaking up area health services into the 15 local health districts (LHDs) that we now have.

They also estimated recurrent costs of implementing tier 5: \$0.287M to support a clinical leadership network and \$1.26M to fund 3 university chairs in intellectual

In the absence of epidemiological and health economic data, KPMG did an esti-

disability medicine, nursing and allied health.

What does the framework look like?

This report was followed by NSW Health establishing and funding in 2011 the **Disability Network of the Agency of Clinical Innovation (ACI)**, and three pilot specialised health services for people with intellectual disability of \$450,000 each. The ACI was established in 2010 to drive continuous improvement in the way care is provided to patients in NSW health system and supports 29 different clinical networks. The ACI is one of the 6 pillars of reform recommended by the Garling Inquiry into Acute Care Services in NSW Public Hospitals (2008). Its core aims are: promoting innovation, giving consumers a say and using evidence. The other 5 pillars are: 1. The Clinical Excellence Commission with an overview of clinical governance, 2. The Bureau of Health Information to provide information on activity and outcomes, 3. the Health Education, and Training Institute (HETI) managing training not just for clinicians, undergraduates and vocational training but also non-clinical leadership and management, 4. NSW Kids and Families, and 5. Rural Health. The 3 3-year pilot specialist health services are:

1. **The Metro-Regional ID network (MRID.net)** based at St Georges Hospital in Kogarah, which provides local and regional multidisciplinary outreach clinic to the Illawarra and other parts of NSW.
2. **The Fairfield Specialist Intellectual Disability Health Service** is an community based team of the Children’s Hospital at Westmead, co-located with disability services, extends its service to Western Sydney, with a focus on young people with intellectual disability facing transition to adult health services and considers added complexity from multicultural diversity.
3. **North Sydney Intellectual Disability Health Team** is based in Cremorne, which promotes a specialised General Practitioner service run by the Centre for Disability Studies. Its outreach will extend to the Central Coast LHD. The 3 pilot projects have oversight and support from steering committees but also meet to compare processes and report to the ACI Disability Network through the Models of Care Subcommittee. These pilot projects are developing formative evaluation processes. KPMG have also been appointed to provide an external evaluation of the benefits of these pilot projects and the Intellectual Disability Network of the ACI which will take place between October 2012 and April 2015.

The ACI Disability Network was founded in 2011 under the chairmanship of Professor Les White, the Chief Paediatrician of NSW and a parent of a young person with intellectual disability and initial scoping sessions encouraged attendance of all interested clinicians, parents, carers and advocates for people with an intellectual disability, representation from NSW Health, Disability Services Partners, Non-Government organisations, and anyone with an interest in improving the services.

These initial discussions led to a framework of 4 Subcommittees whose two chairmen are also members of the Executive Steering Committee, along with other senior stakeholders. The Executive Steering Committee is co-chaired by Les White and Maria Heaton, a parent of a child with intellectual disability and winner of the parent of the year award 2012; all committees are supported by the network manager, Tracey Szanto. Each subcommittee has now been asked to define strategic aims for the next 6 and 12 months.

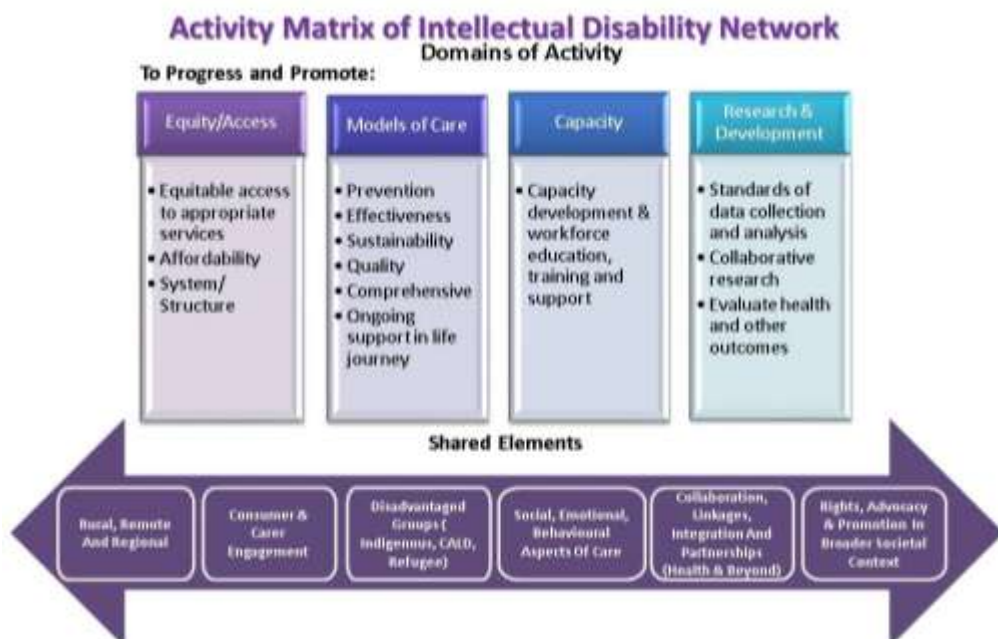
The following are a sample of the initiatives of each of the **subcommittees**:

- **Access and Equity** are drafting a survey to identify specialist health services and gaps.
- **Research and Development** are drafting a survey of current research and have a project looking at linking data systems between **Health and Disability Services** to understand and monitor health usage by people with an intellectual disability.
- **Workforce and Capacity** is mapping current workforce development processes and developing strategies to change attitudes and improve communication of health employees around people with intellectual disability.

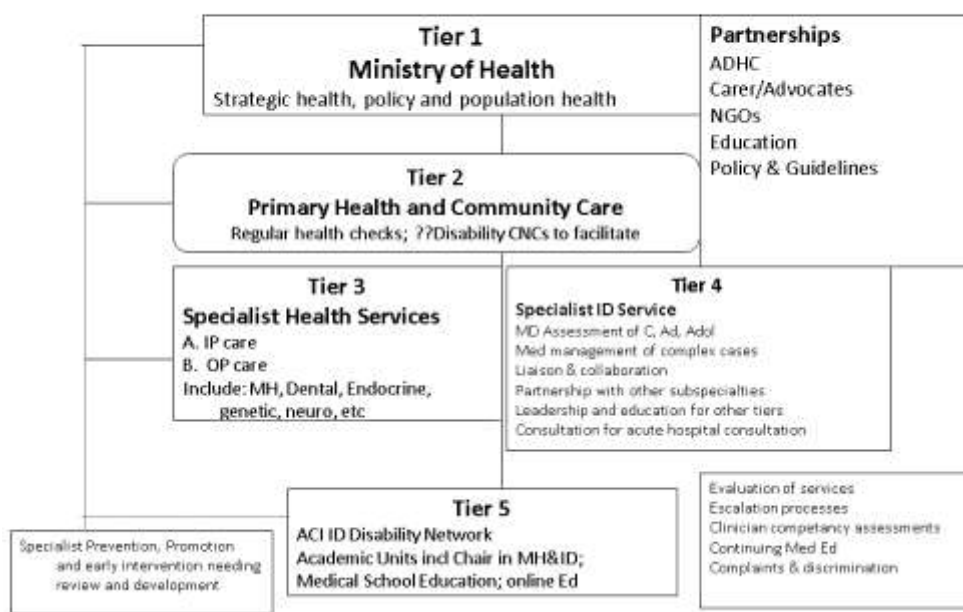
- **Models of Care**, of which I am co-chair with Dr. Robert Leitner, are working on how to better understand the different components of the tiered structure of services and what each tier is doing to consider the special needs of people with an intellectual disability and how to improve the interaction between each tier. This involves holding forums on different components of the services, such as Corrective Services and Forensic Mental Health Services Initiatives, and in the near future General Practice and Medicare Locals.

It is also important to help people with an intellectual disability and their carers and advocates to better understand and use the health system. We have produced a **draft document on the “Responsibilities and Rights for Carers and Advocates of People with an Intellectual Disability to enable equity of access to Health Services in NSW”** which is reproduced later in the newsletter as part of the consultation process, and **“Pathways to Care for Children and Adolescents with Intellectual Disability Challenging Behaviour and Mental Health Problems”** which we shall present in an edition later this year.

The network had a successful first annual half day workshop on November 15, 2012, which enabled a wider participation particularly of consumers and carers to how different components of the network are developing. Prof Eric Emerson of Lancaster and Sydney Universities gave a notable **keynote presentation on “Improving health and lives: The Learning Disabilities Observatory”** on how the same issues of health inequality and access to health care are being tackled in UK. On a background of socially inclusive intellectual disability specific policies, increasingly



NSW Service Framework for People with ID and their carers



ambitious legislation regarding disability equality and accumulating evidence of poorer health of people with intellectual disability and institutional discrimination in health care systems, the UK government set up the National Specialist Public Health Observatory (LDO) in 2010 with 1 million pounds annual budget for 3 years (www.improvinghealthandlives.org.uk).

The LDO has established important partnerships, and has provided an evidence based approach to examining the access of people with intellectual disability to health care. The LDO has summarised the evidence on current health status and the multifactorial determinants to health. It has worked to make the risk factors and the service usage data localised. With General Practice data extracts they have charted a rise in general health check-up for people with intellectual disability, with details of investigations performed, whether they have a stable home, are in employment, and receive social and or community care. The LDO has audited the extent to which each local administrative district have made “reasonable adjustments” (legal terminology for health service adaptations for people with intellectual disability) to enable access to services including dental, ophthalmology services and cancer screening. The LDO has developed audit tools for Autism health and employment services and disseminated a Royal College of Psychiatry Report on practitioners enabling people with mild intellectual disability and mental health problems to access mental healthcare services. The LDO has reported on rates of unnecessary admissions to hospital due to inadequate management of chronic conditions in the community

and reviewed the quality of care of in-patient services for challenging behaviour.

Currently, there is a further confidential enquiry into deaths of people with learning difficulties. The LDO is promoting positive messages and information on the positive contributions people with an intellectual disability can and do make to our communities and the barriers to that participation (Fulfilling Potential: building a deeper understanding of disability in UK today, 2013). The LDO has demonstrated that major health institutional change can be achieved with political will, serious academic leadership and funding, and the strength of the National Health Service of UK (NHS) data systems.

What is the future for the Framework for Health Services for people with Intellectual Disability?

Compared with the NHS, I think the ACI Disability Network of clinicians and services and Specialist Health Pilot Studies start from a weaker service and academic base for people with intellectual disability. However, there is a wealth of motivation, concern and professionalism to make a start to the institutional change needed in NSW.

I am impressed with the extent to which I see strong advocacy leading to awareness raising of these health needs for example in the accounts of the pilot projects efforts to get a better deal for their patients from the broader health and disability systems. There is nothing like

experience of a successful service provided to make it happen again.

I am convinced that change requires a strong voice and partnership with consumers and advocates. The health service is a complex system and I feel it is important to educate consumers and their carers and advocates about these service systems and how to get the best out of this network of clinicians. Evidently data is important as it speaks directly to managers on the effectiveness of a service but currently our data systems are weak on information about people with an intellectual disability, especially across funding structures, state, federal, private, NGOs.

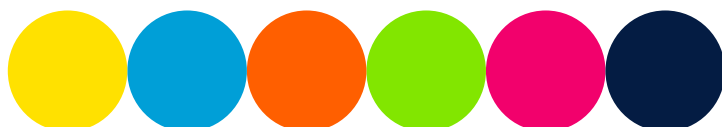
We shall need better training and multi-disciplinary involvement within mainstream services on people with an intellectual disability. It is my view that two other important drivers of change are clinical research and human moral, ethical and legal development (Evans et al, 2012).

As medicine advances, so specialist academic expertise needs to be nurtured to keep abreast of scientific progress which in turn needs to promote the dissemination of advances of knowledge to mainstream services. Despite current financial caution in all governments, there is a growing recognition of the human rights of people with intellectual disability and a political will to make progress in our health and welfare institutions. Hopefully the Disability Network and Pilot Projects will build evidence of their impact and worth and guide future political, clinical and research direction and investment in NSW. ●

Postscript: Opportunity remains for people to contribute to these potential developments and the ACI Disability Network. Issues of mortality and unnecessary foreshortened life expectancy are emotive concerns. However I feel that chronic health and mental health problems are central to improving the quality of life of people with intellectual disability. In a subsequent article I shall return to report on the developments in NSW for mental health and wellbeing.

References

Please see www.schoolink.chw.edu.au for a full list of references from this article.



Beyond the walls of the play therapy room...



Angie Zappala and Carmen Pannucio
Behaviour Support Practitioners
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Ageing, Disability and Home Care

Lucinda Mora and Kellie van Sebille
Senior Clinical Consultants
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Background

Eighteen months has passed since six Ageing, Disability and Home Care; NSW Department of Family and Community Services employees completed their initial training in therapeutic play through Play Therapy International (PTI). The aim was to build upon the success of phase one of the Play Therapy Pilot initiated by Lucinda Mora in 2008 (OT, Play Therapist and Senior Clinical Consultant). Since then, the ADHC trainee play therapists have discovered a world of powerful possibilities. They have realised their capacity to connect, nurture and heal individuals with an intellectual disability using a creative arts therapy.

What is Play Therapy?

Play is a natural medium for self expression and is critical to childhood development. As Landreth (2002) states "Birds fly, fish swim, children play." Within the boundaries of a safe and emotionally supportive play environment, the child is provided an opportunity to play out their feelings and problems.

Therefore play therapy is a non-judgmental, non-directive and non-interpretative psychological intervention that offers young people an opportunity to 'play out' their feelings using toys rather than words in a safe therapeutic environment.

Play therapy provides the child the chance to master their world as they create, develop and maintain their own sense of self (Schaefer, 2011), particularly when children do not have the words or capacity to share their needs and wants. **The toys become the child's words and their play becomes their language** (Landreth, 2002). The therapist then reflects upon what they see, hear and feel in order to support the child to gain insight.

Play therapy outcomes are different for each child and are possible, regardless of stage of development, gender, socio-economics, language, intellect, ethnicity or culture.

The Paradigm: To direct or not to direct

Many models of play therapy exist which either fall under the category of directive or non-directive play therapy. The ADHC trainee play therapists work non-directively using Axline's (1969) principles. Some of these key principles include accepting the child as they are; **going at the child's pace and following the child's lead. Within a session, if a child wishes to stand quietly, talk, paint a picture, make something in the sandtray or bang the drums, the responsibility to make the choice is the child's.**

The Clients

Therapeutic play services are being provided in Metro North region to children aged 4 to 16 with mild to severe intellectual disabilities, who present with a range of difficulties. These include issues relating to communication, anxiety, social isolation, family separation, grief and loss, attachment issues and trauma.

The Effects: Beyond the walls of the Play Therapy Room

There has been strong evidence of positive changes within session and across settings. The following statements illustrate these changes. Children have learnt to express and regulate their feelings and assert their own needs. Others' have learnt how to connect emotionally with other children and adults. Parents and teachers report improved concentration, problem solving and on-task behaviour.

"There has been strong evidence of positive changes within session and across settings..."

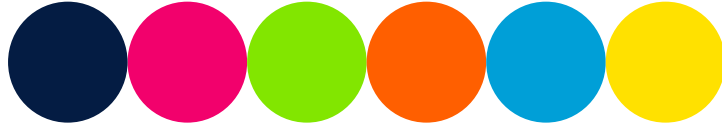
The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) is being used to evaluate outcomes. A statistically significant improvement on total SDQ scores was found ($p = .008$) indicating that the play therapy intervention is obtaining positive outcomes. In addition to this measure, therapists are asking parents and caregivers to rate goals before and after intervention. Parent rating scores indicate a significant improvement ($p = .007$). Analysis suggests that most caregivers and the children themselves are rating positive changes in emotional, behavioural and social states.

Caregivers have reported:

"Instead of keeping his feelings inside, he will tell us verbally now." (Grandmother of 10 year old child).

"My son can now regulate his temper and tends to calm down a lot quicker by himself." (Father of 16 year old adolescent).

"I used to say that my son was practically non-verbal. With the help of play therapy he has gone ahead leaps and bounds in his communication. Just amazing. Not to mention he initiates affection to us now, going up and giving his dad a hug now is a priceless sight to see." (Mother of 6 year old child).



Further information:

There are several pathways that can lead to becoming an accredited play therapist. For assistance in understanding the development of play therapy in Australia and information about training, visit the Australasian Pacific Play Therapy Association (APPTA) www.appta.org.au

Play therapy courses are becoming more available in Australia. Practitioners considering becoming Play Therapists will need to investigate providers and their accreditation options thoroughly. A short course in play therapy will not equip practitioners with all they need, to work effectively and safely with children. Play Therapists are certified by recognised profes-

sional organisations and participate in clinical supervision specific to play therapy. ●

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Family & Community Services
Ageing, Disability & Home Care

reviews...



Book Review: Fragile X Syndrome: Diagnosis, Treatment and Research

Edited by Randi J Hagerman and Paul J Hagerman. John Hopkins University Press. (Recommended for professionals) This superb 480 page book is a must for the professional with any interest in fragile x syndrome. Topics covered in part one include epidemiology and the associated cytogenetic and molecular findings, present research regarding protein studies and neuropsychology of the fragile X syndrome. The second part of the book covers treatment and management strategies including genetic counselling, medical follow up, psychopharmacology, psychotherapy, education, occupational therapy, speech and language therapy and protein and gene therapy. This new third edition is not only a very current review but in addition makes for fascinating reading. It is the one definitive text about fragile x syndrome. Available from the Fragile X Alliance Inc for \$88.00.

Organisation Review: www.sdn.org.au

As a not-for-profit organisation established in 1905, SDN is one of Australia's most experienced and trusted leaders in early childhood education and care. SDN is a holistic children's services organisation providing mainstream child care and preschool for 3000 children in NSW and the ACT as well as specialist services for children with high support needs and for families facing challenges. They provide a range of early intervention and support services to help children with disabilities, developmental delays, autism spectrum disorder, speech impairments and behavioural problems. Some of the services provided include brighter futures (an early intervention service), child and family resource centre in Granville which includes a toy library and a parent information stay and play group. Community of learners is an early intervention support service for children with disabilities. SDN Beranga is autism-specific service in Rooty Hill that branches into 13 centres. Visit the SDN website for more information.

Website Review: www.boxofideas.org

This website is a fantastic resource for parents that need ideas about everything! It is described as a one stop shop for 1000s of ideas, guidance and information on everything from early years to employment. You are able to search resources/ideas such as book lists, video talks by professionals, in-depth definitions of learning difficulties on the website for something specific or join the discussion with other parents online. There are two main sections of the website,

- *Practical skills for home*; this includes hobbies and leisure, independent living skills, social and emotional behaviour and study skills and attention.
- *Practical skills for education and the workplace*: includes preschool, primary school, secondary school and further education, higher education and employment.

This website is extremely practical and will be helpful for parents and professionals.



less heat, more warmth...

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I like stories. I particularly like true stories that have about them a sense of unreality, stories that leave the listener wondering **whether they've just been privy to someone's weird life experience, or have simply been entertained by an urban myth.** This following story is true. It is a story that I have told many times to teacher groups at workshops and seminars to illustrate an important concept.

Here's the story:

Many years ago a close friend of mine was enrolled in a **"body work" course.** During one of the workshops on this course, participants were asked to lie on the floor and get into a meditative state. When they were about five minutes into their relaxation, just as they were experiencing a wonderfully sublime state, the teacher slammed two saucepan lids together. Such a thunderclap had the obvious effect. Some people swore at the teacher, others sat in bewildered amazement, while a fair few were in tears, too startled to speak. The obvious question, **"Why?" was demanded of the teacher.** She explained, rather perfunctorily, that she wanted them to experience what she called a **"startle reaction."** I guess they did.

After a short time was spent processing how the participants had felt about what

had happened, she asked them to again lie on the floor and meditate. Trusting lot that they were they complied, only this time they were forewarned that in three minutes she would bash the saucepan lids together. After about two minutes people started to get unsettled, the fidgeting became more obvious and the general restlessness more pronounced. The atmosphere became increasingly charged as the three minute deadline approached. About a half minute after the deadline had elapsed the sense of anticipation became excruciating, so much so that someone finally snapped **and yelled out, "Slam the bloody lids together!"** It was only after the lids had been banged that participants began to relax.

Leaving ethical considerations of this experiment aside, how is this story relevant to our management of some children who have emotional or behavioural problems? Quite simply, it is to do with expectation and belief. If we substitute the saucepan lids for a regular clout over the ear, belittling cruel statements or constant ridicule, then we can gain a small (very small) measure of understanding of the expectations of these children.

If a child has grown up in an abusive environment – either physically or emotionally – then that child will carry around a **'memory store' (Dodge, 1986) of what their world is like.** And for such children their world is a none too pleasant place. When these children experience a temporary reprieve from such abuse, such as when they go to school or come to

Redbank, locked into their body and mind is the strong belief that the world is a dangerous place, that adults cannot be trusted, that adults abuse. It is not uncommon for them to expect that the abuse will continue and will go about trying to recreate the abusive environment from which they've come. Just like the poor fellow who wanted the saucepan lids hit together to ease his sense of anxiety, these children will go around with a sense of dreaded expectation that

"The better the behaviour you expect, the better the behaviour you will get..."

may only be temporarily relieved by having adults conform to their negative view of the world, the belief that adults will eventually hurt them in one way or another.

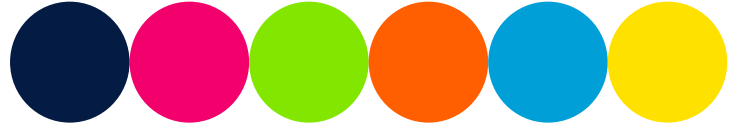
How can we deal with this?

An obvious initial strategy is that of being aware that this can actually occur. That these children can use intimidating tactics, provocative gestures, hurtful, cruel and foul language in an attempt to get the adult to fulfill the abusive role. Knowing this is the first step in preventing ourselves from reconfirming the child's world view. By seeing the child's provocative actions for what they are, can allow us to approach these children with less heat and more warmth. Implicit in some of these provocative actions is the notion that the children are also testing you to see if you can be trusted not to hurt them and not reject them.

Remember, when dealing with these kids **don't be surprised if their behaviour gets worse before it gets better.** In fact, expect it to.

Another useful strategy is that of having some stock phrases or planned language at the ready. Such language is of particular importance when we feel under pressure and are not sure of what to do next. When dealing with these children we need to come from our head (planned) and not from our gut (reactive). Rather than get into a power struggle with the child and threaten something in the heat





of the moment that we cannot follow through later, or threaten something that is punitive and only serves to reconfirm **the child's hostile view of the world, it is better to say something that allows both the child and the adult some time to cool down.** Something that provides an opportunity for both to reflect upon what is happening. An example of one such phrase, which I use quite often with oppositional children who continually refuse to follow **instructions is: "I want you to make a good choice, so you will need to follow the instruction. I'll give you a couple of minutes to think about it and I'll come back and check on you."**

This provides some breathing space for the child to think about their actions and, more importantly, shows the child that despite their having behaved in a provocative and challenging fashion, the adults around them will remain calm (outwardly at least) and not become hostile towards them.

Further, it allows the adult to work out what they will do next. The adults, by behaving in such a controlled manner, are modelling to the child a different way of being in the world. They are showing that, even when under pressure, adults can still be caring, supportive and nurturing, while at the same time being firm, persis-

tent and consistent. Even though it may be difficult to discern in some children any behavioural or attitudinal change while they are at Redbank, the effects of modelling appropriate behaviour is powerful and should not be underestimated.

As important as the child's expectations of the world are to them, are the adult's expectations of what they believe the child can – or can't – achieve. The better the behaviour you expect, the better the behaviour you will get. Always expect a lot. And leave the saucepan lids in the cupboard. ●

resources...

- *Alive 90.5 fm Australian Spectrum with Ross* (Your Editor of the Global Gazette). Proudly sponsored by Global Disability & Health Care Services. Tuesday night 9 to 12 pm for all Australian blues, roots, jazz, folk, indigenous and contemporary music. **Studio guests. Blues, Folk and Jazz Gig Guide. tomorrow's weather today and music. Internet Radio Streaming world-wide online at www.alive905.com.au** [follow the Listen Live links]
- *Fragile X Syndrome- Clinical and Molecular Aspects (2009) Version 2* is a stand-alone interactive CD-ROM integrating the genetics and clinical features of fragile X syndrome. It is produced by Associate Professor Sylvia Metcalf from the University of Melbourne and Dr Jonathan Cohen from the Fragile X Alliance. The program covers clinical diagnosis, laboratory diagnostics, and personal perspectives and includes high quality media such as videos, animations and interactive images from Australian families. Multiple choice questions, glossary of terms and references are also included. This program will be useful for students studying human genetics, medical and biomedical courses, and for continuing professional education. Available from the Fragile X Alliance Inc for \$44.00
- The **Australian Institute of Health and Welfare's Mental Health Services in Australia** website has been updated. The website describes the activities and characteristics of the wide range of health care and treatment services provided for people with mental health problems in Australia ranging from general practitioners to psychiatric disability support services. <http://mhsa.aihw.gov.au/services/>.
- The *MindSpot Clinic* is a free telephone and online service for Australians with stress, worry, anxiety, low mood or depression. It provides mental health screening assessments, therapist-guided treatment courses and referrals to help people recover and stay well. The MindSpot Clinic is fully funded by the Australian Government Department of Health and Ageing and its team includes psychologists, psychiatrists, social workers, and indigenous mental health workers. Visit www.mindspot.org.au.
- **Siblings Australia have set up a new closed Facebook group, 'SibChat', for adult siblings to share experiences and information about services that might be helpful to them or to their brother or sister with a disability or chronic illness (including mental illness).** Visit <http://www.facebook.com/groups/209185819206044> or search SibChat on Facebook.
- *Carers NSW* has a free six week group counselling program called Talk-Link. The program is run over the telephone and is free for carers from across NSW. Using teleconferencing, a group of six to eight carers and two trained facilitators get together over the telephone, at the same time each week, to explore issues around caring. The program runs for six consecutive weeks with each weekly session lasting for one hour. Contact **1800 242 636** or email nccp.admin@carersnsw.org.au.
- *Small Steps* is a program that aims to raise awareness and improve the recognition of anxiety disorders in children. It is a free community service run by the Mental Health Association NSW. They offer free 'anxiety awareness' seminars for primary school staff (teachers, principals, administrative staff) and parents. A Small Steps seminar will usually run for about an hour and can be held at your local school. To book a small steps seminar for your school staff or parents contact **02 9339 6088** or smallsteps@mentalhealth.asn.au.
- *Shoalhaven Special A's (SSA)* is an athletics based program designed specifically for children with special needs. The focus is on having fun, improving fitness and developing skills in a safe, relaxed environment. SSA is run by members of the Nowra Athletics Club and volunteers from the Shoalhaven Community. Term 2 Program starts on 6 May and ends 24 June. Sessions are held on Monday afternoons at Willandra. For more information phone **0432 256 030** and speak to Julianne or email info@shoalhavenspecialas.com. There is also a website - www.shoalhavenspecialas.com.
- Disability resources in community languages are available from *NDCO*. There is information about the NDCO program in Arabic, Chinese, Dinka, Filipino, Hindi, Khmer, Urdu and Vietnamese. There is also information about disability, and support for students. Information can be found at <http://pubsites.uws.edu.au/ndco/links/resources.htm#five>
- The *Royal Australian and New Zealand College of Psychiatrists (RANZCP)* have launched a new 'Find a Psychiatrist' online directory. It includes details of consultant psychiatrists in private practice. Visit www.ranzcp.org/find-a-psychiatrist.

getting students ready for life after school...

Getting students ready for life after school – top tips for schools and services

Nicole Ison, Team Leader
Western Sydney National Disability Coordination Officer Program
University of Western Sydney, Equity and Diversity Unit
Contact: ndco@uws.edu.au

The Western Sydney National Disability Coordination Officer Program (WSNDCO) is funded by the Australian Government and works to improve the transition and participation of people with disabilities (including chronic medical conditions and mental health conditions) into post-school education, training and employment. WSNDCO is hosted by the University of Western Sydney Equity and Diversity Unit. There are 31 NDCO regions across Australia. To find an NDCO in your area, go to

www.innovation.gov.au/ndco. You can find out more about the WSNDCO Program and access a large range of information and resources in the areas of education, training and work at www.uws.edu.au/ndco.

The WSNDCO program has developed a series of *Get Ready* resources for young people with disabilities, their parents and carers, and for schools and services. These resources are based on our top ten tips of the key ways that young people with disabilities can be supported to plan for a successful life after school. Our top ten tips are evidence-based and were developed using a multi-stage process which included:

- a detailed review of transition planning literature and research evidence
- a review of relevant legislation, policy, and existing resources
- grouping of tips under ten key message themes
- consultation with experts in the area of further education, training and employment for people with disabilities

There are so many things for young people to think about when getting ready for life after school – What do I want to do? Work? Study at Uni? Study at TAFE or another registered training organisation? Maybe an Apprenticeship or Traineeship? A Transition

to Work Program? Where do I find out about what's involved? Who can help me?

For young people with disabilities there are even more questions - What support might I need? Where can I get it? What are my rights? And importantly, how will all of this fit with the rest of my life? Our NDCO resources can help young people, and those supporting them, to answer these questions.

“There are so many things for young people to think about when getting ready for life after school ...”

A lot of transition planning takes place when students with disabilities are still at school, particularly with regard to planning for further study or work. Young people who plan their transitions well, with help where needed, are likely to have a better outcome than those who don't (Stewart, 2009). While there is a need for future research and transition program evaluations to increase the overall strength of research evidence in this area (Stewart et al., 2010; McDonagh et al., 2006), there is some consensus within literature around best practice principles and guidelines. We have used these to guide our work.

Here are our top tips for schools and services:

1. **Get ready early** – It is very important for young people to start transition planning as early as possible
2. **Get the big picture** – Help young people to identify their goals and interests, and how their disability may affect their future study or work
3. **Get connected** – Make connections with people who can help the transition
4. **Get to know the options** – Support students to research different post-school options and identify what is realistic

5. **Get the skills** – Focus on employability skills your students will need for future study and work – which do they have and how can they develop others?
6. **Get organised** – It's really important for young people to be organised and manage their time effectively
7. **Get support** – Provide emotional and practical support and identify other types of support young people may need
8. **Get them involved** – Help your students gain experience that will be valuable in the future
9. **Get to know about rights and responsibilities** – Help young people to learn about their rights in education and employment and how they are protected
10. **Get confident** – Encourage young people to practice standing up for themselves and taking responsibility

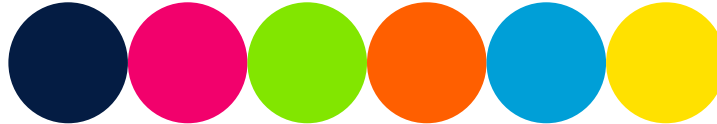
You can find much more detailed information and advice at <http://pubsites.uws.edu.au/ndco/get-ready%20NDCO/educators.htm>. You can also download copies of our comprehensive workbooks and guides for young people and parents from www.uws.edu.au/ndco/getreadytoptips
We'd love to hear from you with feedback on any of our resources! ●

References:

McDonagh, J.E. (2006). Growing up ready for emerging adulthood: An evidence based for professionals involved in transitional care for young people with chronic illness and/or disabilities. *University of Birmingham*. Available: <http://www.transitioninetwork.org.uk/resources/research.aspx>

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Stewart, D., Freeman, M., Law, M., Healy, H., Burke-Gaffney, J., Forhan, M., Young, N., & Guenther, S. (2010). The transition to adulthood for youth with disabilities: Evidence from the literature. *International Encyclopedia of Rehabilitation*. Center for International Rehabilitation Research Information and Exchange. Available: <http://cirrie.buffalo.edu/encyclopedia/en/article/110/>



reading list...

Evans, E., Howlett, S., Kremser, T., Simpson, J., Kayess, R. and Trollor, J. (2012). Service development for intellectual disability mental health: human rights approach. *Journal of Intellectual Disability Research*. Vol 56, Iss 11, Pp. 1098-1109.

A very useful critique of the current situation, based on the current empirical evidence from the literature

Schroeder, S. and Courtemanche, A. (2012). Early prevention of severe neurodevelopmental behaviour disorders: An integration. *Journal of Mental Health Research in Intellectual Disabilities*. Vol 5, Iss 3-4. Pp. 203-214.

This meta-analysis reviews a substantial amount of literature. It is an interesting take on early intervention.

Simonoff, E., Jones, C.R.G., Baird, G., Pickles, A., Happe, F. and Charman, T. (2013). The persistence and stability of psychiatric problems in adolescents with autism spectrum disorders. *Journal of Child Psychology and Psychiatry*. Vol 54, Iss 2, Pp. 186-194.

This is a longitudinal study of adolescents with Autism. Only a few predictions were found.

Skokauskas, N., Sweeney, E., Meehan, J. and Gallagher, L. (2012). Mental health problems in children with Prader-Willi Syndrome. *Journal of Canadian Academy of Child and Adolescent Psychiatry*. Vol 21, Iss 3. Pp. 194-203.

This is an interesting study that looks at children with Prader-Willi and their parents.

Sormanti, M. and Ballan, M.S. (2011). Strengthening grief support for children with developmental disabilities. *School Psychology International*. Vol 32, Iss 2. Pp. 179-193.

This article includes practice guidelines for school-based mental health professionals working with children with a developmental disability who have experienced loss.

Szeftel, R., Mandelbaum, S., Sulman-Smith, H., Naqvi, S., Lawrence, L., Szeftel, Z., Coleman, S. and Gross, L. (2011). Telepsychiatry for children with developmental disabilities: Application for patient care and medical education. *Child and Adolescent Psychiatric Clinics of North America*. Vol 20, Iss 1, Pp. 95-111.

This article reinforces the importance of collaborative care and the use of the technology around us on patient care.

Thompson, T. (2013). Autism research and services for young children: History, progress and challenges. *Journal of Applied Research in Intellectual Disabilities*. Vol 26, Iss 2. Pp. 81-107.

This is a nice overview of the history and the way forward. A historical review of Autism and the way it has been viewed over time.

every student, every school ...

Every Student, Every School – strengthening education for students with additional learning and support needs in NSW public schools

Melissa Clements
Director, Disability, Learning and Support
Department of Education and Communities

On 27 March 2012, the NSW Minister for Education, the Hon. Adrian Piccoli MP, announced the implementation of a learning and support framework in all 2,240 NSW public schools across the state, through a strategy known as 'Every Student, Every School'.

Implementation of the learning and support framework is being facilitated through a wide range of projects that are designed to strengthen educational experiences and outcomes for the full range of students with disability in NSW public schools and their classroom teachers and support staff. Projects are being progressively implemented in 2012 and 2013.

This important reform strategy builds on existing NSW Government commitments in special education and is supported by additional funding over 2 years from the **Australian Government under the 'More Support for Students with Disabilities' National Partnership Agreement**.

The Catholic and Independent school sectors are also benefitting from this National Partnership through their own funding agreements with the Australian Government.

Every Student, Every School is needed because currently there are around 90,000 students in NSW public schools who have additional learning needs because of disability. Around 80 per cent of these students are enrolled in regular classes in their local public school. Many students need adjustments in their day to day learning, whether or not they have a formal disability diagnosis. We need to make sure that we provide every student with the best possible education that we can, and build the capabilities of teachers and support staff to meet the educational needs of students and obligations under the Commonwealth *Disability Standards for Education 2005*.

Every Student, Every School is delivering an increased range of professional learning opportunities for teachers and support staff in NSW public schools to understand and respond to the individual learning and

support needs of their students. This includes scholarships for more teachers to gain a Masters level degree in special education. In 2012, the Department of Education and Communities provided scholarships through this initiative to 158 teachers and a further 200 scholarships are on offer in 2013.

“Many schools now have ongoing specialist teacher support in the school for the first time...”

Access to existing training options in areas of learning for students with disability is also being expanded for more teachers and support staff. This training includes tutor-supported online learning courses in dyslexia and significant reading difficulties, speech, language and communication needs, autism spectrum disorders, motor coordination difficulties and understanding and managing behaviour. These courses have been utilised by the Department since 2009 and are highly rated in feedback from more than 10,000 individual teachers, principals and support staff in NSW public schools to date. A new online learning course to support regular **classroom teachers' understanding of hearing loss** will be introduced in term 1, 2013.

New accredited training in the Commonwealth *Disability Discrimination Act 1992* and its Standards for Education is also being developed for implementation in term 1, 2013.

Since the start of term 3, 2012, every regular NSW public school is now allocated a package of Learning and Support resources, made up of 2 components - specialist teacher positions and annual flexible funding. These resources support students with lower levels of additional learning and support needs and their class teachers, where and when that support is needed. Students do not need a formal disability diagnosis to access support through these resources.

With a significant increase in resources directly allocated to schools under this initiative, many schools now have ongoing specialist teacher support directly in the school for the first time. Principals, through their school learning and support teams, have the flexibility to decide how best to

use their allocated Learning and Support resources to meet the needs of their students, including using flexible funding for additional teacher or learning support of **teacher (teachers' aide) time in the school**.

Students with a disability who have moderate and high level additional learning and support needs, continue to be supported under current guidelines for individually targeted services in regular and special schools.

Every Student, Every School will also better equip teachers in all school settings to identify and respond to the diverse learning needs of their students. The Department is developing new tools and materials for teachers and schools to identify the skills, abilities and needs of their students in collaboration with parents, and to develop personalise learning and support for students who need it.

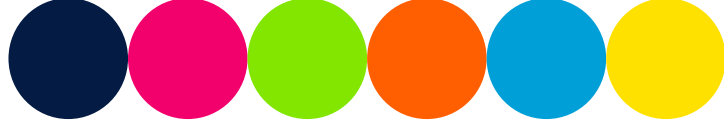
NSW public special schools (Schools for Specific Purposes) have been provided with additional funding in 2012 and 2013 to develop and implement local projects that will network their specialist expertise and project resources with regular schools. These projects are responding to a range of priority areas including: use of technology for curriculum access; case management and support for students with complex needs; supporting transition needs of students with disability; and developing learning and support plans through collaborative partnerships with parents and communities.

The Department is currently developing a new website to support school communities with improved information and resources on the range of ways that NSW public schools support students with disability. Research is being undertaken with a wide range of stakeholders to inform the design of the website, including parents, teachers, regional staff supporting schools and other NSW government agencies. The new website will be launched later this year.

In the meantime, further details of Every Student, Every School and its full range of projects, including a factsheet for parents about support for students in regular classes and information about teacher scholarships, can be found on the Department's website at <http://www.dec.nsw.gov.au/what-we-offer/education-and-training/disability-support/every-student-every-school>. ●



upcoming training and events...



Disability:

2013 Australian National Special Education Conference presented by the **Australasian Special Education Principals' Association** and the **NSW Special Education Principals' and Leaders' Association**. 5th-7th June 2013. Brighton-Le-Sands, Sydney. From \$520 www.gemsevents.com.au/sepla2013

Domestic Violence in a Disability Context. **Association of Children's Welfare Agencies**. 28th May 2013. Sydney. \$220. visit www.acwa.asn.au to register. The Association releases a training calendar per term with several locations across NSW. Definitely worth a look.

Family Advocacy have a series of webinars specifically for parents of students with developmental disability in years 9, 10, 11 and 12. *After School-What Then?*. 2 hour sessions on 14, 16, 17 and 22nd of May. *Inclusive education* seminar on 29th May and a *Supported Living* seminar on the 14th of June. Find out more at <http://www.family-advocacy.com/family-advocacy-workshops-and-events/> or contact 9869 0866 or 1800 620 588.

The **NALAG centre for Loss and Grief** have several scheduled workshops. *Loss & Grief: People with Disabilities*, Dubbo, 2nd August 2013. \$280. Phone 02 6882 9222 or email education@nalag.org.au.

Raising Aboriginal Kids with special needs is a social support group for parents/carers run by **Services Our Way (ADHC)**. 1st Friday of every month 10am-1pm. Nowra. Contact Sharmaine on 4428 6900.

Autism Spectrum Disorder:

Assessing Children: Autism, ADHD or Trauma. **Association of Children's Welfare Agencies**. 30th April 2013. Sydney. \$220. visit www.acwa.asn.au to register.

Asia Pacific Autism Conference presented by **Autism SA**. 8-10th August. Adelaide. \$1390. www.apac13.org.au.

Mental Health:

Young Minds: How do we grow a good person? Supported by a range of organisations. Sydney Town Hall. 17-18 June 2013. www.youngminds.org.au

The *14th International Mental Health Conference* presented by the **Australian and New Zealand Mental Health Association**. 5th-7th August 2013, Surfers Paradise. \$955. You can register at <http://www.anznmh.asn.au/conference/>

St George Hospital Research and Education Centre present a forum on Intellectual Disability, Mental Health and School Education. 31st May 2013. Kogarah. Free! Contact tony.florio@sesiahs.health.nsw.gov.au for more information.

The **NALAG centre for Loss and Grief** present *Working with Complex Trauma and Mental Health*. Tamworth, 13th June 2013. \$480. Phone 02 6882 9222 or email education@nalag.org.au.

Intellectual Disability:

Australasian Society for Intellectual Disability. 48th Annual Conference, Sydney, *'OurTime'*. 6th-8th November 2013. Visit www.etches.com/ehome/ASID2013/97019/ for more information, early bird registration and to learn about key-note speakers. Price ranges from \$110- \$990.

European Association of Mental Health in Intellectual Disability presents the European Congress: *New Horizons for Mental Health in Intellectual Disabilities (IDD)*. 12-14 September. Lisbon, Portugal. 545 Euro. Visit www.mhid.org for more information.

Other:

AGOSCI Conference. *Connect2Communicate*. 1-4th May 2013. Sydney. \$1180. www.agosci.org.au

Training Parents as Case Coordinators by **ADHC Metro North** in Northern Sydney. This course will initially be offered for free to families of children with disabilities who are eligible for ADHC services, aged 0-8 years and live in Northern Sydney. Contact Kimberly Dickens on 9407 1965 or Kimberly.Dickens@facns.nsw.gov.au

Australian Guidance and Counselling Association present their national conference *Building Capacity for Best Practice*. 26-28th June 2013. Brighton-Le-Sands. \$585. Visit <http://www.gemsevents.com.au/agca2013/> for more information and to register online.

AIS School Counsellors Conference - Counselling NOW! 30-31st May 2013. Terrigal, up to \$935. Visit the AIS Courses and Events page on their website www.aisnsw.edu.au to register.

Centre for Educational and Clinical Art Therapy presents several courses throughout 2013 including two day introductions to *Art Therapy*, 4-5th May and 2-3 November. *Master Class for Art Therapists* 31st August- 1st September. They also offer a ten week course starting 1-2nd June and ending in 2014. Newcastle. See www.arttherapycourses.com.au for more information and prices.

Primary Health Care Research Conference. *Allies for better primary health care*. 10-12th July 2013. Sydney. Up to \$850. Visit <http://www.phcris.org.au/conference/2013/> for more information and to register.

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www.schoolink.chw.edu.au

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

the medicine cabinet: mood stabilisers part 2...

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

As mentioned in the previous column, this is the continuation of the mood stabilisers information. These ones have even lesser evidence for use in treatment of mood problems in the intellectually disabled population but maybe used in those children who have intellectual disability and epilepsy. This reflects the relative lack of experience except in epilepsy.

Lamotrigine

Lamotrigine's discovery was serendipitous. One mechanism of action of phenytoin and phenobarbitone for epilepsy was due to effects on folate metabolism. This led to development of a group of folate antagonists drugs called phenyltriazines of which lamotrigine is best known.

There have been both open label and placebo controlled trials to determine whether lamotrigine affects the irritability seen with autism. In one open label trial lamotrigine helped reduce both seizures and difficult behaviours in intractable epilepsy and autism. But in a blinded study there was no significant difference in children with or without epilepsy when given a placebo or lamotrigine (Robb 2010). Lamotrigine is used in child and adolescent psychiatry for the depressive symptomatology associated with bipolar disorder type 1.

The most commonly reported adverse effects are infection, vomiting, rash, fever, somnolence, accidental injury, dizziness, diarrhoea, abdominal pain, nausea, ataxia, tremor, asthenia, bronchitis, flu syndrome, and diplopia. Approximately 11.5% of paediatric patients receiving immediate-release lamotrigine as adjunctive therapy in clinical trials discontinued the drug because of an adverse effect; the adverse effects most frequently associated with discontinuance of lamotrigine therapy in these patients were rash (4.4% of patients), reaction aggravated (1.7% of patients), and ataxia (0.6% of patients) (AHFS accessed 3/4/12).

Besides the need for slow titration of dose to minimise the skin adverse effect of Steven Johnson syndrome (an allergic syndrome) other side effects reported at higher doses include hyperactivity and insomnia. There have also been reports of agitation, activation, irritability and insomnia as well as cognitive blunting.

Care should be taken if adding lamotrigine to sodium valproate in the medication regime as valproate can raise the blood levels of lamotrigine by 200% and thus increased incidence of Stevens Johnson syndrome, the potential fatal skin reaction. Another important interaction is between lamotrigine and ethinyloestradiol which is found in many combination oral contraceptives. Ethinyloestradiol decreases the blood levels of lamotrigine such that during the sugar pill washout the dose of lamotrigine should be decreased to a third of the dose. (Wynn et al 2009)

Topiramate

Topiramate was discovered in 1979 by Bruce E Maryanoff and team for Ortho-McNeill Pharmaceuticals as an anticonvulsant. It is a sulfamate-substituted derivative of the monosaccharide D-fructose. (AHFS accessed 3/4/12).

Topiramate has multiple mechanisms of action including augmenting the GABA-A receptor, and acting as a sodium channel blocker. It also inhibits carbonic anhydrase especially isoenzymes II and IV. Topiramate is also a glutamate receptor antagonist (especially AMPA/kainite subtype). It is also postulated topiramate may also inhibit protein kinase activity and possible serotonin activity on 5HT_{2C} receptors.

Open label trial on n=5 with autism and severe behavioural difficulties together with sertraline and risperidone, n=2 showed much improvement when measuring behaviour of the CGI-I but the other three showed no improvement. Adverse effects were usually mild including sedation and weight loss (Robb 2010). Other notable adverse effects include cognitive problems especially in word-finding difficulties as well as mood problems and visual disturbance that causes persistence of images which is rare, benign but frightening. (Silberstein 2009)

Because of the bitter taste, immediate-release tablets of topiramate preferably should be swallowed intact and *not* broken or chewed but the capsules can be opened and sprinkled on food for those with swallowing difficulties. If the tablets are broken, they should be used immediately since stability of exposed drug beyond a brief period cannot be ensured; any unused portion should be discarded (AHFS accessed 3/4/12).

Levetiracetam

Levetiracetam is an example of rational drug discovery. It is the alpha-ethyl ana-

logue of the nootropic piracetam. It was discovered in 1992 while examining epileptic mice a compound was found to exhibit strong binding potential to an unknown receptor which was later identified as synaptic vesicle protein isoforms. Levetiracetam, a pyrrolidine derivative, is an anticonvulsant agent that is structurally unrelated to other currently available anticonvulsants (AHFS accessed 3/4/12).

An adjunctive antiepileptic, which is primarily used to treat complex partial seizures and primary generalised tonic-clonic seizures. It binds to the synaptic vesicle protein isoform (SV2A) in the brain, a unique mechanism of action compared to the other antiepileptics. SV2A is involved in synaptic vesicle exocytosis (Silberstein, 2011).

“There is significant evidence for the use of antiepileptics in treating epilepsy with comorbid intellectual disability...”

Levetiracetam has been studied in both open label and double blind placebo controlled trials. One open label trial n=10 showed improvement in irritability and aggression in autistic children over a 4 week period. A larger double blind placebo controlled study n= 20 showed no difference between placebo and drug on the Aberrant Behavior Checklist (ABC) with parent and teacher ratings. In fact some children reported adverse effects of agitation and aggression which is similar to findings in epilepsy and mental retardation studies with levetiracetam (Robb 2010).

Adverse neuropsychiatric effects reported during levetiracetam treatment are classified into 3 categories: somnolence and fatigue, coordination difficulties, and behavioural abnormalities

Gabapentin

Gabapentin was discovered in Japan over 40 years ago and then sold onto the pharmaceutical company Warner-Lambert which conducted studies using low dose gabapentin as add-on therapy in

epilepsy management. Warner-Lambert was later acquired by Pfizer and now is available in generic form.

Gabapentin is a structural analogue of the neurotransmitter GABA and hence works at the GABA receptors to have an inhibitory effect but also reduces the amount of excitatory neurotransmitter glutamate. Gabapentin has relaxing anti-anxiety and anticonvulsant effects and is also used in chronic pain therapy.

There has been some preliminary data in use of gabapentin for behavioural problems associated with intellectual disability but the early studies have not been replicated.

Adverse effects include sedation, dizziness, fatigue, and ataxia as well as weight gain, nausea constipation and dry mouth. There have also been reports of blurred vision.

Other anticonvulsants

These include phenytoin, phenobarbitone, primidone, benzodiazepines such as clonazepam, clobazam and diazepam, as well as the newer antiepileptics such as lacosamide, vigabatrin, rufinamide, and tiagabine have not shown promise in early case studies when trialled for behavioural problems but this is not to say that in time there might not be positive studies.

Common adverse effects

All these medications are known to put on weight except for topiramate and levetiracetam and can be sedating. Several of these medications also have significant dermatological adverse effects which can have significant bearing on the patient.

Most antiepileptics cause GI disturbances such as nausea and vomiting, gastric distress, dysphagia, loss of taste, constipation, diarrhoea, and anorexia with or without weight loss. The severity of adverse GI reactions may be minimized by administering the drugs with water or food. The succinimide derivatives such as ethosuximide (only one available in Australia) frequently cause hiccups (AHFS accessed 3/4/12).

All anticonvulsants can produce drowsiness, and for this reason patients should be cautioned that these drugs may impair their ability to perform hazardous activities requiring mental alertness or physical coordination (e.g., operating machinery,



driving a motor vehicle). (AHFS accessed 3/4/12)

Vigabatrin causes retinal atrophy and visual defects which can be permanent so should be monitored. ●

2. Silberstein and Marmura Essential Neuropharmacology the Prescriber's guide. 2011 Cambridge UP Cambridge UK
3. Goodman and Gilman accessed through ACCESS Medicine (through CIAP 8/3/12)
4. Robb AS. Managing irritability and aggression in autism spectrum disorders in children and adolescents. Developmental

Drug	Behavioural Effects	Cognitive Effects
Clonazepam	Irritability, aggression, hyperactivity, disobedience, antisocial activities	
Phenobarbital	Hyperactivity, fussiness, lethargy, disturbed sleep, irritability, disobedience, stubbornness, depressive symptoms	Deficits on neuropsychologic tests, impaired short-term memory and memory concentration tasks
Phenytoin	Unsteadiness, involuntary movements, tiredness, alteration of emotional state	Deficits on neuropsychologic tests; impaired attention, problem solving, and visuomotor tasks

Adverse Behavioural and Cognitive Effects Associated with Anticonvulsants. (AHFS accessed 3/4/12)

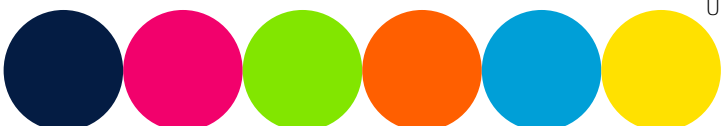
Conclusion

Although when prescribing antiepileptic's for behavioural interventions there is poor evidence, there is significant evidence for the use of antiepileptics in treating epilepsy with comorbid intellectual disability. Care should also be taken when administering psychometric testing with children and adolescents on some of these medications as they can adversely affect their cognitive functions as well as their ability to even read the questions.

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NSW Carer of the Year 2012: Maria Heaton...



Maria Heaton's life revolves around caring for others. Her youngest child Tiarna was just three years old when she died, nine years ago. Tiarna and her brother Tristan who is now 16 were both born with lissencephaly, a rare brain disorder. While caring for Tristan, and raising her eldest child Danika, Maria has also worked as a nurse at the Sydney Children's Hospital and as a volunteer and advocate for various charitable organisations. Through her current work as a paediatric palliative care clinical nurse consultant, Maria supports terminally ill children and their families. Late last year, Maria was named the 2012 NSW Carer of the Year.

You can hear an online interview with Maria with the ABC on the following Link. http://blogs.abc.net.au/canberra/2012/10/nsw-carer-of-the-year.html?site=canberra&program=canberra_drive

Maria was kind enough to give us her acceptance speech to include in our newsletter. It gives us a great insight into the hard work and perseverance that she has achieved. Congratulations Maria.

Across NSW alone there are over 800,000 carers who do exactly what I do on a daily basis. I am in no way unique or special. My life changed with the birth of my son Tristan and daughter Tiarna. Until they came into my life I lived with blinkers on, my focus was very limited, I just thought about my husband Fabian, my daughter Danica, my career, paying off the mortgage and building a future for us. **My children's special needs made me**

broaden my focus; I began to look at life differently. I started to think more about others: appreciate what I had myself and think about how I could use my experiences, knowledge and skills to help other families who were going through the same thing.

We receive support in the way of in home respite; this enables me to pay it back through some voluntary service and also by speaking about my family. I am passionate about people with intellectual disabilities and the inequalities that they face in life. Being from a health background I try to advocate specifically for people with intellectual disability to have better health outcomes.

“Being a carer is like a roller coaster ride; it is full of ups and downs”

For me, being a carer is like a roller coaster ride; it is full of ups and downs. Once you are buckled up there is no getting off. You are in for the long haul. The only thing that will end your role as a carer is the loss of your loved one and that prospect is too painful to contemplate. Caring for a child with a disability is not the same as caring for a child without a disability. When you have a child with a disability you are time poor, financially stressed and are physical-

ly exhausted. It is impossible for a family to cope on their own.

In order to care for Tristan in the best way possible we have needed support to meet **Tristan's needs which are 24/7. The saying, you need a village to raise a child is especially true when it comes to a person with a disability. Families cannot do it alone; they need support in order to care for their loved one in the best way possible. All families are not the same and every family's needs are different therefore they need a choice of supports.**

Briefly with regards to support for people with disability, the way to ensure optimum support is to acquire your disability with an accident in which there is insurance cover. Being born with a disability like Tristan, acquiring a disability due to health reasons or through an accident with no insurance unfortunately does not guarantee you the supports that you need. My hope is that the NDIS will level the playing field so that every person with a disability receives all the support that they need.

I would like to say that since having Tristan and Tiarna our lives have not been all smooth sailing. However, our family has gained so much from these two beautiful children.

1. Tristan has taught me **patience**; he has the most relaxed personality. He just waits for us to meet his needs, he never demands our attention.
2. He has taught me **trust**; he has so much confidence in us meeting his needs. He trusts that we will have his best interests at heart.
3. He has taught me **love**. He has made me understand how to love someone so much that their needs become more important to you than your own.
4. He has taught me to **smile** through pain and suffering.
5. He has the most infectious, happy smile that in his presence I **laugh** more than I do away from him.
6. He has taught me about **spirituality**. **Tristan's reason for being is purely spiritual.** He makes me want to be a better person. He has made me feel for people with disabilities so much that I want to do everything I can to make it easier for them and for families like mine.
7. Every minute of every day, Tristan makes me feel **blessed** to be his mother. He is a very charming boy and anyone who meets him and spends time with him and tries to get to know him will benefit from the experience. The

biggest difficulty is that Tristan is unable to communicate in a traditional way and therefore getting to know Tristan takes time.

Being a carer is a very fulfilling role, I was very career orientated before Tristan and Tiarna, now I just strive to be a good mother and a good person. Life is less about me and more about others. Along this journey I have met many wonderful people that I would have never have otherwise crossed paths with and for this I am grateful. The success of my day is now measured by a smile from Tristan, the opportunity to assist a family like mine, a day of good health and the opportunity for quality family time.

I believe that everyone in life has a choice; our family chose to be happy, to focus on providing Tristan and Tiarna the best quality of life possible and to work on relationships. My achievements would not be possible without the loving support of my husband Fabian and daughter Danica.

And most importantly the only reason that I am here today is because of a couple of very kind and generous hearted people Janice Oliver, Jim Simpson and Prof Les White who have taken time out from their own busy life to nominate me and support me. Thank you from the bottom of my heart. ●



Emotion-Based Social Skills Training for Children with Autism Improves Children's Emotion Skills, Social Skills and Behaviour...

Emotion-based Social Skills Training for Children with Autism Improves Children's Emotion Skills, Social Skills and Behaviour

Preliminary results from the largest intervention study in the field of Autism in NSW are now available. This study examined Emotion-based Social Skills Training (EBSST) which aims to promote the well-being of children with Autism and prevent the onset of mental health concerns. EBSST was developed in the Department of Psychological Medicine at the Children's Hospital at Westmead and aims to develop children's skills in understanding their own and other's emotions, problem solving, and emotion regulation. There are two versions of the program: 1) EBSST for High Functioning Autism and Asperger Syndrome and 2) EBSST for Autism and Mild Intellectual Disability. EBSST is conducted with children aged 8 to 12 years old, their parents and teachers.

In 2010 CHW collaborated with Department of Education and Communities to provide facilitator training to 64 School Counsellors to deliver EBSST to 271 children, their parents and teachers around NSW. The study involved evaluating differences between a treatment group and delayed treatment group. Changes in children's emotion skills, social skills, and behaviour were examined after treatment and at 6-month follow-up.

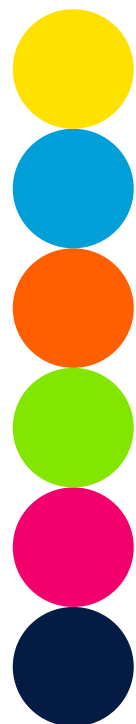
Results indicate that in children with Autism and Mild Intellectual Disability, par-

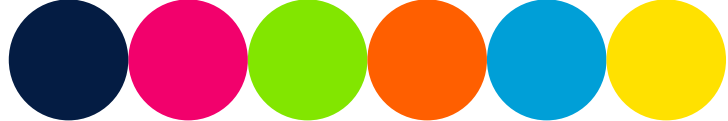


ents and teachers reported significant improvements in children's emotion skills comparing the treatment group to the delayed treatment group. Parents also reported significant improvements in behaviour. The treatment group maintained gains in emotion skills at 6 month follow-up as reported by parents. In children with High Functioning Autism and Asperger's Syndrome, parents and teachers reported significant improvements in emotion skills and social skills in the treatment group but not in the delayed treatment group. Teachers also reported improved social communication skills and parents reported improvements in emotions and behaviour in children in the treatment group, compared to those waiting to receive EBSST. The effect size of the intervention is large, providing statistical evidence to validate the positive feedback provided by those involved in implementation in the schools. The findings also provide evidence of the importance of a model of emotional development in Autistic Spectrum Disorder.

This study supports the effectiveness of EBSST in teaching children with Autism to understand their own and other's feelings and emotion regulation. This study is a great testimony to the strength of the partnership between NSW Department of Education and Communities and the EBSST team at the Children's Hospital at Westmead. Results from the study will be presented at the 2013 Asia Pacific Autism Conference and the International Association for the Scientific Study of Intellectual Disability: Asia-Pacific 3rd Regional Conference.

If you would like more information about EBSST, including how to become a certified in delivering EBSST in 2013 or how a child you know can be involved in EBSST, please email ebsst@chw.edu.au





Responsibilities and Rights for Consumers and their Carers and Advocates of People with an Intellectual Disability to enable equity of access to Health Services in NSW.

Draft Health Guideline for Health Service Consumers with Intellectual Disability.

David Dossetor and the Models of Care Subcommittee of the NSW Agency of Clinical Innovation Disability Network

Introduction

By definition a person with an intellectual disability is less likely to be able to fulfil normal social roles. Their disabilities are likely to disadvantage their access to health services on the basis of limitations of communication skills, problem solving skills and health literacy. However, health services rely on clients identifying a health need and asking for a service. This combination clearly contributes to the recognised problems that people with an intellectual disability have in establishing equity of access for their health needs. The NSW Health system is complex. Frequently people with intellectual disability have special needs that need to be taken into account when providing a service. There is a critical role for a parent, relative, carer, advocate or disability professional (referred to as advocate) to enable a person with intellectual disability to have equity of access. This document, while recognising the primacy of the rights of the individual with disability, outlines the roles that an advocate can have, or needs to have, to enable appropriate equity of access to the NSW Health system and what to do in situations where the service is felt to be inadequate. This involves enabling accurate history taking and communication, understanding the pathways to care and the avenues for review.

The Importance of the History, Past Reports, Current Medications and Asking Helpful Questions.

80% of the information needed for a diagnosis relies on an accurate history. A person with an intellectual disability may not be able to provide this for themselves. An advocate should aim to bring the history of their client to every consultation including the details of the presenting problem, history of previous health problems, history of early life experience, history of family background, current family contact, family history of physical, developmental and psychiatric problems, a history of past physical and mental problems, accurate account of current medications, doses, times, benefits and any side effects since

each medication was started. Information on previous medications, their benefits and side effects; detailed observation on the functioning of their client and any changes. It is a helpful routine to bring copies of other correspondence from other agencies and disciplines, their assessments and interventions. A doctor cannot provide comprehensive assessment and intervention without access to this information. It can be especially helpful to have questions that need addressing written down. Frequently a diary of recent pertinent events is also helpful to make objective the degree of a problem and any associated relevant events.

“There is a critical role for an advocate to enable a person with ID to have equity of access...”

The role of questionnaires.

In the context of time-limited access to a health clinician, it may be helpful for an advocate to access one of a number of questionnaires to facilitate the review of health issues. There are a range of questionnaires that may be helpful to ensure a routine health assessment or review is comprehensive. Access to a **CHAP** (Comprehensive Health Assessment Programme) (www.adhc.nsw.gov.au/__data/assets/file/0019/228106/Health_Care_Policy_Att_12_CHAP_brochure.pdf). The Centre for Disability Health has a range of useful documents to facilitate record keeping and communication with a health clinician. The **Personal Health Record for People with Developmental Disability**, **Pre-assessment questionnaire**, and **Depression Checklist** may be helpful in ensuring a full range of ques-

tions and health issues are considered (www.cddh.monash.org/under Products and Resources). An instrument such as the **Developmental Behaviour Checklist** (www.med.monash.edu.au/spppm/research/devpsych/dbc.html) can be useful to summarise a range of emotional behavioural problems or the **Depression in Children or Adults with Intellectual Disability Checklist** for carers.

Access to the specialist/hospital or private health system is usually through a review by a General Practitioner (GP). It is recommended that everyone with an intellectual disability has at minimum an annual check-up and there is a Medicare rebate for an extended review to enable an annual health assessment. (There are now four Medicare Benefits Schedule items for health assessments based on how long the assessment takes (items 701, 703, 705 & 707, www.medicareaustralia.gov.au).

How to ensure a satisfactory service provision

Good quality health service provision depends on the knowledge and skills of the clinician, the quality of communication between the patient and the clinician, and the level of trust between the clinician and the patient and, therefore the confidence in the relationship. Having a clinician that you respect and hold in high regard is the first element in receiving a good service. There is a certain element of choice in the health systems to be explored if the patient feels that service has not been to their expectations. Much of the value of a GP develops over developing a longer term relationship. It is therefore important to have a GP with whom you get on. The first approach to dealing with an unsatisfactory patient/clinician relationship is to find an alternative clinician to give an opinion or merely to give a second opinion, to enable greater confidence in the first. The first stage of course is to come prepared to your clini-



cian with specific questions you would like answered. It is helpful to ask for a **copy of the clinician's report so that the discussion is documented.** It is always reasonable to question advice. It is important to ask about the limitations of any advice and the risks of success and failure, and benefits of treatments and side effects.

Escalation of concern when worried about the quality of service and advice

The quality of a service depends upon the level of trust and communication described above, and the vast majority of patients trust their clinicians and respect and value the advice given. Occasionally a patient may feel poorly treated or that they have received an unsatisfactory service. There are ways of responding to this constructively. As described above the first is to speak to have a meeting with the clinician to raise concerns and questions. If this is not sufficient it is quite reasonable to seek a second opinion, preferably with the support of the first clinician. In the hospital service the

next stage may be to talk to another member of the professional team such as a nurse or social worker. Hospitals also **have a patient's advocate or patient's friend** as a service to help patients or their families enquire about the processes of health provision and look for better solutions.

Complaint processes

Should such systems of further enquiry or advice not provide resolution, there are formal complaint processes. One can write to the hospital through the Chief Executive or concerning a GP to the Division of General Practice for the location. It is possible to ask for copies of the medical records under Freedom of Information legislation and the process can be followed according to the NSW health website.

If it is felt that the professional has been negligent or harmful it is possible to make a complaint to the Health Care Complaints Commission. If there has been a failure to provide a service on the

basis of discrimination due to intellectual disability it is possible to seek advice from the Disability Discrimination Commissioner (www.hreoc.gov.au/about/president_commissioners/innes.html).

In conclusion

The health system is a complex industry and getting the best from its service involves understanding the service structure as described in the Health Services for People with Intellectual Disability (see **"Better Health Services for People with Intellectual Disability in NSW: The Agency of Clinical Innovation Disability Network"** in this edition). There are ways of ensuring that you get the optimum use and benefit of that service through enabling quality communication. There are ways of asserting your concerns to enable a review of the service provided and if necessary formal ways of registering your dissatisfaction. ●

Comments on this document to the editor would be welcomed
schoollink@chw.edu.au

promoting resilience...

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

Late last year I attended the **CHERI conference "Promoting Resilience 'Stacking the odds in kids' Favour" 6-7 September 2012.** I listened intently with my intellectual disability filter.

Dr Sam Goldstein, neuropsychologist, author and educator from the USA noted there is no one definition of resilience and that it is more than bouncing back from a positive adaptation in the context of past or present adversity. Dr Goldstein **'s interest in resilience began after his past child patients' were returning to him** as adults with their own children. Those that he thought would be troubled were fine and those who he thought would be fine were troubled. He theorised that good coping skills were the key. Dr Goldstein then outlined that resilience is predicted by three factors 1. within the child, 2. within the family, and 3. in the community.

Resilience factors for youth with a Learning Disability:

- Temperamental qualities that allow the individual to elicit positive responses from others.
- Special skills and talents and the motivation to use them to an advantage in life.

- Nurturing caregivers providing structure, rules, and security.
- Supportive adults who foster trust.
- Openings or opportunities at a major life transition.

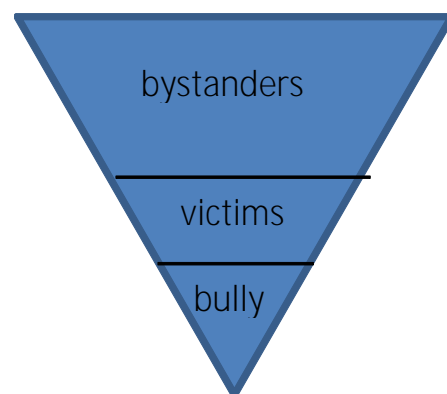
Five strategies to foster a resilient mindset:

- Teach empathy by practicing empathy.
- Teach responsibility by encouraging contributions.
- Teach decision making and problem solving skills that foster self-discipline.
- Offer encouragement and positive feedback.
- Help children deal with mistakes.

A/Prof Vijaya Mani Cavasagar from the Black Dog Institute discussed three processes leading to resilience. Coping was the first immediate process, adapting was the second medium term process and that resilience was the third long term process. She commented that mental illness occurred when an individual slipped between the cracks of coping and adaptation.

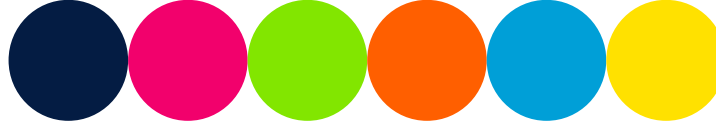
Bullying

A/Prof Marilyn Campbell then discussed **bullying and "Do students who have been bullied need resilience training?"**. In Australia 30% of students report being bullied and 50% cyber bullied. She commented that most victims are vulnerable and include students with an Autism Spectrum Disorder, a disability, gay, lesbi-



an, bisexual and transgender (GLBT) or those who suffered from anxiety - generally children who are different. A/Prof Campbell highlighted that bullying is deeply embedded in society and to only train the victim in resilience skills fails to acknowledge the dyadic relationship between the victim, bully and bystanders. Her first approach is to focus on the majority of the population who are the bystanders. She suggested that many **bully's cannot be taught certain skills, such as empathy** after the age of about 8 years of age, and that whilst training the victim after an event sends a message that they are the ones with the problem.

She suggests that bystanders be taught to walk away or leave chat rooms, text or email the student who was bullied afterwards, report the bullying anonymously, ostracise the bully and to defend the victim. A/Prof Campbell suggested to use motivational interviewing with the bully



and to ask the bullied “how do you want me to help you?”.

Other Research

The conference motivated me to explore more about the resilience of people with intellectual disabilities. When searching the internet and other academic databases there was an obvious lack of material on the children themselves. Mothers were a common focus concerning children with disabilities and although the parents levels of coping and resilience are most important, it only composes one **third of Goldstein’s predictors of a child’s resilience.**

The main research article focusing on children and young people identified was **by O’Sullivan, Webber and O’Connor in 2006.** Through interviewing young people with an intellectual disability, their carers and other supports they identified three strategies to promote resilience:

1. Teaching young people social skills and more age appropriate behaviours
2. Structuring the environment
3. Removing the young person from triggers of challenging behaviour

The focus was on pre-empting possible problems rather than only teaching coping strategies as often the nature of their disability results in rigid and inflexible **behaviours.** **O’Sullivan et al also highlighted the need for community awareness of the diverse behaviours that people with an intellectual disability exhibit to prevent**

criticism and vilification by strangers and exclusion in community activities.

In Summary the principles of resilience are similar for typically developing young people and those with intellectual disabilities, including factors within the individual, family and community. With young people with an intellectual disability it is especially important to accept aspects of **the child’s temperament influenced by their disability that cannot be changed,** to create environments for success and self-confidence and to educate the community in the diversity of behaviour. More research needs to be undertaken on the resilience of children with intellectual disabilities. ●

References

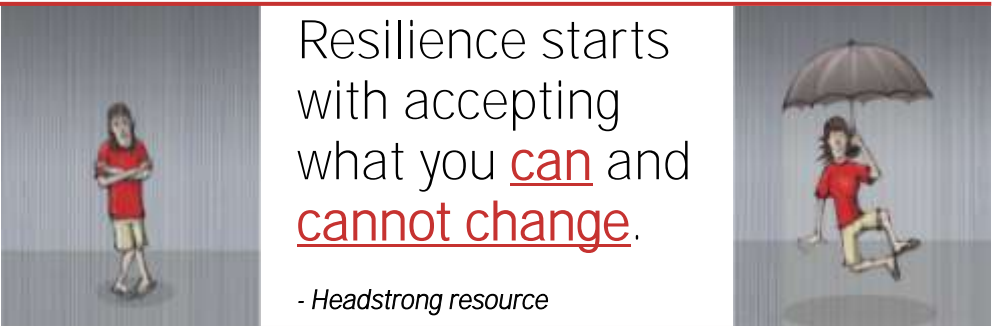
O’Sullivan, J.L., Webber, L.S. and O’Connor (2006) Young People with an intellectual Disability: Risk and Resilience. In

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Resilience Resources

- Presentations from the Promoting Resilience: Stacking the Odds in Kids’ Favour can be accessed here: <http://www.cheri.com.au/PromotingResilienceStackingtheOddsInKidsFavour.htm>.
- Headstrong a curriculum resource on mood disorders, mental health and resilience available by the Black Dog Institute on www.blackdoginstitute.org.au
- Biteback an online program to help develop skills in resilience and promote overall wellbeing in typically developing 12-18 year olds www.biteback.org.au.
- Journal of Intellectual Disability Research special edition on resilience and parents of children with an intellectual disability Volume 53 part 12 pp 955–956 December 2009.
- Emotion Based Social Skills Training for children with Autism and Intellectual Disabilities www.ebsst.com.au



Resilience starts with accepting what you can and cannot change.

- Headstrong resource

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

The beautiful artworks in this newsletter are taken from the participants of the **Operation Art project** at the Children’s Hospital at Westmead. You can find out more at www.artsunit.nsw.edu.au

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

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