

CHW

S C H O O L



# mental health *Link* and intellectual disability...

## coordinators message...

It's Time.....

Welcome to the inaugural edition of the Children's Hospital at Westmead (CHW) School-Link Newsletter. The NSW School-Link Initiative is an existing partnership between NSW Health and The Department of Education and Training and has been working with mental health prevention, promotion and early intervention, pathways to care and school counsellor training for over ten years. The CHW has recently joined this state wide initiative. The theme of this newsletter and forthcoming editions and what distinguishes the CHW School-Link Initiative from your local Area Health Service School-Link team, is our special focus on the mental health of children and adolescents with an intellectual disability.

Children and adolescents with an intellectual disability experience mental health problems at a rate three to four times higher than that of children and adolescents without an intellectual disability. This statistic highlights a need to focus our attention on this vulnerable group of young people, in an effort to aim to close this statistical gap and provide effective interventions when needed. This statistic also highlights the need for the array of staff that care for young people with intellectual disability to further advance their mental health and intellectual disability literacy skills and collaboration to ensure the best outcomes for the child or adolescent. What this statistic fails to tell us however, are the challenges that each young person faces when experiencing a mental health problem or disorder. From our valued discussions with school counsellors in 2009, the complexities that communication limitations, challenging behaviour, and other health and environmental stressors place on diagnosis and intervention are clear.

This CHW School-Link Initiative, which is funded by the Mental Health Drug and Alcohol Office, aims to 'tackle' the gaps in the support of staff who work with children and adolescents with an intellectual disability not only to ensure services and intervention to those in need but to facilitate mental health prevention and promotion and ultimately an improved quality of life. Like a football coach we will travel with you on this journey over the next four years and together we will improve the mental health of children and adolescents with an intellectual disability.

Take your time to browse through our first edition. Please send your comments about this issue and suggestions for future articles to: [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au). We look forward to your feedback.

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

*Our first feature article is an excerpt from the literature review conducted by the Children's Hospital at Westmead School-Link team in preparation for the needs analysis into children and adolescents with mental health problems and disorders and an intellectual disability.*

The prevalence of psychopathology in children and adolescents with an intellectual disability is much higher than in the general population. Both Australian and overseas studies have found that the rates of psychopathology in children and adolescents with an intellectual disability are in the vicinity of 40-50 per cent and that this population is at a four to five times greater risk of psychiatric disorder than children and adolescents without an intellectual disability (Rutter et al., 1970, Corbett, 1977, Einfeld & Tonge, 1996).

A Swedish study by Gostason in 1985 (cited in Dykens, 2000) estimated the prevalence rate to be as high as 70 per cent. Einfeld and Tonge (1996) reported on some of the difficulties in being able to obtain accurate prevalence rates due to factors such as: a scarcity of studies on children and adolescents with mental health problems and disorders and an intellectual disability compared to adults; a lack of standardised methods of assessment of psychopathology for this target group; stud-

[Table of Contents](#) *See Back Page*

# feature article: mental health and intellectual disability continued...

ies with sample sizes which are too small to make accurate measurements from; and insufficient detail around presenting symptoms of psychiatric disorders.

Follow-up studies conducted by Einfeld and Tonge (2000) and also by Einfeld et al. (2006) confirm the earlier estimated prevalence rates of psychiatric disorders in children and adolescents with an intellectual disability as 40.7 per cent, compared to 7-10 per cent in the general population as an epidemiologically derived population in a multicentre study in NSW of children and adolescents aged between 4-18 years of varying levels of intellectual disability. Einfeld and Tonge (2000) refer to a study by Richardson and Koller which further indicates that the prevalence of behaviour disturbance in individuals with an intellectual disability remains the same from childhood into young adulthood.

## Assessment

Einfeld and Tonge (2000) report that the under-recognition of combined mental health problems and disorders and an intellectual disability is in part due to *'diagnostic overshadowing'* where a clinician regards the presenting symptoms to be sufficiently explained by an individual's intellectual disability and does not consider that the presenting symptoms may be due to a psychiatric disorder.

Fletcher et al. (2007) note that individuals with an intellectual disability can exhibit the full range of psychiatric disorders including affective disorders, anxiety disorders, psychiatric disorders, personality disorders and various other disorder clusters. The Diagnostic Manual of Intellectual Disability (DM-ID) outlines that people with a mild intellectual disability are more likely to be associated with psychiatric disorders, while people with a profound intellectual disability are more likely to be associated more with behaviour problems, and people with moderate and severe intellectual disability are associated with both psychiatric disorders and behaviour problems.

Hemmings (2007) notes the problems associated with the use of language based standard diagnostic criteria with people with an intellectual disability, especially as the intellectual disability becomes more severe and communication becomes limited. This may be a problem as the Australian Institute of Health and Welfare (AIHW, 2008) note that 60 per cent of people with an intellectual disability have severe communication limitations.

A review by DeNoyers Hurley (1996) found that many children and adolescents with an intellectual disability do not reach their full potential due to limitations placed on them by untreated psychiatric disorders. She also found that if a psychiatric disorder is left untreated from childhood or when it first appears, the condition tends to develop into a

more serious disorder in adulthood. DeNoyers Hurley (1996) states that; *'it is imperative that paediatricians are alert to the signs of psychiatric disorder in children and adolescents with MR/DD so that referral for appropriate services be accomplished.'*

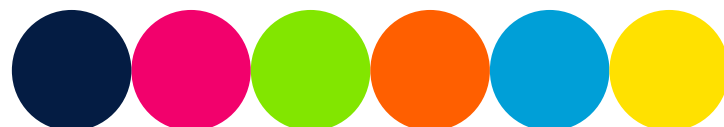
## Pathways to Care

Despite the high prevalence of mental health problems in children and adolescents with an intellectual disability there is evidence from the literature that there are a lack of services to meet the mental health needs of children and adolescents with an intellectual disability (McCarthy & Boyd 2002). McCarthy and Boyd report on how young persons with mental health problems and intellectual disabilities in the UK fall between a number of health care providers such as child and adolescent mental health services, disability services and paediatricians. The gaps in service provision to this population have been described by Cass et al. (1996 cited in Scior and Grierson, 2004) as *'the white hole'* as often the child is left without any service.

Both pathways to care and service provision within the Australian context for this population are not much different to what has been reported in overseas studies. In both of their 1996 and 2000 studies Einfeld and Tonge found that less

than 10 per cent of young people with an intellectual disability and a clinically significant psychiatric disorder receive specialist mental health services (2000). In order to provide a more satisfactory clinical service to individuals with an intellectual disability and psychiatric disorder both report that this would require approximately 54 full-time specialist psychiatrists across Australia. The Dual Diagnosis Project, conducted by Queensland Health and the University of Queensland in 2002, were aware of only two psychiatrists who work full-time in dedicated positions within Australia- one in Adelaide and the other in Melbourne.

One of the key findings from the McCarthy and Boyd study (2002) was that the majority of subjects (64%) with persistent challenging behaviour from childhood into adulthood and those with a diagnosed psychiatric disorder from childhood received no specialist mental health care. The main explanation given as to why children and adolescents with an intellectual disability and mental health problems and disorders are not accessing appropriate services is that there is a lack of recognition within primary care services as to how to manage mental health issues for this population. McCarthy and Boyd see the educational setting as the universal provider and agency for children and adolescents with an





intellectual disability and see the school setting as being the best place to start in terms of training and establishing close links with specialist mental health services. They further support and stress the importance of identifying mental health problems in children and adolescents with an intellectual disability *well before* their transition into adulthood. Failure to do this often results in mental health problems becoming more chronic in adulthood and can adversely affect successful transition into adult services. Einfeld and Tonge (2000) also strongly support both availability of early assessment intervention and treatment services for children and adolescents as the persistence of serious mental health problems can start from an early age.

Mohr et al. (2002) in their research acknowledge that service systems within both health and community organisations are struggling to deliver mental health services to this population group. *‘Many professionals feel ill equipped to assess and treat mental health disorders in this population’*. Mohr et al. (2002) further state that professionals who work separately to help individuals with an intellectual disability in addition to mental health problems often find themselves at a *‘dead end’*. Mohr and Couits strongly advocate for a collaborative approach and see this as the only way that individuals with an intellectual disability and mental health problems can

receive the services that they need. *‘Only with a collaborative effort between these two service systems (MH & ID), and in some cases with additional specialist input, will a person with an intellectual disability and disturbed behaviour that may be indicative of a psychiatric disorder receive appropriate assessment, treatment and support’*, (Mohr et al., 2002).

In the case study which Mohr et al. (2002) presented in their research they found that positive outcomes for the client were achieved only when services followed the key elements of a collaborative model.

Most of the research and studies around service provision and pathways of care for mental health problems and disorders and an intellectual disability are focused around adults with an intellectual disability. There are very few studies which address the pathways to care needs of children and adolescents with these needs. A literature review by Hudson and Chan (2002) identified a number of significant gaps and factors affecting access to mental health services for people with an intellectual disability and mental health problems. The main barriers to access they listed were: a lack of understanding of this population by general practitioners and caregivers; a lack of specialised training for mental health practitioners; the complexity of

definitions and symptoms of mental illness which make a diagnosis difficult; and separatist attitudes of mental health and disability services.

## Conclusion

This literature review has outlined the complexities in diagnosing mental health problems and disorders in children and adolescents with an intellectual disability which is further supported by the varying prevalence rates reported in the literature. Throughout this report the Einfeld and Tonge (1996) prevalence rate of 40.7% will be used. The lack of specialist services especially for children and adolescents with an intellectual disability has been identified by several authors, as having significant consequences for the successful early intervention of mental health problems and disorders. The literature then suggests that in order for the adequate care of the large percentage of children and adolescents that may experience mental health problems and disorders specialised services are required. ●

Excerpt from Dosssetor, D., Caruana, J., Goltzoff, H. and Saleh, H. (2009). *Leading the Way in Mental Health and Intellectual Disability. A Focus on the needs of Children and Adolescents in Schools for Specific Purposes in NSW*. The Children’s Hospital at Westmead.

# Emotion Based Social Skills Training ...

## CHILDREN WITH AUTISM, THEIR PARENTS, & TEACHERS: A NEW TRAINING PROGRAM

The Children’s Hospital at Westmead in association with The Department of Education and Training NSW is researching two innovative training programs that address social and emotional difficulties in students with Autism Spectrum Disorders. The programs were developed by a team of clinicians at the Children’s Hospital at Westmead and University of Sydney, and build upon the DET Autism Training for School Counsellors. This exciting collaborative project is being offered for the first time in a school setting and we welcome your involvement in this program.

### What is the Emotion-based Social Skills Training program?

EBSST is a group training program that aims to provide training for school counsellors to be accredited EBSST group facilitators; build school counsellors’ knowledge of emotional and skills in addressing the social and emotional difficulties of children with Autism; enhance students’ knowledge of emotional and social skills and the application of these skills in specific contexts; provide an environment for students to practice their emotional and social skills and receive feedback; provide parents with training regarding the ways in which they

can respond to their child’s emotions and behaviour; provide teachers with training to address the social and emotional deficits in children with Autism; parents and teachers are included in the EBSST program to encourage skills to be maintained over time, and to help their child/student use social and emotional skills in the home, school and other environments.

### What training and support will be provided to school counsellors?

- An intensive 2 day training and accreditation course for school counsellors in how to effectively deliver the EBSST program including manuals for school counsellors, students, parents and teachers. Other materials include videos, scripted Powerpoint presentations, social stories and visuals.
- Ongoing clinical supervision and support from clinical psychologists at the Children’s Hospital at Westmead.
- Access to the EBSST website and discussion board.

### What students are eligible for EBSST?

Students aged 8-12 years old, who have a confirmed or suspected diagnosis of an Autism Spectrum Disorder (including Autism, Asper-

ger’s Syndrome, and Pervasive Developmental Disorders – Not Otherwise Specified) and:

- ability within the average or above range or
- mild intellectual disability.

Two EBSST programs have been developed: (1) students with Autism Spectrum Disorder and ability within the average or above range; and (2) students with Autism Spectrum Disorder and mild intellectual disability.

**What does EBSST involve?** EBSST involves training and accreditation, program delivery including parent participation and research

**The EBSST program will provide school counsellors with new skills for working with children with Autism, their parents, and teachers; school counsellors and teacher professional development and supervision.**

### Who can I contact for more information?

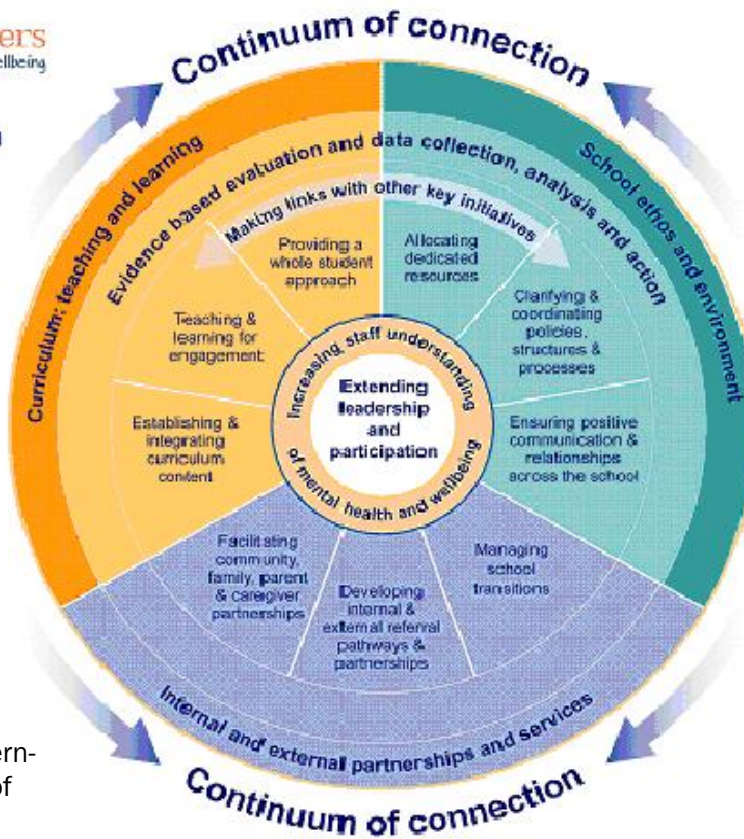
If you have any questions or would like more information about this exciting and innovative opportunity to develop your skills in working with children with Autism Spectrum Disorder please contact Jan Luckey from DET or Dr Michelle Wong from the Children’s Hospital at Westmead on [ebssst@chw.edu.au](mailto:ebssst@chw.edu.au). ●

# guest writer: MindMatters...



## MindMatters Implementation Model

for a whole school approach to mental health and wellbeing



MindMatters is a national mental health initiative for secondary schools funded by the Australian Government Department of Health and Ageing.

MindMatters is a resource and professional development program supporting Australian secondary schools in promoting and protecting the mental health, social and emotional wellbeing of all the members of school communities.

MindMatters is beginning its 10th year of working with schools. During this time MindMatters has trained over 100,000 school-based or school-related participants and has successfully placed mental health and wellbeing on the education agenda. MindMatters is now the most used mental health promotion, prevention, and early intervention resource in Australia for schools with secondary enrolments and the most attended national professional development for Australian schools.

MindMatters provides a strategic whole school approach to mental health and wellbeing through the resource and a suite of Professional Development. The whole school approach uses multiple strategies that have a unifying purpose and reflect a common set of values. It requires that

all stakeholders, parents, students, staff and the community work together to create a protective environment that promotes mental health and wellbeing on both the social and emotional levels.

The MindMatters whole school approach is an implementation process with clear action. It is fundamentally about creating a Continuum of Connection to support the mental health and wellbeing of all students, including those experiencing high support needs.

The MindMatters Implementation Model is presented in the following diagram.

The key dimensions are clearly differentiated by colour.

- School ethos and environment
- Curriculum; teaching and learning
- Internal and external partnerships and services.

The model also identifies four enablers for a whole school approach:

- Extending leadership and partici-

pation

- Increasing staff understanding of mental health and wellbeing
- Making links with other key initiatives
- Evidence-based evaluation and data collection, analysis and action.

The redeveloped resource, with new suite of professional development are foundational and continuing supports for the development of the 'Whole School Approach'.

An essential part of this approach is the support of all students including those experiencing mental health difficulties. MindMatters run a two day workshop for staff working closely with these students. During the two days participants examine proactive strategies for maintaining mental health and wellbeing. Identification, self-referral, case management, online counselling, debriefing, referral pathways, transitions, agency networks, re-entry into formal schooling and confidentiality. All of these are considered in the context of the whole school approach to most successfully supports students. For more information about MindMatters professional development please visit [www.mindmatters.edu.au](http://www.mindmatters.edu.au) or contact your state project officers;

Jason Pascoe – 0423823180,  
[jason.pascoe@pa.edu.au](mailto:jason.pascoe@pa.edu.au)

Maryanne Vorreiter – 0401140326,  
[maryanne.vorreiter@pa.edu.au](mailto:maryanne.vorreiter@pa.edu.au)

### Focus Module:

*Students Experiencing High Support Needs in Mental Health*

*18th and 19th of March*

The Glades Wedding and Conference Centre 270 Hillsborough Rd Warners Bay NSW

*29th-30th of June*

Liverpool Catholic Club, Cnr Joadja and Hoxton park Roads, Liverpool NSW

2010 dates for other sessions are on the Mindmatters website for registration. ●



# upcoming training...

**Keep Them Safe information sessions in 2010.** State-wide information sessions have been held in over 530 locations across NSW for all key mandatory reporters. An additional 30 information sessions will be run across NSW starting mid-January. The locations will be determined according to area demand. To register your interest, email [Nsi.kts@det.nsw.gov.au](mailto:Nsi.kts@det.nsw.gov.au)

## Free Information Seminar: Crossroads-which path to choose?

These free seminars are aimed at students with disabilities, their parents and educators. The seminars will give facts, tips and advice on disability supports post school. **Katoomba:** Wednesday 17<sup>th</sup> March 2010, Katoomba Golf Club. **Hawkesbury:** Wednesday 24<sup>th</sup> March 2010, Windsor Function Centre. 9.30am-2.00pm Morning tea and lunch provided. Registration essential: please contact Michelle Hayter [mhayter@uws.edu.au](mailto:mhayter@uws.edu.au) or Julia Strang [Julia.Stranf@cwcc.nsw.edu.au](mailto:Julia.Stranf@cwcc.nsw.edu.au)

## Redbank House Lecture Series.

The Redbank House Lecture Series is a forum for presentations by experts in child and adolescent mental health and family therapy, held at Westmead Hospital on the first Friday of every month, 1:30pm-2:30pm. In 2010 videoconferencing will also be available. 2010 dates for your diary are; 5th February, 5th March, April-Holiday, 7th May, 4th June, 2nd July, 6th August, 3rd September, 1st October, 5th November and 3rd of December. Venue: Lecture theatre 3, Education Block, Westmead Hospital. Enquiries and to be added to the distribution list please email Kerry Gunning [kerry.gunning@wsahs.nsw.gov.au](mailto:kerry.gunning@wsahs.nsw.gov.au) or phone 9845-6577. There is no cost involved and there will be a calendar of speakers circulated for next year. Attendance is open to any interested professionals.

## The Mental Health Professionals

**Network** run workshops designed to foster collaboration by bringing together a range of local mental health professionals from a range of disciplines. 11th March Milperra, Wollongong, Maitland, 15th March Dunedoo, 16th March Parramatta, Castle Hill, Point Piper; Many more dates online, See [www.mhpn.org.au/workshops](http://www.mhpn.org.au/workshops)

## Assessment and Diagnosis of Autism Spectrum Disorders.

In this course you can learn about ASD classifications, characteristics of ASD, indicators of ASD in infants, screening tools, standardised diagnostic and assessment tools, 3-stage assessment model, report writing and follow up and differential diagnosis, including ADHD, other developmental disabilities, language disorders, learning disabilities and emotional disorders (e.g. anxiety, depression). They also run the **Intervention Approaches for Autism Spectrum Disorders** workshop which focuses on Autism specific intervention programs, social skills training, facilitating communication, Positive Behaviour Support, classroom and curriculum modifications, therapy for co-morbid mental health issues and alternative interventions. These workshops are held throughout the year. You can find dates on the Autism Spectrum Australia website [http://www.autismspectrum.org.au/index.php?mn=1-3&option=com\\_events&Itemid=73](http://www.autismspectrum.org.au/index.php?mn=1-3&option=com_events&Itemid=73). The first dates for 2010 include Assessment: 4<sup>th</sup> of March and Intervention: 5<sup>th</sup> of March 2010, both at a rate of \$300.

The NSW Department of Sport and Recreation provide workshops around sport and physical activity to increase the inclusion of people with a disability. Modules are targeted towards people with a disability, school staff, clubs and coaches. For more information visit the departments website [http://www.dsr.nsw.gov.au/training/disability\\_ed.asp](http://www.dsr.nsw.gov.au/training/disability_ed.asp)

## Macarthur Disability Services

offers a professional development program throughout the year. Courses include Effective Supervision (2<sup>nd</sup> February), Strengths Based Assessment (23<sup>rd</sup> February), Understanding Boundaries (17<sup>th</sup> March) and Managing Challenging Behaviours (23<sup>rd</sup> March). More information and enrolment online at <http://www.mdsservices.com.au/training/enrolmentform.html>. All one day programs are \$135. For more information contact Jaye Toole on 02 4621 8400.

## Behaviour Management: Encouraging Positive Behaviour in Students with Downs Syndrome at School.

Friday 30th April, 9.00am-3.00pm. Rydges Hotel, Rosehill. \$132 for non members contact [admin@dsansw.org.au](mailto:admin@dsansw.org.au) for a registration form. Ask about other courses also available.

**Learning Links** offers a wider variety of workshops for professionals, parents and carers at a range of prices for the different groups, book online for the best price [www.learninglinks.org.au](http://www.learninglinks.org.au) or call 02 8568 8200; *Including children with Autism Spectrum Disorders in the Classroom-Practices and Priorities*, 19<sup>th</sup> April, Peakhurst, 6.00pm-8.30pm; *Play and Learning for Children with Autism Spectrum Disorder* is run in several locations from 6.00pm-8.30pm, 2<sup>nd</sup> March Narellan, 16<sup>th</sup> March Peakhurst, 30 March Brookvale, 27<sup>th</sup> July Maroubra, 23<sup>rd</sup> August Peakhurst, 27<sup>th</sup> October Peakhurst, 9<sup>th</sup> November Mt Pritchard; *Stop Think Do- Applications for Classroom Teachers and Health Professionals*, 24<sup>th</sup> March and 2<sup>nd</sup> September, Peakhurst 6.00-9.00pm; *Working with Families who are Grieving- Issues Surrounding Diagnosis of a Disability in Children*, 8<sup>th</sup> and 15<sup>th</sup> March, Peakhurst, 6.00pm-9.00pm and 1<sup>st</sup> and 2<sup>nd</sup> of September, Mt Pritchard, 6.00pm-9.00pm.

For general courses about mental health problems and disorders try the **Black Dog Institute** who run Master class workshops and training for psychologists such as treating mood disorders with CBT. Get more information online at [www.blackdoginstitute.org.au/healthprofessionals](http://www.blackdoginstitute.org.au/healthprofessionals) and follow the links to education and training

## Macarthur and South West Sydney HACC Training Project.

*Dual Diagnosis* reviews major disorders and services issues such as assessment and treatments, 24th March, 9.30-4.30, Bowral. *Positive Approaches to Behaviour Management* is ideal for those working with a client with an intellectual disability, 20th April, Wakely. \$25 for HACC services from certain LGA's, \$50 for non HACC services. Email the HACC Training Coordinator [hactrain@mdsservices.com.au](mailto:hactrain@mdsservices.com.au) Or call on 4621 8400. Limited places in all workshops, so be quick.

## The Training and Behaviour Intervention Support Service

offers several practical workshops for professionals, carers and parents. *Basic Makaton: Key Signing* (28<sup>th</sup> January, 9.30-2.30, \$40), *Disability and Sensory Issues* (24<sup>th</sup> February, 10.00-2.30, \$40), *Music Therapy* (31<sup>st</sup> March, 10.00-2.00, \$40), *What is Epilepsy? How can it Affect Behaviour?* (6<sup>th</sup> April, 10.00am-1.00, \$25). Enquiries and registration to Benjamin Fulham or Bianca Kovacic [tabiss@interactiondisability.com](mailto:tabiss@interactiondisability.com), 1300 668 123.

## Autism and Augmentative and Alternative Communication: Research to practice.

This workshop will detail the characteristics of individuals on the Autism and how these characteristics interface with the features of Augmentative and Alternative Communication. Case studies will be used. 26<sup>th</sup> March 2010, Northcott Conference and Function Centre, 1 Fennell St, North Parramatta, NSW. 8.45am for 9.00am-4.00pm. \$350 for non-members. Contact Harriet [harriet.korner@northcott.com.au](mailto:harriet.korner@northcott.com.au) and 02 9890 0157 This workshop is part of the AGOSCI National Tour, see [www.agosci.org.au](http://www.agosci.org.au) for more information



## case study...

"The following case study gives a nice exposition of how small things that require little time can make surprisingly large differences. Christopher Z is an 8 year old boy with epilepsy, autism, and severe intellectual disability, who comes from a non-English speaking background. He was referred for a psychological consult by his neurologist owing to a recent exacerbation of behavioural difficulties in both the home and school environments. At the time of referral Christopher was attending a support class for children with an intellectual disability, having transitioned from an SSP the previous term, at his parents' insistence. His parents were requesting support and advice regarding Christopher's needs, in view of his slow progress academically, and escalating behavioural issues.

Initially, the family expressed that their main worry was Christopher's slow academic progress. They also expressed concerns about behaviours such as frequent loud vocalisations, and perseverative interests (e.g. repeatedly taking milk bottles from the fridge and pouring the contents down the sink, taking keys and coins and dropping them into drains). He also required a lot of attention and time at home – with dressing, feeding, toileting; and also with supervision (vis a vis the above behaviours, and also because he would abscond – to go looking at gutters on the street). They also expressed frustration because they were repeatedly being called to collect Christopher from his new school due to absconding, and behavioural problems.

From talking to the different agencies involved with supporting Christopher, the most evident issue concerned various communication breakdowns. Although well-informed about his medical condition and needs, Mr. & Mrs. Z had very little access to information about autism and intellectual disability, and conceptualised Christopher's issues in a medical rather than developmental framework. They were also very reluctant

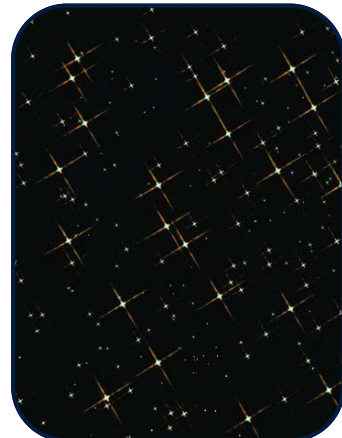
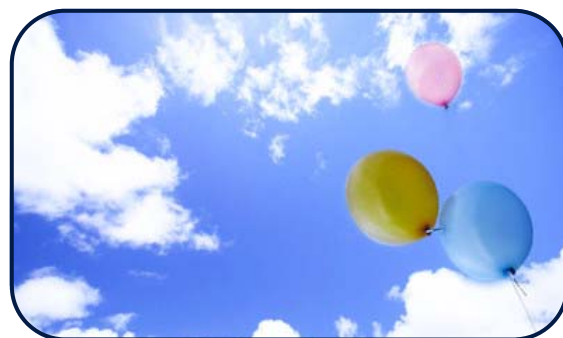
### they were very grateful to discuss and learn about autism and intellectual disability

to accept 'help' (which for cultural reasons they associated with obligation and indebtedness), but were very amenable to advice and direction. They also held a number of misconceptions around the role of government 'disability' services, and the different schooling options available for children with high support needs. As such, by reframing interventions (such as school, disability, respite) as entitled services (rather than 'support'), and portraying them as part of Christopher's recommended medical treatment, the family were much more willing to engage. They were also very grateful for the opportunity to discuss and learn about autism and intellectual disability, as a way of making sense of many of the behaviours they had struggled to manage in Christopher, and his slow progress and development.

Transitioning Christopher back into a more specialised school setting (once the family understood and was happy to support this) redressed the key school-based concerns (which had been around the inappropriateness of the support-class' general curriculum, leading to Christopher becoming bored & frustrated with general classroom activities (which was leading to some emerging aggression, and exacerbating the problems with absconding). A collaboration between the ADHC community team and school staff then enabled integration of school based behaviour and communication strategies into the home environment.

Ten months on, and Christopher clearly remains a young boy with significant disability, and his family continue to face their own challenges in coming to terms with his high and ongoing support needs, and his medical prognosis. However, what was striking for me about this case was how, through inviting a dialogue with the family, and opening communication channels and encouraging collaboration between public health, education, and disability services; doing remarkably little was successful in bringing about some very real changes for both Christopher and his family. ●

Louisa Carroll  
Clinical Psychologist  
Department of Psychological Medicine  
The Children's Hospital at Westmead



# a day in the life of a SSP School Counsellor...



**the relationships staff build with students is significantly protective against the many risk factors in the lives of these students**

I was a 'brand new' school counsellor when I landed at Rowland Hassall School (RHS) in 2008. The learning curve was so steep that at times I wondered if leaving behind my role as a secondary school trained Dance and Drama teacher was a wise move. My task was and still is, to support 40 students enrolled from grades 3 to 12, all of whom have mild/moderate intellectual disabilities as well as multiple mental health diagnoses. Additionally school counsellors who work in special settings such as Schools for Specific Purposes (SSPs), Tutorial Centres or in schools with support classes have the additional challenge of meeting the needs of the several other schools to which they have been allocated.

In spite of all this I truly enjoy working in such a ridiculously busy and exceptionally challenging environment. I am inspired by the level of commitment, care, compassion and positivity the teaching and support staff display, despite the physical and psychological risks that their work can sometimes involve. It is evident that the relationships staff build with each student is significantly protective against the many risk factors often present in the lives of students. The students have such significantly diverse support needs considering their varying levels of cognitive ability, as well as multiple diagno-

ses including Autism, Fragile X, Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Conduct Disorder, Reactive Attachment Disorder, Anxiety and Depression which are all managed 'under the one roof'. Behaviour management strategies require daily review in efforts to minimise triggers and preventing difficult behaviours and negative interactions. Additionally, the learning styles of students are so vastly different requiring flexibility and adaptability in promoting safe and respectful behaviour and learning.

At Rowland Hassall School I provide two and a half counsellor days a week have been allocated to assist 40 students with highly complex needs. External agencies are vital in providing counselling and support for students and their families. Therefore the majority of school counsellor time at Rowland Hassall School is spent following up on referrals, liaising with caseworkers and paediatricians, meeting with teachers, executive and regional personnel, parents and carers to co-ordinate DET and external supports. Additionally, every student's educational needs and diagnoses must be regularly reviewed. Despite significant efforts to plan my days and to work proactively, I often find myself in a reactionary mode and my best laid plans must be changed, requiring flexibility and patience.

Providing counselling for students with an intellectual disability and mental health diagnoses can be a great challenge. Nearly every student at RHS has a severe language delay or disorder. Consequently talk-based therapies can be frustrating for some students (and the counsellor!). Generally speaking, getting back to basics has proved most useful. The important work of building therapeutic alliances and relationships with students can be difficult due to attachment and trust issues. However if a relationship can be built, its therapeutic value is substantial. Spending time in the playground with students and joining their activities is a great way to begin this process.

Basic reflective listening techniques can be particularly helpful for students with an intellectual disability because they are often limited in their ability to accurately recall, express, summarise and reflect upon their experiences and to understand their feelings. These basics are utilised often and anywhere, including the playground, to promote emotional literacy. Motivational Interviewing skills are valuable in assessing the likelihood of behaviour change and in working with ambivalence. Some Cognitive Behaviour Therapy strategies when simplified, adjusted and supported by visual aids can be useful for some students. Skills in play therapy are also very useful. Counselling sessions can usually be sustained for about 20 minutes depending upon the student's ability to maintain concentration.

Counsellors working in these types of environments need to work collaboratively to find support not just for students but for themselves. Further relevant research and professional development in the areas of intellectual disability and mental health will continue to enhance the skills of counsellors. Establishing a network of SSP counsellors could provide opportunities to share information, experience and debrief with colleagues in similar circumstances. Further, working in partnership with a mentor in the Health sector could provide invaluable support for counsellors in SSPs, particularly if the counsellor is inexperienced.

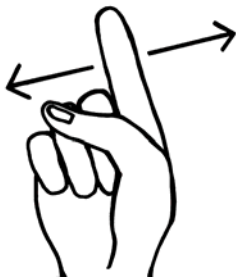
Improving outcomes for students with an intellectual disability and mental health diagnoses and for those who support them is a challenging and worthwhile endeavour. I am continually learning and feel truly thankful for the opportunity. ●

Kellie Van Sebille  
School Counsellor  
Rowland Hassall School



# laminare, cut-out and keep behaviour cards...

These picture cards are from [www.dotolearn.com](http://www.dotolearn.com) and are not for commercial use. They can be used with students with or without the words written below! Enjoy! Share your similar resources with us; email [schoolink@chw.edu.au](mailto:schoolink@chw.edu.au)



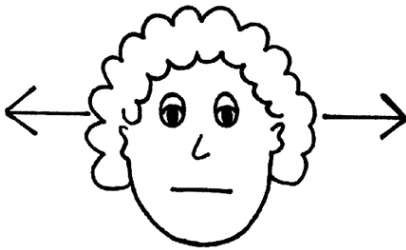
do not



cry



no biting others



no



no hitting



no yelling



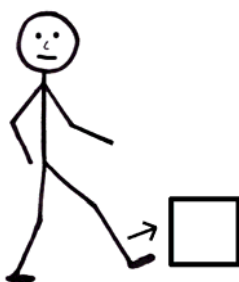
no kicking



no crying



no biting



kick

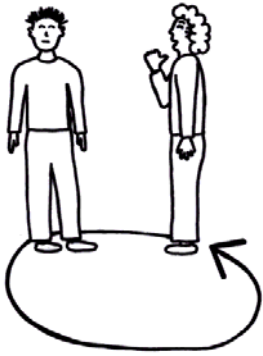


hit

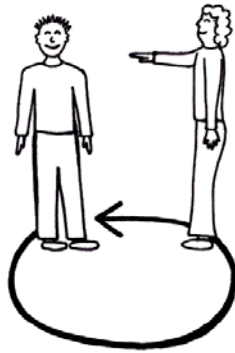


No hitting self





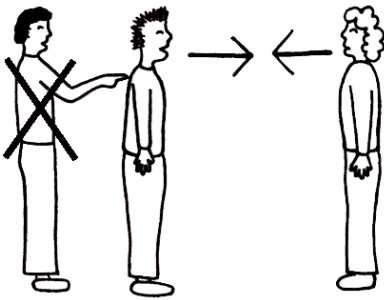
my turn



your turn



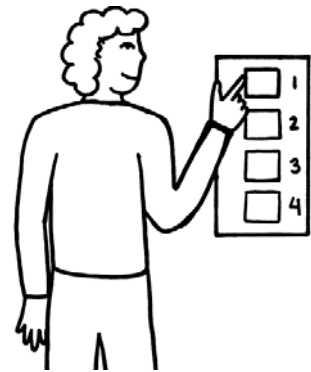
I don't know



don't interrupt



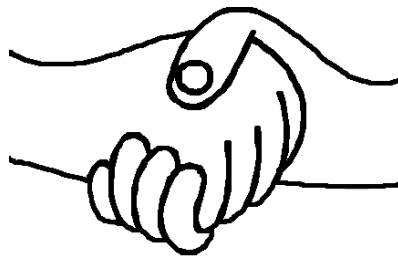
listen



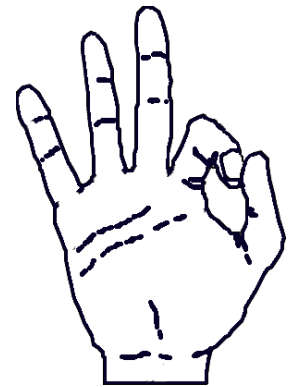
check schedule



hello



shake hands



okay



thumbs up



don't touch



yes

## resources...

- EDNA for Schools Website. Their much loved calendar which has previously been sent to schools is now only available online, see [http://www.edna.edu.au/edna/go/schooled/schools\\_events](http://www.edna.edu.au/edna/go/schooled/schools_events) for this year's events. Happy year of Biodiversity!
  - Innovative Resources' range of therapeutic card sets, books and stickers are used by human service professionals in myriad roles and cultures. They promote optimism, respect, hope and fairness. Very simple and easy to use. [www.innovativeresources.org](http://www.innovativeresources.org)
  - The NSW Council for Intellectual Disability (NSW CID) has a number of fact sheets which discuss and provide information about issues important to people with intellectual disability. Please feel free to make copies of these fact sheets or call them on 02 9211 1611 or 1800 424 065. <http://www.nswcid.org.au/standard-english/se-pages/fact-sheets.html>
  - The NSW CID website also includes access to annual reports and any past and upcoming events about intellectual disability.
  - Educational Experience inspires young minds through the use of toys and educational material. Visit at [www.edex.com.au](http://www.edex.com.au)
  - The Australian Institute of Family Studies (AIFS) clearinghouse provides access via the internet to resources that may be useful for professionals; services providers and families of children with intellectual disabilities <http://www.aifs.gov.au/cafca/resources/disabilities/disabilities.html>
  - For more general health information, try checking out *healthInsite* [http://www.healthinsite.gov.au/topics/Intellectual\\_Developmental\\_and\\_Learning\\_Disabilities](http://www.healthinsite.gov.au/topics/Intellectual_Developmental_and_Learning_Disabilities)
  - Australian Domestic and Family Violence Clearinghouse has a special collection about disability. Research on factors concerning domestic and family violence against people with disabilities, and evidence and evaluation of strategies aimed to address such violence, are critical to strengthening our understanding and response to disabled members of our communities. While comprehensive information about domestic and family violence against people with disabilities is limited, available research suggests that women with disabilities experience significantly higher levels of violence than other women, while facing greater challenges to accessing support and assistance. The Clearinghouse database contains a wide array of research and resources on issues related to people with disabilities, including information about prevalence and service practice, as well as resources for clients and workers. On the International Day of Disabled Persons (December 3<sup>rd</sup>, 2009), the Clearinghouse released a Special Collection of materials on domestic and family violence against people with disabilities. The information and resources are adult based but still an interesting read. <http://www.adfvc.unsw.edu.au/specialcollectionsdisability.htm>
- The *Raising kids together* information kit is for families from Afghanistan, Iraq and Sudan who have a child or young person with a disability



and for those who support them. The information includes what to look for if think parents think their child may have a disability including more about disability, available services and how to get them, rights and responsibilities in accessing disability services and some important phone numbers and how to use interpreters. The kit comprises an information booklet in English translated into Arabic, Assyrian, Dari, Juba Arabic and Dinka and a DVD with voice over in the five community languages. You can find this resource on the Ageing, Disability and Home Care website by using the link below. <http://www.dadhc.nsw.gov.au/dadhc/People+with+a+disability/Raising+kids+together.htm>

- Project to Improve the Learning Outcomes of Students with Disabilities in the Early, Middle and Post Compulsory Years of Schooling: Research Report and Teacher Resource Booklet. This project by the Department of Education, Employment and Workplace Relations identifies ways to improve learning outcomes of students with disabilities enrolled in mainstream classes in the early, middle and post-compulsory years of schooling. The focus is on the activities, interactions and materials that make classroom practice inclusive and that lead to improved outcomes for all students. Attention was also directed to the professional development need of teachers so that they acquire the knowledge and skills to implement inclusive classroom practices. Download at [http://www.dest.gov.au/sectors/school\\_education/publications\\_resources/profiles/learning\\_outcomes\\_students\\_disabilities.htm](http://www.dest.gov.au/sectors/school_education/publications_resources/profiles/learning_outcomes_students_disabilities.htm)

## reader invite...



Subscribe to our  
E-list!

Send us an email with your  
Name and any Email Address to

[schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)

Please forward this newsletter to  
other professionals interested in Men-  
tal Health and Intellectual Disability

**Join NOW!!**



# reading list...

## Oldies but Goodies

AIHW (Australian Institute of Health and Welfare). (2008). *Disability in Australia: Intellectual Disability*. Bulletin no.67, Cat. No. AUS 110. Canberra: AIHW.

**General information about intellectual disability in Australia. Great for statistics about this population.**

Einfeld, S.L. and Tonge, B.J. (1996). Population Prevalence of Psychopathology in Children and Adolescents with Intellectual Disability: I Rationale and Methods. *Journal of Intellectual Disability Research*. Vol 40, Iss 2, Pp. 91-98.

**Australian study (with findings in the article below) about the prevalence of psychopathology. This paper shows the implementation and planning process of the research.**

Einfeld, S.L. and Tonge, B.J. (1996). Population Prevalence of Psychopathology in Children and Adolescents with Intellectual Disability: II Epidemiological Findings. *Journal of Intellectual Disability Research*. Vol 40, Iss 2, Pp. 99-109.

**Findings from the Australian study above that found a very high percentage of psychopathology in children and adolescents with an intellectual disability. Set the precedent for many studies to follow.**

Einfeld, S.L., Piccinin, A.M., Mackinnon, A., Hofer, S.M., Taffe, J., Gray, K.M., Bontemp, D.E., Hoffman, L.R., Parmenter, T. and Tonge, B.J. (2006). Psychopathology in Young People with Intellectual Disability. *JAMA*. Vol 296, Iss 16, Pp. 1981-1989.

**A study of children and adolescents with intellectual disability and comorbid mental health problems. Results show problems can be persistent followed by a discussion of interventions.**

Emerson, E. and Hatton, C. (2007). Mental Health of Children and Adolescents with Intellectual Disabilities in Britain. *British Journal of Psychiatry*. Vol 191, Pp. 493-499.

**Discusses prevalence rates in Britain and the risk factors. Interesting to compare their results with the Einfeld and Tonge (1996) study above.**

Fletcher, R., Loschen, E., Stravrakaki, C. and First, M. (2007). *Diagnostic Manual- Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, New York.

**This manual discusses the different types of mental disorders and how they manifest with intellectual disability. Similar to the DSM, it provides criteria and information about each disorder. A must have reference book.**

Hendren, R., Birrell Weisen, R., and Orley, J. (1994). *Mental Health Programs in Schools*. World Health Organisation, Geneva WHO/MNH/PSF/93.3 Rev.1.

**This paper reviews literature on models for**

**mental health promotion in schools. It is a good international overview from the World Health Organisation.**

McCarthy, J. and Boyd, J. (2002). Mental Health Services and Young People with Intellectual Disability: is it Time to do Better? *Journal of Intellectual Disability Research*. Vol 46, Iss 3, Pp. 250-256.

**A large issue is services for children and adolescents with mental health problems and disorders and an intellectual disability. It is interesting to see that very limited services are available for this population in the UK who seem to be ahead of the Australian community.**

Parmenter, T.R., Einfeld, S.L., Tonge, B.J. and Dempster, J.A. (1998). Behavioural and Emotional Problems in the Classroom of Children and Adolescents with Intellectual Disability. *Journal of Intellectual and Developmental Disability*. Vol 23, Iss 1, Pp. 71-77.

**Study which found that students in segregated schools with intellectual disability have higher levels of behavioural and emotional disturbance when compared with students in a mainstream setting with intellectual disability.**

Sawyer, M.G., Arney, F.M., Baghurst, P.A., Clark, J.J., Graetz, B.W., Kosky, R.J., Nurcombe, B., Patton, C., Prior, M.R., Raphael, B., Rey, J.M., Whaites, L.C. and Zubrick, S.R. (2001). The Mental Health of Young People in Australia: Key findings from the child and adolescent component of the national survey of mental health and wellbeing.

**Australia's first insight into the state of the nations mental health and wellbeing. A good foundational read for general information about mental health in the general population of children and adolescents.**

White, P., Chant, D., Edwards, N., Townsend, C. and Waghorn, G. (2005). Prevalence of Intellectual Disability and Comorbid Mental Illness in an Australian Community Sample. *Australian and New Zealand Journal of Psychiatry*. Vol 39, Pp. 395-400.

**Further evidence for prevalence rates in an Australian sample. Adult data.**

## 2009

Bouras, N. (2009). Editorial: Mental Health and related issues for People with Intellectual Disability. *Current Opinion in Psychiatry*. Vol 22, Pp. 429-430.

**This whole issue is a great read so we have added the editorial here which gives a great overview of all the research articles. Some are general articles whilst others are reviews of international perspectives. Particular interest is the Totsika and Hastings research on persistent challenging behaviour in children and Kauffman and Hung on special education.**

Burton-Smith, R., McVilly, K.R., Yazbeck, M., Parmenter, T.R. and Tsutsui, T. (2009). Service

and Support Needs of Australian Carer Supporting a Family member with Disability at Home. *Journal of Intellectual and Developmental Disability*. Vol 34, Iss 3, Pp. 239-247.

**Investigates the support needs of carers supporting a family member with a disability. Although general and not focused on intellectual disability, it is good to read an Australian study from this perspective.**

Emerson, E., McConkey, R., Walsh, P.N., Felce, D. (2009). Editorial: Intellectual Disability in a Global Context. *Journal of Policy and Practice in Intellectual Disabilities*. Vol 5, Iss 2, Pp. 79-80.

**This editorial opens the way to investigating a global view of intellectual disability. We don't always think about intellectual disability in other countries, now might be the time to start. We can definitely use the information to look at the way other countries (especially low income countries) put policies into practice. Another interesting theme is the shift into mainstream services and away from specialist services.**

Hudson, A., Reece, J., Cameron, C. and Matthews, J. (2009). Effects of Child Characteristics on the Outcomes of a Parent Support Program. *Journal of Intellectual and Developmental Disability*. Vol 34, Iss 2, Pp. 123-132.

**Discusses a specific parent program for families supporting children and adolescents with difficult behaviour and intellectual disability. Literature overview of efficacy from previous studies with a current detailed examination of the characteristics of the child and its effect on the program. Interesting to learn about signposts if you haven't already encountered this program.**

Murphy, G. (2009). Challenging Behaviour: A Barrier to Inclusion? *Journal of Policy and Practice in Intellectual Disabilities*. Vol 6, Iss 2, Pp. 89-90.

**A short interesting read about quality of life and social inclusion. Something to think about.**

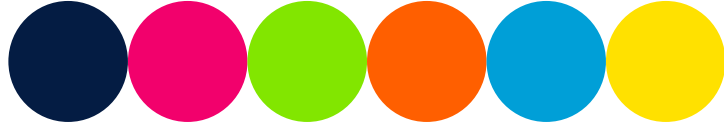
Rose, R., Howley, M., Fergusson, A. and Jament, J. (2009). Mental Health and Special Education Needs: Exploring a Complex Relationship. *British Journal of Special Education*. Vol 36, Iss 1, Pp. 3-8. **Discusses the challenges for teachers and the training needs required to help understand this complex relationship.**

Slee, P.T., Lawson, M.J., Russell, A., Askell-Williams, H., Dix, K.L., Owens, L., Skrzpiec, G. and Spears, B. (2009). *Kidsmatter Evaluation Executive Summary*. Flinders University.

**An interesting development in prevention and early intervention. Can access the final evaluation report on [Kidsmatter.edu.au](http://Kidsmatter.edu.au).**

Yen, C.F., Loh, C.H. and Lin, J.D. (2009). Prevention of Mental Health Problems in People with Intellectual Disability. *Current Opinion in Psychiatry*. Vol 22, Pp. 447-451.

**As found in our own research at the hospital, this article suggests paucity in research on prevention of mental health issues in people with intellectual disability.** ●



## in the news...

### Anglicare's Kingsdene to close at end of year

Steven Deare- Parramatta Advertiser 16th Feb 2010

SUPPORTERS of Kingsdene (Independent Special School) at Telopea are preparing to close it at the end of the year because of a stalemate with government. Anglicare director community care Ian Jackson said there had been no progress in the battle to save the school for children with intellectual disabilities. The charity says it cannot continue to contribute \$1.2 million of the \$3.37 million required to run the school each year, and wants the government to increase its share.

"We've had no more correspondence with the government," Jackson said. "We are working with families to transition next year." Anglicare will help 15 families find supportive schools or respite centres for their children for 2011.

In December Federal Education Minister Julia Gillard offered emergency funding of \$350,000 to help the school continue until 2012, but that was not enough for Anglicare.

Jackson and his peers want a long-term solution. "It's not sustainable for a charity to run a school at a \$1.2 million loss each year," he said.

### Breaking Point

Wendy Carlisle- ABC Four Corners: 15/02/2010

The heart-rending story that tells what it's like to live with a disability, or to care for someone who is disabled, in Australia today. Reporter Wendy Carlisle meets the families the nation has neglected.

The system of assistance for people with a disability in Australia is broken. Carers know it, charitable organisations know it and so do the governments. Now the federal government says something must be done. It's holding an Inquiry, with the intention of creating a new and fairer system. It's even considering a national disability insurance scheme. But will the system be reformed in time to save the families now at breaking point?

In Sydney, 65 year old Dick Jones showers his profoundly disabled son Robbie. It's a task he does willingly but at his age he doesn't know how long he can keep giving his son the care he needs. He's been told the only way to get more help would be to abandon his child and leave him in the care of the state.

Amanda Royle's 9 year old daughter Rosie is deaf and blind, cannot speak, and is intellectually disabled. On her own with two other children to look after, Amanda is in desperate need of assistance that the system cannot provide.

These families are desperate and they are not alone. Across Australia it's estimated that there are 1.5 million people with a severe disability. Only a small proportion of them receive any direct physical care from government or charities. The vast majority rely on family and friends to help them survive.

Watch online at <http://www.abc.net.au/4corners/content/2010/s2817123.htm>

### Disability Accommodation Program

[www.billshorten.fahcsia.gov.au](http://www.billshorten.fahcsia.gov.au) 16/02/2010

IN 2008 the Rudd Government committed \$100 million to the State and Territory Governments to build a total of 313 new places in Supported Accommodation Facilities to be completed by June 30, 2012. This was part of record funding delivered to the States through the jointly-funded National Disability Agreement. The NDA will deliver an extra \$1.9 billion, \$1 billion from the Federal Government and \$900 million from the States over five years. The Federal Government's contribution to state-run disability services will reach more than \$1.25 billion a year by the end of the agreement in 2013. This compares to \$620 million in 2007.

### Autistic pupils unfairly treated

Bruce McDougall- Daily Telegraph 08/01/2010

GROWING numbers of students suspended for violence, aggressive behaviour or repeated disobedience have a serious mental disability such as Autism. More than 69,000 students receive long or short suspensions in public primary and secondary schools each year but parents believe a huge proportion of have a disability and should be helped instead of disciplined. Principals report increasing numbers of children entering school exhibiting mental illnesses and the number of children with autism has exploded by more than 65 percent in the last three years.

A NSW parliamentary inquiry is underway into the education of students with a disability or special needs. In 2009, the public school system had 204 autism classes in regular and special schools.



facts and figures...

## Interesting Facts to Know!

21st of March is World Down Syndrome Day! It aims to promote awareness and understanding of Down Syndrome. See [www.worlddownsyndromeday.org](http://www.worlddownsyndromeday.org)

The prevalence of Autism in Australia is estimated to be about 1 in 160. This is based on a Western Australian study of children aged 6-12 years. Macdermott *et al* (2007). *The Prevalence of Autism in Australia*. Report prepared for the Australian Advisory Board on Autism Spectrum Disorders

Famous people with a mental illness include; Abraham Lincoln, Winston Churchill, Vincent Van Gogh, Mariah Carey, Isaac Newton, Brooke Shields, Agatha Christie and Ernest Hemmingway! [www.naminj.org](http://www.naminj.org)

In NSW 282,000 people were receiving community care or disability services support in 2008-09. That figure is expected to rise by about 26 per cent to 356,500 by 2014. 15/02/2010 [www.smh.com.au](http://www.smh.com.au)

The Australian Institute of Family Studies found that carers and families of people with disability experience high rates of mental health problems, poor physical health, employment restrictions, financial hardship and relationship breakdown.

AIFS (2008). *The Nature and Impact of Caring for Family Members with a disability in Australia*. Research report number 16, Melbourne.



## reviews...



### Book Review: The Clinician

More of a journal than a book, the Clinician is a publication produced by CAMHSNET (Child and Adolescent Mental Health State-wide Network). Volume three focuses on Acceptance and the Autistic disorders. Filled with papers and cases studies, this volume discusses diagnosis, assessment, neurobiology, genetics, interventions, family interventions, teaching social skills, pharmacotherapy, teachers and the classroom, self injury and many parent stories. A interesting read, especially for first timers to Autism. Order for free from the Better Health Centre.

[www.health.nsw.gov.au/pubs/bhc.asp](http://www.health.nsw.gov.au/pubs/bhc.asp) or 9887 5450



### Website Review; *Inspire foundation* [www.inspire.org.au](http://www.inspire.org.au)

Delivers online programs for youth that prevent youth suicide and improve mental health and wellbeing. Their projects include [reachout.com](http://reachout.com) (improve understanding of mental health issues), [betweenthelines.net.au](http://betweenthelines.net.au) (focuses on drug and alcohol issues) and [actnow.com.au](http://actnow.com.au) (discusses social issues). Includes a research library with access to past documents. May be useful for students with mild intellectual disability only.



### Organisation Review; *ASSID* Australasian Society for the Study of Intellectual Disability <http://www.assid.org.au/Default.aspx?base>

Promote the research and understanding of intellectual disability, bring together people with an interest in the field if intellectual disability and promote high standards of practice in the field of intellectual disability. Search their website for research, publications and events. Look out for their annual conference, this year is the 45th to be held in late September.

## conference reviews...

### Healthier Lives Forum August 11 2009.

The NSW Council for Intellectual Disability (CID) hosted a health forum: *Healthier Lives – pathways to better health for people with intellectual disability* last August 2009. The forum highlighted the myriad of health issues that affect people with an intellectual disability, and access to mental health services was a key concern as expressed by delegates with and without an intellectual disability.

At the forum, CID in collaboration with DADHC launched a series of excellent health fact sheets, including mental health, that are in both an easy to read format with pictures and standard text format. The fact sheets are very useful as they can be used with people with ID, parents or anyone who needs an easy to read resource. Fact sheet topics include: mental health; me and my medication; some signs of sickness; after visiting the doctor, going to hospital for surgery; finding a new doctor with more coming soon.

The fact sheets are free and available in PDF format for download on the following site:  
<http://www.nswcid.org.au/health/ee-health-pages/easy-fact-sheets.html>



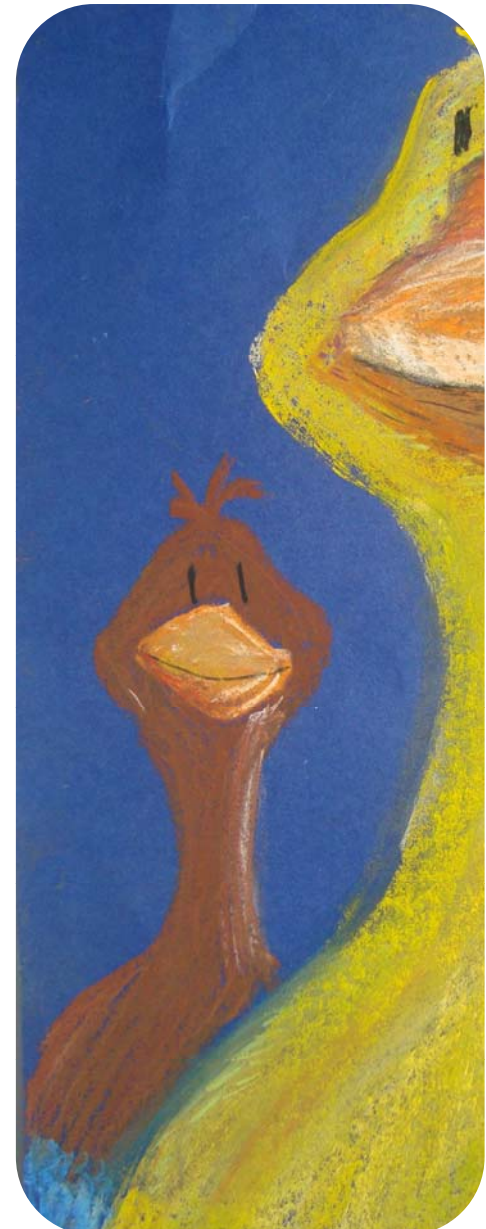
### Making the Links: Mental Health and Intellectual Disabilities

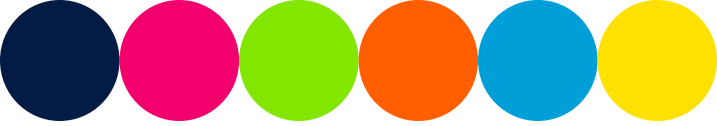
Sydney South West Area Health Service School-Link and their Adolescent Community Mental Health Service hosted a one day conference called Making the Links: Mental Health and Intellectual Disabilities. The conference had a great variety of speakers including developmental psychiatrists, PBIS staff, school staff and DADHC representation. The day finished with an active discussion about case studies that were submitted by various participants.

The conference highlighted the complexities associated with students' behavioural and emotional problems in special education settings. A follow up to this conference will be offered in early 2011.



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





## a note from David Dossetor...



### How much should we worry about the Mental Health Needs of Children and Adolescents with or without Intellectual Disability?

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

The planned closure of Anglicare's Kingsdene Independent Residential School for adolescents with intellectual disability made me wonder about how much we should be worrying about children and adolescents with intellectual disability in the context of our understanding of the mental wellbeing of those without intellectual disability. Kingsdene is the only residential school in NSW, and possibly Australia, that caters for young people with severe intellectual disability and complex behavioural, developmental and psychiatric problems. In these times, why should the spectrum of services appear to be deteriorating? Does the great media reaction suggest that this closure represents a sentinel event of the wider public/private service system? Knowing some of these families personally leads me to have some direct experience of what remarkable, committed and loving families these are and I have some understanding of the extraordinary hardship and adversity they cope with. The failure of funding for these special needs not only has major risk of breakdown of some families but also risks more serious adverse events.

How much concern should our community show

about the mental health of children and adolescents (Stanley *et al*, 2005)? The 50% growth in the number of children in care between 2002 and 2007 concerns me (Wood Inquiry, 2008). The recent significant increase of young people in juvenile detention centres concerns me. The number of children and adolescents that are homeless concerns me (36,000 teenagers on any night in Australia) (National Youth Commission, 2008). The level of welfare for homeless 12 year olds, often in refuge accommodation (so long as they are not violent) concerns me.

I witness these changes from the nature of clinical presentations over time. Particularly as the level of disturbance with risk to self and others of young people presenting to our emergency department is getting worse, more frequent and presenting younger. Does this mean the children and adolescents are becoming more disturbed over time? Are our families and community becoming less able to help them grow up? Epidemiologists may argue that things aren't changing, or that we are medicalising problems or that our standards of child protection are becoming more sensitive or that these aren't psychiatric problems. Maybe kids are growing up quicker. Those that I talk to in community work, education, health or mental health all say things are changing and getting worse whether you look over thirty years or the last five or ten years.

The reasons and the changes are complex. The economic growth and productivity of the last 20 years may mean higher expectations for everybody, but why should or could the emotional

wellbeing of this group be worse off? Amongst some of the multiple factors associated with national prosperity that may influence child development and wellbeing I shall mention four. First is the dramatic decline in the average amount of time parents spend with children by 20 hours less per week, over the last generation, largely related to both parents working (and the dramatic increase in "screentime"). Second is the decline of the extended family and of social capital networks in our community and increase of social isolation for many families. Third, measures of quality of family relationships show an increase in the emotional intensity in relationships associated with urbanisation and industrialisation. These measures of "expressed emotion" show a rise in the frequency of criticalness, hostility of, or emotional over involvement with children or other next of kin. These qualities of emotional communication affect the emotional development of children and others with mental wellbeing problems. Finally and possibly the strongest evidence is the influence of and changes in financial relative inequity which is shown to be a powerful driver of a whole range of factors. The World Bank has shown that across the western world, the percentage of a population that earn less than 50% of the median wage is closely correlated with community rates of psychiatric disorder, which is mainly depression and disruptive/criminal behaviour (Emerson, 2004). The recent analysis by Wilkinson and Pickett (2009) amplifies the implications of inequity. Even across the different states of the USA, they argue that the extent of financial and social inequity (the top 20% versus the bottom 20%) is causally related to a host of health as well as mental health factors, including infections, obesity, heart disease, substance abuse, depression, violence and even murder. Rates for these indices for the whole population are about 5 times





greater between the most unequal countries and the least unequal countries. In fact, even the top 20% are less healthy in more unequal communities. Australia may not be as severely affected by inequity as the USA but is this an inevitable consequence of the last decade of globalisation and corporate success?

What about children with intellectual disability? These children and families are affected by the same pressures yet they also suffer an extra risk factor of biological difference or disadvantage. It is found that rates of psychiatric disturbance are three to four times higher in these young people (Einfeld and Tonge, 1996). We also know that the risk of psychiatric disorder is related to the number of adversities that a child and family are exposed to but this rate goes up exponentially with the increase in the number of adverse factors. Emerson (2004) has shown that intellectual disability also exposes you to higher rates of adversity partly through greater social disadvantage. Accordingly, it does not surprise me that the demand for disability services, respite services and health and mental health services is growing for young people with intellectual disability. The frequency with which I encounter distressed parents who are preoccupied with thoughts of murder and suicide makes me concerned that as a community we aren't doing enough.

With the economic growth we should get better in the way we do things. People are better educated, have more access to knowledge through the internet and other media, and indeed there are advances in health and mental health sciences. Special education and training of parenting skills is the intervention found to have the biggest impact in the mental health of children and adolescents with intellectual disability

(Diggle *et al*, 2003). School culture has a big influence on social, emotional and psychiatric wellbeing, and schools can be a centre for community connection and even mental health promotion (Hendren *et al*, 1994). Behavioural, psychological and medical interventions also have growing scientific evidence of their value. For me the measure of a civilisation is how we deal with our most disadvantaged, disabled and disturbed. Young people with intellectual disability and other neurodevelopmental disadvantage are a special needs group that necessitate priority.

The Children's Hospital at Westmead School Link Initiative has the potential to be a part of finding ways of doing things smarter for the mental wellbeing of children and adolescents with intellectual disability, by using a collaborative approach in: promotion, prevention and early intervention, increasing workforce education, and improving pathways to care. The worth of this project will depend on partnership with others who share our concern. Ultimately our collaboration is with the young people with intellectual disability and their families. I don't think the average member of our community knows or understands how difficult it can be to care for, support and love a child or adolescent with intellectual disability particularly in the context of the additional challenge of associated emotional or behavioural problems. This level of community stigma and alienation really concerns me. ●

#### References:

Diggle, T., McConachie, H. R. & Randle, V. R. (2003). Parent-mediated Early Intervention for Young Children with Autism Spectrum Disorder. *Cochrane Database Systematic Review*. Vol 2, Art. No. CD003496. Accessed February 2009

Einfeld, S.L. and Tonge, D.J. (1996). Population Prevalence of Psychopathology in Children and Adolescents with Intellectual Disability: II Epidemiological Findings. *Journal of Intellectual Disability Research*. Vol 40, Iss 2, Pp. 99-109.

Emerson, E. (2004). Poverty and Children with Intellectual Disabilities in the World's Richer Countries. *Journal of Intellectual and Developmental Disability*. Vol 29, Iss 4, Pp. 319-387.

Hendren, R., Birrell Wisen, and R., Orelly, J. (1994). *Mental Health Programmes in Schools*. Division of Mental Health, WHO (World Health Organisation).

National Youth Commission. (2008). *Australia's Homeless Youth Project Summary*. Accessed via [www.abc.net.au/tv/oasis/pdfs/Homeless\\_summary.pdf](http://www.abc.net.au/tv/oasis/pdfs/Homeless_summary.pdf) February 2009.

Stanley, F., Richardson, S., and Prior. M. (2005). *Children of the Lucky Country? How Australian Society has Turned its Back on Children and Why Children Matter*. Pan Macmillan: Australia.

Wilkinson, R., Pickett, K. (2009). *The Spirit Level: Why More Equal Societies Almost Always Do Better*. Allen Lane: London. Accessed February 2009.

Wood, J. Justice. (2008). *Report of the Special Commission of Inquiry into Child Protection Services*. State of NSW, Special Commission of Inquiry in Child Protection Services in NSW. [www.dpc.nsw.gov.au/publications/news/stories/special\\_commission\\_of\\_inquiry\\_into\\_child\\_protection\\_services\\_in\\_new\\_south\\_wales](http://www.dpc.nsw.gov.au/publications/news/stories/special_commission_of_inquiry_into_child_protection_services_in_new_south_wales). Accessed February 2009.

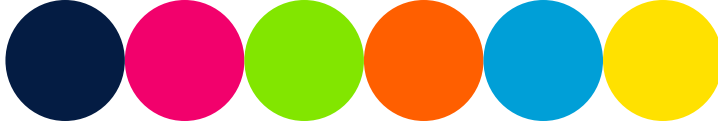
## Operation art project...



Operation Art is a project that encourages students from Kindergarten to Year 10 in all NSW schools to create artworks for children in hospital. It is an important state-wide visual arts exhibition that focuses on creating a positive environment to aid the healing and recovery process of young patients.

Operation Art is a way of involving young people in the special work of The Children's Hospital at Westmead – a total healing environment where design, decoration, facilities, gardens and art combine with the best possible medical care to help comfort and heal young patients.

*For more information on getting your SSP involved in Operation Art for 2010, Join our email list! Email us at [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)*



## contents...

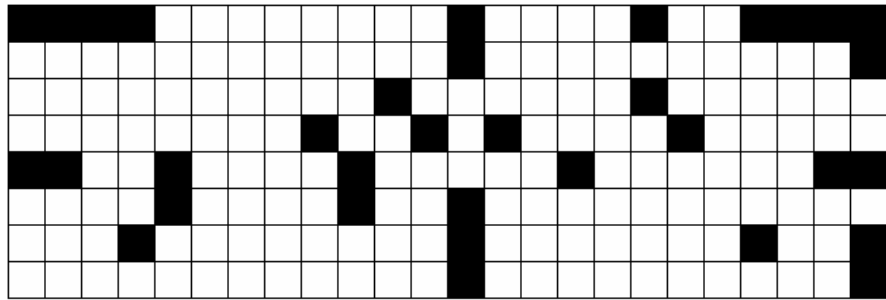
- 1 Coordinators Message: Its Time  
*Jodie Caruana*
- 1-3 Mental Health and Intellectual Disability Literature Review  
Excerpt from Dossetor, D., Caruana, J., Goltzoff, H. and Saleh, H. (2009). *Leading the Way in Mental Health and Intellectual Disability. A Focus on the needs of Children and Adolescents in Schools for Specific Purposes in NSW*. The Children's Hospital at Westmead.
- 4 Guest Writer: Mind Matters  
*Maryanne Vorreiter and Jason Pascoe*
- 5 Upcoming Training
- 6 Case Study  
*Louisa Carroll*
- 7 A Day in the life of a SSP School Counsellor- Rowland Hassall Special School  
*Kellie Van Sebille*
- 10 Resources
- 11 Reading List
- 12 In the News
- 13 Reviews: Book, Web, Organisation, Conference
- 14-15 A Note from David Dossetor:: How much should we worry about the mental health needs of children and adolescents with or without intellectual disability?  
*Associate Professor David Dossetor*

## amusements...

### Fallen Phrase

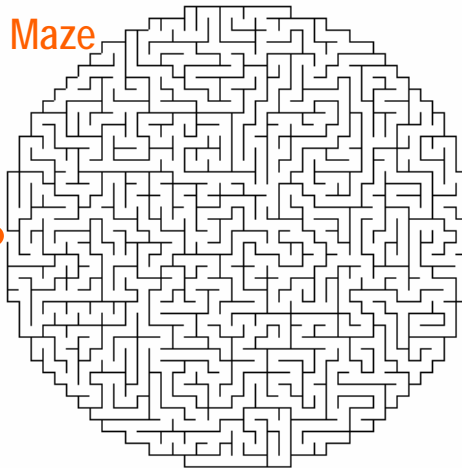
*Hint: Findings by Einfeld and Tonge (1996)*

Instructions: Use the letters below the columns to fill in the blocks to form a special phrase. Once you use a letter, cross it off.



T I L S A H  
T I O N T O I W D T H I L N  
I R T E L T E C T U T L A I O T I H T H A Y  
P X A E C E H A T A E L D I A L B G T E T T  
I H T E S L M U D R T N D I T H E I L I L Y  
A N D N R L E D E E T F A N R S A B A E E R N E  
T N P O L H E S C U A S E W I S L O U C I T T H  
E N O B L F U C R N A M M E T A H E S N A R E S

### Maze



### Unscramble



*Hint: Something we should all do*

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

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

## contact us...

The Children's Hospital at Westmead  
School-Link Initiative  
Department of Psychological Medicine  
Cnr Hawkesbury Rd and Hainsworth St,  
Westmead NSW 2145  
[schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)  
P: 9891 7208 F: 9891 7222

CHW School-Link Newsletter Editor  
Hebah Saleh [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)

