



mental health and intellectual disability...

coordinators message

It takes a village to support a child...

Our inaugural edition of the CHW School-Link Newsletter proved very popular and we were delighted with the overwhelming amount of positive feedback. Over 160 people have subscribed to our newsletter e-list so far, reflecting the keen interest in the emotional wellbeing of children and young people with an intellectual disability. I attended a [Schools First](#) community partnerships forum last month and their slogan "it takes a village to raise a child" struck a chord. If our e-list is anything to go by our village that raises children with an intellectual disability consists of school counsellors, principals, teachers, school nurses, occupational therapists, speech therapists, physiotherapists, family therapists, psychiatrists, psychologists, counsellors, case managers, social workers, pharmacists, dieticians, paediatricians, program coordinators, policy officers, respite staff, university students in training and last but not least all the wonderful parents and carers.

This school term has marked the beginning of a CHW School-Link Supervision Pilot for school counsellors of Schools for Specific Purposes in the Sydney West DET region (photo from our inaugural meeting above). The CHW scoping project last year identified that school counsellors of students with an intellectual disability require access to interagency expertise. The supervision pilot will be implemented over terms 2 and 3 2010 and results will be reported in forthcoming editions of this newsletter. If the pilot is successful our aim is to potentially replicate this model in other areas across the state over the next four years. So stay tuned.

On another exciting front we have developed a CHW School-Link website, www.schoolink.chw.edu.au. This site is in its early stages but will house the CHW School-Link newsletter and other resources for your use. We hope that over time this website will grow and be a wealth of information on the mental health of children and adolescents with an intellectual disability.

Our School-Link team is shrinking but expanding at the same time! Hebah, our project officer has taken maternity leave for the birth of her daughter Amelle, and I am also about to embark on the journey of motherhood, returning to CHW in early 2011. We are in the process of appointing a locum position who will write to you in our next edition. In the meantime please use the school-link@chw.edu.au for all correspondence and much welcomed contributions and feedback.

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

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Associate Professor David Dossetor

A Framework for Professional Practice: Behind the Scenes of the Educational Program and Book

Donna White, David Dossetor, and Lesley Whatson

Introduction

Children and adolescents with intellectual disability are at greater risk of developing mental health issues than their typically developing peers (Einfeld & Tonge, 1996; Emerson, 2003). This is due to the cumulative effects of developmental, biological, psychological, social and cultural difficulties (Hatton & Emerson, 2004; Hulbert-Williams & Hastings, 2008; Wallander, Dekker, & Koot, 2006). Mental health services available to this population within New South Wales are limited (Steitz, 2008) and services often don't meet the complexities of the associated needs of young people with intellectual disability and emotional/behavioural disturbances (Jess et al, 2008; Scior & Grierson, 2004). Professionals often have inadequate training in developmental disabilities and dual diagnosis (Costello et al., 2007; Phillips, Morrison, & Davies, 2004; Whitehurst, 2008) resulting in lack of expertise and confidence in working with this population (Mohr, Phillips, Curran, & Rymill, 2002; Tsiantis et al., 2004). There is also poor interagency collaboration across services that weaken the effectiveness of service delivery (Worrall-Davies, Kiernan, Ander-ton, & Cottrell, 2004).

This article briefly describes a partnership between the Department of Psychological Medicine at The Children's Hospital at Westmead and the Statewide Behaviour Intervention Service, Ageing Disability and Home Care (ADHC, Department of Human Services NSW) to develop, implement and evaluate an educational program for professionals working in child mental health and intellectual disability. This involved a multi-phased project that began in September 2007 and will finish in June 2010. The project has developed a framework of core clinical interventions; developed, implemented and evaluated a 2-day training seminar program; and edited a book of clinical papers.

The educational program provides a holistic framework that considers the 'biological, developmental, family, educational, social, and cultural contexts of children and adolescents with intellectual disability' and provides an evidence based perspective about the 'specific interventions that can effect change and improve the quality of life' of young people with intellectual disability, and their families (White, in press). The training events, based on the framework, were aimed at building staff capacity in order to promote the social, behavioural and emotional well-being and mental health of young people with intellectual disability (White, in press).

Project Phases

The Training Curriculum Project progressed through a number of phases so that key goals could be achieved. These phases are listed below (see White, in press for a detailed description of phases 1-4).

Phase 1

This involved the *development of a framework of core clinical interventions* that included a literature review, analyses of clinical and training data, expert opinion, review of existing resources and curricula, and a clinical forum. The framework consisted of four clinical domains that focused on: understanding and integrating scientific approaches; the impact of disability and family well-being; individual emotional and behavioural well-being; and integration of service systems (White, Dossetor, & Whatson, 2008).

Phase 2

A *training needs analysis* (TNA) was conducted that necessitated surveying clinicians to establish a consensus view of the core content requirements of the proposed framework. The TNA also identified the topics within the framework that were the highest priority for inclusion in the training events.

Phase 3

This entailed the development of a *two-day seminar program* for professionals that focused on the developmental, emotional and behavioural needs of young people with intellectual disability. It also included the collation of papers, on topics across the four clinical domains of the framework, from clinical experts into an *edited book* to supplement the information in the training events.

Phase 4

This phase was concerned with the *implementation and evaluation of the educational program* through three training events in 2009. Pilot training events were implemented in two regional centres in New South Wales and evaluated extensively. Feedback from these pilot events resulted in modifications to the training event content that was then implemented in metropolitan NSW. The results from the evaluations revealed positive outcomes for participants with increased knowledge, confidence and positive attitudes to multidisciplinary and interagency collaboration, and application of learning to work practices.

Phase 5

The last phase of the project has involved investigation of *sustainability* options to allow for the educational program to be available for future professional development once the project is completed at the end of June 2010. A further training event is to be held on 7-8 June 2010 as part of the sustainability plan.

Conclusion

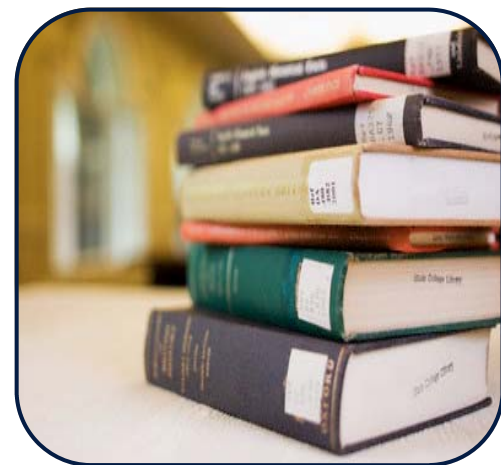
Since 2007, the Training Curriculum Project has achieved all its key goals including training of 300 professionals in 2009 and an edited book that is believed to be the first in its genre. The develop-

ment of the framework and training events has provided a network of professionals with expertise that has become the basis of enhanced partnerships across agencies. The focus is now on moving towards prevention and early intervention, staff competencies across agencies, and clarifying pathways to care. The project has also provided a learning environment that has fostered interagency collaboration in new and existing projects and clinical work e.g., the Developmental Psychiatry Clinic, Triple P Stepping Stones training.

In addition, presentations at conferences in South Africa, Sydney and Tasmania have enabled peer review of the project and framework at international and national levels. Abstracts have recently been accepted to present the project outcomes at conferences in Brisbane and Rome at the end of 2010. By sharing the research with professionals in child mental health and intellectual disability, and providing ideas on the practical application of core interventions, it is hoped that this will help meet the developmental, behavioural and emotional needs of young people with intellectual disability. ●

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Shared Care Family Support Program

MORE THAN JUST RESPITE – A HOLISTIC AND THERAPEUTIC APPROACH TO WORKING WITH MULTI-STRESSED FAMILIES

The Shared Care Family Support (SCFS) Pilot program is a new and innovative program, set up in 2007 by Interaction Disability Services, to provide clinical and case management support to families of children aged 7 to 15 with an intellectual disability and challenging behaviours/high needs. SCFS aims to prevent the incidence of breakdown in families with children with intellectual disability and challenging behaviours by providing support primarily across the family home and a facility environment, which acts as a controlled environment in which a dedicated and trained staff team implement a behaviour management/skill building program for each individual child.

The centre based care allows thorough assessment of each child and their challenging behaviour and provides an opportunity to trial effective behaviour management strategies. Access to the centre based facility is offered in a predictable yet flexible format, being a combination of mid week and weekend stays or solely midweek or weekends only, also with an option to opt out of access to the facility and commence in home support sooner.

SCFS also offers brokerage funding that can be used by each family to access specialist support, services, or equipment as needed and in accordance with family goals.

The philosophy behind this program is to work alongside the whole family to provide sustainable and tailored intervention whilst collaborating effectively with all other agencies/professionals working with that family. Having a facility that the families can access voluntarily and in a regular and predictable manner gives the family the chance to 'recharge',

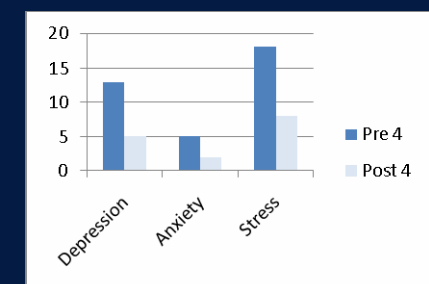
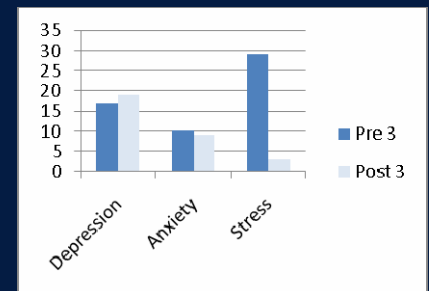
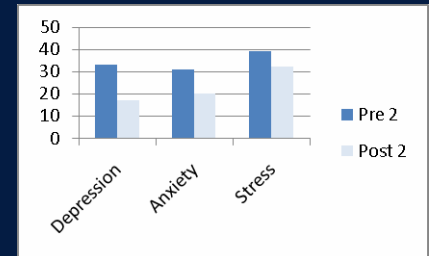
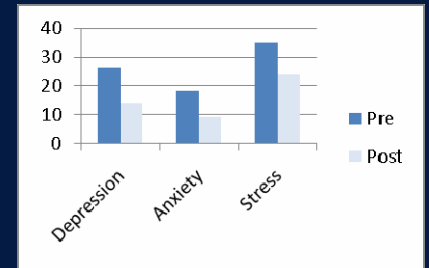
which helps with more meaningfully engaging with clinical programs within the home environment. It further gives the family an opportunity to better plan and structure their life, which can often be missing when having a child with a disability. The program also offers home based support, whereby a worker will work alongside, demonstrating and coaching families in preventing and managing their child's behaviour at home, based on the strategies found to be effective in the facility environment.

Working with multi-stressed and multi-needs families also requires working creatively, collaboratively, and in a staged approach. The SCFS program works with each family's goals, and considers how the clinical strategies can be made to 'fit' for each family such as to make it sustainable.

Families that have accessed this program have reported increased confidence when managing their child's behaviour and that they can 'see' the strategies work as a result of in-home support. Families have reported increased hope and have been more successful in adopting the strategies once seeing them work and with active support beside them.

This program has also demonstrated decreased parental psychopathology, improved understanding of reasons for behaviours resulting in better behaviour management, increased skills in clients, amongst other benefits as a result of the combined services provided. Below are collected measures outlining generalised decreases in parental psychopathology over the course of time in the program. ●

Natalie Robbins (SCFS Program Manager) & Jessica Radovan (SCFS Clinician / Psychologist), Interaction Disability Services
www.interactiondisability.com/





facts and figures...

Interesting Facts to Know!

Between 1981 and 2003, there were large increases in the number of Australian students with disability attending school. The number of students with severe or profound limitations rose by 260%. The number of students with disability overall increased by 93%. In part, this was related to the reported prevalence rates of disability and the large increase in the reported prevalence of ADHD and autism-related disorders (AIHW 2008).

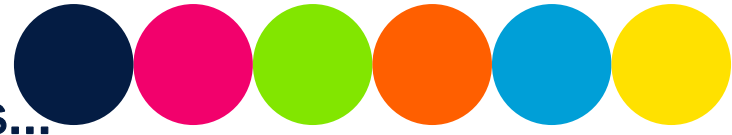
Sensory Processing Disorder (SPD) is the inability to use information received through the senses in order to function smoothly in daily life. SPD is not one specific disorder, but rather an umbrella term to cover a variety of neurological disabilities." - Carol Stock Kranowitz, *The Out-of-Sync Child*

Social and communication skills are taught incidentally when parents, carers and educators are receptive to child-initiated interactions and use them as teaching moments (Hart & Risley, 1995).

Type 1 Diabetes M is up to 35 times as common in people with intellectual disability (Anwar, Walker & Frier 1998 in [AIDC 2009](#).)

The total number of children with an intellectual disability under 15 in NSW is between 12 989-38967. The number of children with an intellectual disability from a Culturally and Linguistically Diverse (CALD) background is 2284- 6854. The total number of children with an intellectual disability from an Aboriginal background is between 531- 1593 (Hadia Baassiri, Cross Cultural Clinical Consultant CHW).

in the news...



Update on the NSW Inquiry into the Provision of Education to Students with a Disability or Special Needs

The NSW Inquiry into the Provision of Education to Students with a Disability or Special Needs has held three public hearings since the deadline of written submissions on the 26 February 2010. The inquiry was established in response to concerns raised by teachers and parents about the adequacy of funding for special education places and support services and the assessment process for children with disabilities or special needs attending New South Wales schools. The hearings were held on the 22 and 23 March 2010 and the 10 May 2010 at which various government and non government advocacy groups were invited to appear. If you are interested in the transcripts of these meetings they can be downloaded at: www.parliament.nsw.gov.au

The evidence gathered from the inquiry will form the basis of a report that the Committee will present to Parliament in mid 2010. This report will include recommendations to the New South Wales Government regarding how to address the issues raised during the inquiry. The Government will have six months in which to respond and everyone who participates in this inquiry will receive a copy of the Committee's recommendations and the Government's response.

"We can only try to come up with some solutions based on the evidence that we are given. We cannot solve individual issues, but our hearts go out to those parents and teachers who are struggling every day. I refer to parents such as the one who rang me in tears about having to be an advocate for their child and fighting for what they need from day one, having lack of sleep, but still wanting to make a submission to this inquiry. We say thank you to all of you. We can only try to live in your shoes for a little while, but we hope, and will use our best endeavours, to make some sense of what is going on in the community, unravel the web and make some recommendations to Government."

The Hon. R. M. Parker (Chair) - transcript from the first public hearing 22/03/10
[http://www.parliament.nsw.gov.au/Prod/parliament/committee.nsf/0/d6d917eba7ea7229ca2576ef000b29fd/\\$FILE/100322%20Corrected%20transcript.pdf](http://www.parliament.nsw.gov.au/Prod/parliament/committee.nsf/0/d6d917eba7ea7229ca2576ef000b29fd/$FILE/100322%20Corrected%20transcript.pdf)

Mad as Hell Campaign

A national independent campaign has been launched to support a National Disability Insurance Scheme designed to fund essential services and supports for people living with a disability. Full details are available from www.australiansmadashell.com.au. The organisers are aiming to gather the names, email addresses and postcodes of as many people as possible to support the introduction of a national disability insurance scheme. Click on the website above to register your name.

Teena Caithness Receives Award

Teena Caithness was the recent recipient of the Speech Pathology Australia Elinor Wray Award for her outstanding contribution to Speech Pathology. Teena has been working in the speech pathology industry for 25 years and has recently moved from Sydney where she was working with ADHC to Melbourne taking up a position with the organisation Scope. Congratulations Teena!



CHW Fellow of Psychiatry wins RANZCP Trainee

Congratulations to CHW's first ever fellow of psychiatry (intellectual disability) Dr Rameswaran Vanitambay who was the successful recipient of the Royal Australian and New Zealand College of Psychiatrists 2010 Committee for Research Congress trainee award for his presentation: *Models of care for people with intellectual disability: What is the evidence?* The Congress Trainee award is for a sum of \$1,000 and is presented to the trainee who has been judged by the Committee for Research to have given the best presentation at Congress.

Masterchef contestant cooks up a storm for kids with learning disabilities

Masterchef top 24 contestant Adele Fragnitio of Adelaide knows too well the employment challenges for people with an intellectual disability. Before the series started Adele had dreams of opening a café with her son. "I want to fulfil my dream and turn my passion for food into a little café with my son Michael," says Adele, adding that Michael has a learning disability (dyspraxia). "Michael hasn't really been given a chance at a good job and it'd be wonderful to work with him in our own café - we'd make a great team I reckon." According to the show she has now broadened her vision and is looking to open a cooking school for children with an learning disabilities.

upcoming training...

Intellectual Disability:

ASSID Conference: The 45th Conference of The Australasian Society for the Study of Intellectual Disability (ASSID): "Seeking Excellence". The following topics will be explored: Partnerships; Positive Supports; Service Provision; Ethics; Autism; Behaviour; Health; Aging; Quality of Life; Social Inclusion; Education; Individualised Funding; Relationships; Advocacy; Mental Health and Families. Dates: 29 September – 1 October, 2010, Location: Brisbane <http://www.assid.org.au/>

Save the Date: NSW Council for Intellectual Disability and Western Sydney Intellectual Disability Support Group present a forum on strategies for improving the health of people with intellectual disability. The day is for: family members and carers, people with intellectual disability and service providers. Cost (including lunch): \$10 for Family Members/Carers /Students \$55 for Service Providers, Free for People with Intellectual Disability
Date: 22 June 2010, Blacktown NSW
<http://www.nswcid.org.au/standard-english/se-pages/future-events.html>

Challenging Behaviour:

Hosted by: Functional Assessment and Behavioural Interventions Clinic (FABIC)
Conducting a Functional Behavioural Assessment for People Using Challenging Behaviours. This course is conducted by the Functional Assessment and Behavioural Interventions Clinic (FABIC) and targets those professionals and carers working with individuals using challenging behaviours. Date: Thursday, July 29, 2010, Time: 8.30-4.30pm, Location: NSW Leagues Club, 165 Phillip St Sydney, Price: \$220. **Positive Behavioural Interventions for People Using Challenging Behaviours** aims to provide a new and innovative experience in the application of individualised behavioural strategies that are skills-building and preventative, not reactive. Date: Friday, July 20, 2010, Time: 8.30-4.30pm, Location: NSW Leagues Club, 165 Phillip St Sydney, Price: \$220. Register with www.fabic.com.au

Macarthur Disability Services offers a professional development program throughout the year.
www.mdservices.com.au/training/enrolmentform.html.

Disability:

CHERI Conference: Moving to succeed: Supporting motor difficulties and utilising new technologies Most students with motor impairments also present with other difficulties such as poor attention (ADHD) and executive functioning, language disorders and learning problems. This conference will discuss evidence-based approaches to the concepts, recognition, assessment and support strategies for motor disorders and various overlapping impairments. This conference will be of great interest to educators, therapists, especially occupational therapists and physiotherapists, psychologists, GPs and paediatricians. Date: 2-3 September 2010 Venue: Westmead Hospital, Education Block. www.cheri.com.au/conferences.html

Working with Families who are Grieving-Issues Surrounding Diagnosis of a Disability in Children. 2nd of September, Mt Pritchard, 6.00pm-9.00pm. Hosted by Learning Links www.learninglinks.org.au

Communication strategies for Children with Multiple Disabilities. Course Date: Monday 2nd and Tuesday 3rd August. and **Strategies for Supporting the Educational Development of Children with Disabilities and Unique Behaviours.** Course Date: Late September/early October. Hosted by the The Royal Institute for Deaf and Blind Children's Renwick Centre for Research and Professional Development. For these courses and more register online at www.ridbc.org.au/renwick/courses/continuing_calendar.asp

Hosted by People with a Disability: **Responding to Abuse and Neglect** this seminar Understanding the frequency and severity with which people with disability experience abuse and neglect is the first vital step in the challenge to prevent this crime. This important training is designed for anyone working in the disability sector. It will guide participants through their obligations and help them discover some simple tools to use in their workplace to build the capacity of people with disability to protect themselves from abuse and neglect. Cost: \$300 (ex GST)- 17 Aug 2010 Wollongong NSW, 9 Sep 2010 Sydney NSW, 17 Sep 2010 Logan QLD, 21 Sep 2010 Bowral NSW

Responding to Sexual Assault this short course is essential for anyone working with people with intellectual disability. The myths and facts surrounding sexual assault are explored and the reasons why men and women with intellectual disability experience much higher rates of sexual assault than people without disability are examined. Cost: \$650 (ex GST) 3-4 Aug 2010 Bowral NSW, 31 Aug-1 Sep 2010 Wollongong NSW
13-14 Sept 2010 Logan QLD www.pwd.org.au/archive/10/July2010-June2011.pdf

Mental Health:

Mind Matters www.mindmatters.edu.au
Focus Module: Students Experiencing High Support Needs in Mental Health explores identification, self referral, case management, online counselling, debriefing, referral pathways, transitions, agency networks, re-entry into formal schooling and confidentiality will be addressed in this workshop. Date: 29-30 June 2010, Liverpool

Focus Module: Transitions explores a range of transitions for students and school staff including between schools, regions, cultures, health agencies, work, training and care facilities. Participants will use a set of principles to successfully plan for successful transitions for school community members. Dates: 19 July 2010, Newcastle and 3 August, Sydney
Focus Module: Communities do Matter explores the diversity both of, and within communities and examines how schools can work in respectful partnerships that will enhance school planning and action to support positive community mental health and wellbeing. Date: 17 August Parramatta

The Australian and New Zealand Mental Health Association 11th International Mental Health Conference: Depression & Anxiety: Who, What, Where, When and How? will be held at the Holiday Inn Surfers Paradise Wednesday 18th August - Friday 20th August 2010. For more information: www.anzmmh.asn.au/conference10/

Autism Spectrum Disorder:

Play and Learning for Children with Autism Spectrum Disorder is run in several locations from 6.00pm-8.30pm, 27th July Maroubra, 23rd August Peakhurst, 27th October Peakhurst, 9th November Mt Pritchard
www.learninglinks.org.au

Aspect Recipe for Success is an innovative program designed to assist families to better understand and manage the challenging behaviour of their children in the home. These 3 day courses are free, 9.30-2.30, Southern Sydney, 28th, 29th and 30th June; Moree, 19th, 20th and 21st July; Nowra, 2nd, 3rd and 4th August; Byron Bay, 23rd, 24th and 25th August; Western Sydney, 20th, 21st and 22nd September www.autismspectrum.org.au

8th Annual Redbank School Conference, Thursday 19th and Friday 20th August 2010. Managing students with Aspergers Syndrome, child and adolescent brain development and its relation to learning and behaviour, motivation and resilience in students, Charles Darwin and poetry!
www.redbank-s.schools.nsw.edu.au

case study...

Lesley Whatson
Leader of the Children's Team
State-wide Behaviour Inter-
vention Service of NSW
Ageing Disability and Home
Care (ADHC)

The case study below provides a simple yet powerful illustration of the value of involving an adolescent in their own behaviour support planning.

Selin C is a 15 year old of Turkish descent with Prader Willi Syndrome, ADHD and significant anger regulation problems. She has a moderate level of intellectual disability and attends a school for special purposes in her local area. Selin likes to present as a regular teenager and invents stories about having friends over and going to parties. She is very conscious of her appearance and takes great interest in her clothes, accessories and hair. Selin has an amazing capacity for imitation and copies the mannerisms and turns of phrase of her older siblings.

Selin is currently accessing an ADHC centre-based respite service that is a considerable distance from her home. There has been a decision made to transition Selin to an alternate service much closer to home where she can also have more regular stays. The staff at Selin's respite service know her well and have developed useful ways of preventing and diffusing challenging behaviour; they are happy to share their learning about Selin with the new team. Selin's current key worker at respite is keen that Selin be involved as far as possible in sharing information about herself and hopes that Selin can describe what she finds most helpful when she is upset.

With the help of an ADHC Psychologist, Selin and her respite key worker captured essential parts of a typical stay on video – Selin's arrival routine, participation in activities around the house, preparation for accessing the community and packing up to go home. After showing Selin some footage, the key worker and Psychologist sat together to view the DVD; they talked through what strategies were being utilised and for what purpose. The Psychologist asked questions such as, "Tell me what you are doing here? Why is that important?" and the key worker would explain

Staff report that the strategies Selin suggests, such as a quick walk or taking a break from a task she is finding frustrating, are consistent with their own discoveries.

the usefulness of the strategy. In this way, the bones of the Behaviour Support Plan were formed. From here, a loose script was developed that became the narrative (voice over) on the DVD.

Importantly, on the DVD, Selin introduces herself and talks about the things she likes most about respite stays. The DVD includes an informal "interview" by her key worker during which she talks about the things that make her angry and how staff can help her manage at these times. Staff report that the strategies Selin suggests, such as a quick walk or taking a break from a task she is finding frustrating, are consistent with their own discoveries.

Reflecting with Selin after watching the DVD, she was able to tell us that she really enjoyed the experience of helping people understand how to offer support. She commented on how good it was to be able to say "I don't like that bit, can we film it again?" Selin has agreed that she will get a copy of the DVD, both respite teams will get a copy and her Case Manager will put one on her file.

The family report that they were excited to see Selin in the respite setting on DVD – they were surprised at how independent she was in so many tasks. The current respite team describe making the DVD as very affirming of their efforts and are relieved that critical information will be shared. The Psychologist now has a foundation for any further behaviour assessment and intervention work, in addition to a positive relationship with Selin. The new respite staff report that the DVD version of the Behaviour Support Plan has been a useful tool in preparing for Selin's first stay. ●



a day in the life of a Developmental Paediatrician



Jacqueline Small
Paediatrician
Disability Specialist Unit
Children's Hospital at Westmead

It is not uncommon that I am told by other people who work with children with developmental/intellectual disabilities that they would not want my job, as much of my work involves provision of developmental paediatric input to a multidisciplinary diagnostic and assessment service. I suspect this is related to the parents' expression to other workers of their distress and grief at finding out that their child has a life long intellectual disability. A personal story told by a mother of a teenage boy with autism and intellectual disability, who, over the years, had been quite violent, reinforced for me the impact of the period of diagnosis. Despite her personal experiences of physical injury and damage to her home, it was recollections about the period of diagnosis that were of lasting impact for her. Undoubtedly it is crucial for parents to be fully informed about their child's disability, and expectations for the future, yet how we do this may not always be as helpful for families as we might wish for their adaptation to the diagnosis.

There are few paediatricians who work exclusively in a diagnosis and assessment team for children suspected to have developmental disability, as I do. I have been able to develop my practice in developmental disability, seeing school age children with complex problems and leading a team that can see adults as well. I have listened to many stories told by families

Undoubtedly, paediatricians have an important role in many health related needs of children with a disability.

from varied cultures, heard of the struggles to obtain services, and the challenges for the whole family of the long term impact of disability. My professional connections have extended beyond the community child health network in which I was trained, to include many doctors, advocates and other professionals in the world of intellectual disability. My paediatric training has equipped me pretty well for provision of a holistic service that recognises that the needs of the family are central to the child's quality of life, as well as the importance of consideration of social, economic and general health determinants of outcomes for children with disability.

Undoubtedly, paediatricians have an important role in many health related needs of children with a disability. Recent surveys have confirmed this. Families often need a key medical contact who can understand the range of complex health, educational and social issues that can arise, and they tend to look to their paediatrician for advice and management.

From a scientific perspective, few areas of medicine approach research into intellectual disability for degree of interest. The potential benefits to understanding normal cognitive development must be enormous if we can understand the causes of intellectual disability and autism. From an advocacy perspective, the needs of people with an intellectual disability have long been under recognised and neglected. People with an intellectual disability are vulnerable and often experience the compounding impact of poverty. We should be encouraged by recent federal and state achievements (eg the possibility of a disability insurance scheme to provide better and ongoing services, a strategic framework in NSW for health services), the increased political action at elections, and increasing public awareness

(eg Four Corners recent programme). From a professional perspective, working closely with colleagues from other disciplines, eg education, case work, provides me with much reward, and substantially reduces the frustration we often feel about "other" services and the gaps that often exist between services.

Despite this group of children and young people clearly being vulnerable and at risk, how often are they identified as such? Australia has ratified the United Nations Convention on the Rights of Persons with Disabilities (2008), and the optional protocol (2009). Article 25 Health would seem to have many important implications for us as health service providers. Do children with a disability receive "those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons" (<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>) ? Are our services structured to positively contribute to the welfare of the child with a disability and their family, or do they add to the stress and frustration experienced by parents, and perhaps at times, allow clinical problems to develop, due to lack of services for detection, diagnosis and management, until they further impair functioning? Do we have the appropriate training and expertise within our health systems to meet the needs of children and young people with disabilities? How many of us are aware of our national obligations under this Convention?

Working with children with developmental or intellectual disability is often challenging, and some times frustrating, but it is mostly rewarding. The role of the paediatrician, is but one of many professionals involved, yet, often it is an important role in contributing to improved health and quality of life outcomes. ●

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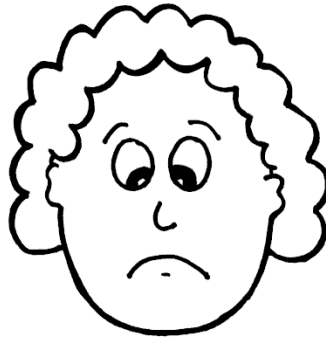
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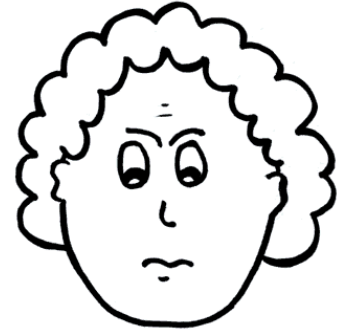
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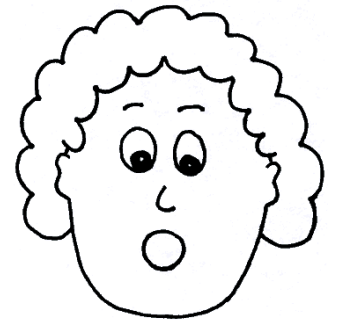
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scared



excited



surprised



proud



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headache



stomach ache



tooth ache



ear ache

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resources...

Mental Health Promotion, Prevention and Early Intervention for children with ID:

How Does your Engine run? The Alert Program® for Self-Regulation
The Alert Program (AP) is for children 8-12 years of age with sensory processing and/or learning impairments. The Alert Program assists children who have learning disabilities and attention problems (as well as typical children) to understand the basic theory of sensory integration related to arousal states. Through the program, children learn a repertoire of strategies that enhance their abilities to learn, interact with others, and work or play. Children not only learn to monitor their level of alertness, but improve in self-esteem and self confidence. If children are intellectually challenged or developmentally younger than the age of eight, the program's concepts can be utilized by parents or staff to facilitate optimal functioning.

7-8 August, Brisbane QLD –

10-11 August, Melbourne VIC –

14-15 August, Sydney NSW –

To register go to this website www.sensorytools.net

Stop Think Do

The aim of this program is that children can use the Stop Think Do social problem solving method for resolving conflicts. Adults can also use Stop Think Do to manage children's behaviour, in this case directly sharing the responsibility for problem solving with the child. Specific applications for this program include anxiety, ADHD and Asperger Syndrome.

Applications for Classroom Teachers and Health Professionals, 2nd September, Peakhurst 6.00-9.00pm

Applications for Parents, 24th June, Peakhurst, 6.00pm-9.00pm

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

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Education Training:

Literacy Goes Digital: Digital resources can be used to enhance effective literacy instruction. This course will explore a range of digital resources readily available to primary classrooms and how to utilise the potential of resources including learning objects, online tools, visual simulations and interactive whiteboards. Teachers will be involved in hands-on learning activities that can be transferred directly to classroom practice. Course *Date:* Monday 2nd, 2010 *Target Group:* Teachers of special education and aides K-12. Details online at www.aisnsw.edu.au.

The Training and Behaviour Intervention Support Service offers several practical workshops for professionals, carers and parents. *Writing Social Stories* (24th June, 9.30-2.30, Free, Parents only). www.interactiondisability.com/TABISS.pdf

Reference List: Clarifying concepts of disturbance, disorder and mental illness in children and adolescents with intellectual disability by David Dossetor from page 16

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the medicine cabinet

Psychotropic medications in children and adolescents with an intellectual disability

George Liangas Child Psychiatry Fellow with special interest in intellectual disability

This is the first of a series of articles addressing the use of medications in children and adolescents with an intellectual disability for emotional, behavioural and psychiatric disorder. It will attempt to cover the type of information helpful for non-medical people working with these children. The idea arose from a discussion with school teachers who were concerned to understand the appropriateness of medication and contribute to their optimal management.

While there is no medication that can treat intellectual disability, many children and adolescents (and for that matter, adults) with intellectual disability are on one or several prescribed medications. There are two main reasons why these people may be taking these medications:

1) People with intellectual disability are at increased risk of having other mental and physical disorders. Some co-existing mental disorders include Attention-Deficit/Hyperactivity Disorder and anxiety disorders. Some co-existing physical disorders include epilepsy and diabetes. Having multiple coexisting disorders can blur the picture of what is happening to the child's body or mind, and can make the child's life quite difficult. A comprehensive assessment helps to clarify what illnesses are contributing to the children's problems. Each coexisting problem needs its own management, and medication is often a very important part of this.

2) People with intellectual disabilities have problems that may not be explained by a simple diagnosis, but may still benefit from medications. Behavioural disturbances such as aggressive behaviour and self-injurious behaviour are such examples. Such behavioural disturbances have an increased likelihood of an associated medical or mental disorder but not always. With such problems, it is most important that their clinicians look for and manage things that may be contributing to these problems. It is also important to use non-medication strategies to manage the problems, such as environment modification and behavioural interventions. Medication may also help, especially when the behaviours are severe. They often help by decreasing the body's arousal, thus allowing the other interventions to be used more effectively.

Being astute about the changes caused by medications can help determine the most appropriate treatment regimen, and hence improve quality of

life. Since many of these children find it difficult to communicate how a medication makes them feel, the observations from the people spending time with them is most valuable. Picking up any changes in symptoms, and identifying side-effects such as agitation, changes in appetite and constipation are useful observations. Often these effects happen soon after the introduction, alteration or cessation of a drug. Missing doses or taking the wrong dose can be other problems. Sometimes the source of the problem can be quite innocuous, e.g. a drug interaction with an over-the-counter drug or herbal remedy. While non-medical people would not be expected to sort out complex medication effects, picking up changes in behaviour can be very useful information. Therefore it is important that there is good communication with parents, carers, teachers and clinicians regarding these children's medication and general well-being.

The key to good medication management is good communication. Parents hold responsibility for managing their children's medication, on the advice of their doctor. Although direct communication by doctors with the school is optimal, in practice in most situations time prevents this. Medical confidentiality may also affect open communication. Accordingly parents and schools need clear communication arrangements over concerns. Similarly parents need to have good communication arrangements with their doctor.

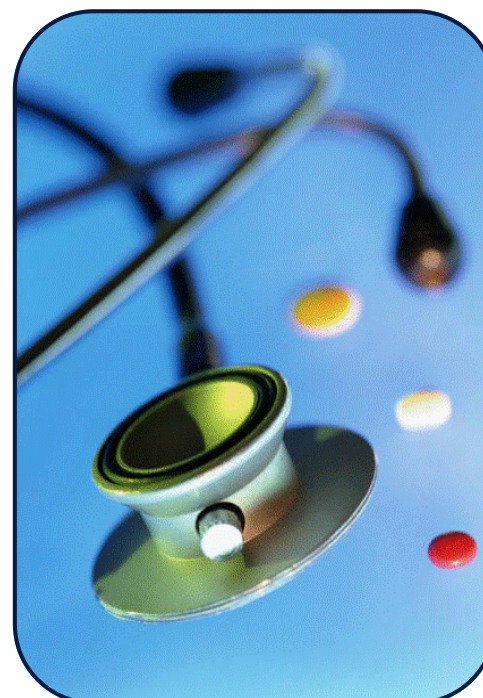
The key to good medication management is good communication. ..parents and schools need clear communication ...similarly parents need to have good communication arrangements with their doctor.

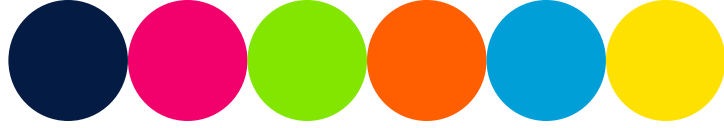
Future articles in 'the medicine cabinet' will examine individual or groups of medications used commonly in this population, and will provide general information about their use. Remember that this information is very general, so if you have specific questions or concerns, you are encouraged to discuss them with the parents, carers or treating clinicians.

The next four CHW School-Link Newsletter issues will focus on the following medications and associated classes:

- 1) [Ritalin](#) and other stimulants
- 2) [Risperidone](#) and other common antipsychotics
- 3) [Epilim](#) and other anticonvulsants and mood stabilisers
- 4) [Lovan](#) and other common antidepressants

Acknowledgements: Many thanks to Anne Flint and Barbara Flemming and other staff at Holroyd School for their ideas and suggestions that inspired this page!





journal review

Emotional and behavioural difficulties in young children with and without developmental delay: a bi-national perspective. Emerson E & Einfeld S. 2010 *Journal of Child Psychology and Psychiatry* 51(5): 583-593.

Little is known about the relationship between cognitive development and psychopathology in 2-3 year old children. This study compares the 11,389 UK Millennium cohort and 4,600 Longitudinal Study of Australian Children. Even by 2-3 years old there is an increased rate of psychopathology and learning ability with a general linear association of psychopathology with the lower half of the ability level. There is also an additional threshold-based association of psychopathology with the lowest 3% in the distribution of ability. In addition psychopathology is also partially related to greater risk of exposure to adverse socio-economic circumstances (more evident in the UK sample). Given the persistence of emotional and behavioural problems in children with intellectual disability and the 3-4 times greater prevalence, this study indicates the need for investment in early intervention for mental health prevention and promotion for at risk children with early signs of developmental delay not just those with normal development.

this study indicates the need for investment in early intervention for mental health prevention and promotion for at risk children with early signs of developmental delay not just those with normal development.

Plomin et al, 2004 found no such threshold effect of ability and psychopathology. Accordingly the jury is still out on whether the same gene-environment interaction mechanisms cause psychopathology at all ability levels. The threshold finding in this study suggests that biology and genetics has a greater direct effect in those in the lowest 3% of ability.

Have you been to a conference, read a book or visited a website that you loved? Send us an overview to:

schoollink@chw.edu.au

conference review...

Forum at ANGLICARE: the Adolescent Years: The Challenges and Need for New Policy Direction in Disability
April 2010

Parents, carers, counsellors, social workers, departmental representatives and academics came together on Friday, April 23rd 2010 for a forum on the needs of families and carers of children with severe to profound disabilities.

Hosted by ANGLICARE Sydney, the forum heard from key practitioners on the importance of developing a continuum of support for families and carers, overcoming the social stigma and the isolation experienced by carers and families, as well as developing a rights-based approach that better accounts for the rights of both the person with a disability as well as other members of their family.

ANGLICARE which runs a wide range of other disability and carers support programs, is seeking to even better understand the needs of families of children with severe to profound disabilities, ad-

vocate on their behalf and work towards developing better policy options for support and respite.

Kingsdene Special School Principal and forum organiser, Anna Green said the forum was an important way to raise the complex needs faced by thousands of Australian families and discuss practical solutions for care and support.

"The mental health and wellbeing of carers, parents and especially the siblings of children with disabilities is an area that receives not nearly enough attention from policy makers and is little understood in the broader community."

"One of the things we know from decades of working with families and children with severe to profound disabilities is that there is no one-size fits all solution to providing care and support both to the child with a severe intellectual disability and their families", said Ms Green.

"This is why it is vital that carers, families, service providers and governments work together to develop real solutions to ensure the appropriate care for children with disabilities whilst ensuring the wellbeing of the families and carers."

reviews...



Website Review: *CHW School-Link*

www.chwschool-link.edu.au

The Children's Hospital at Westmead School-Link Initiative has created a website to host past and current issues of this newsletter and to house other resources on the topic of mental health and intellectual disability of children and adolescents.

The new website will allow the myriad of interagency staff to access information and resources on a central website. The website is in its infancy and over time we expect this resource to grow and thrive to support the three main areas of School-Link:

- 1) Assisting in the pathways to care for children and adolescents with an intellectual disability and mental health problems and disorders.
- 2) Supporting the implementation of school based mental health promotion, prevention programs, and early intervention programs for this group.
- 3) The mental health training and education needs of school counsellors and other professional staff who work with children and adolescents with an intellectual disability who are at risk of a mental health problem or disorder.

Suggestions and comments are welcome by emailing schoolink@chw.edu.au



Organisation Review:

Interaction Disability Services

<http://www.interactiondisability.com>

Interaction Disability Services Ltd has the vision to be an innovative organisation which will empower people with a disability to meet their own needs in the community. Its objectives are to:

- Empower people with a disability to be fully included in their community, achieving their greatest possible independence and autonomy.
- Promote and uphold the rights and dignity of people with disabilities.
- Educate all people to be sensitive and responsive to the needs of people with disabilities.
- Monitor current policies and procedures in provision of services and support for those receiving a service.
- Offer advice to government and non-government bodies.
- Consider all issues affecting the interests of the organisation and to promote/oppose legislation/measures affecting those who receive a service from Interaction Disability Services Ltd.

conference review, an international perspective...

Help me Grow: A workshop on developing community paediatric services delivered by Paul

Dworkin, Professor of Paediatrics at Connecticut, New England, USA.

March 2010

Professor Dworkin presented to a group of developmental and community paediatricians, child psychiatrists and a range of allied health colleagues in March this year, on the successful program of linking at risk children and families to the services they need to promote optimal development. His model has been so successful that it has been expanded and replicated multiple times around the world. There are 4 components:

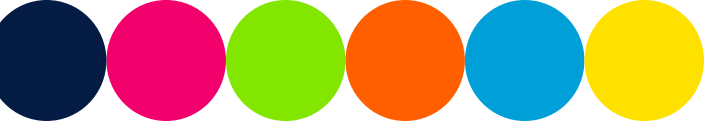
1. training child health providers in effective developmental surveillance and screening;
2. an inventory of community based program resources, with defined selection criteria, goals, activities and capacity;
3. a single point of telephone access for referral and monitoring to link to appropriate services;
4. data collection for evaluation and further modification.

The lynch pin to this model is the telephone access line that provides clinically skilled telephone case management. These telephone clinicians match the case referred to the services available (including for location, culture and type of service), avoiding duplication of service provision (a major cost saver). This telephone case management links health providers and families with the full spectrum of services from Family Support Services, Specialist Developmental Services, Child and Adolescent Mental Health Services and Early Care and Education Programs. This includes Healthcare management groups, Government Departments and Services, Private Practitioners, Not for profit and Non Government Organisations and Volunteer Organisations. Of note it takes an average of 6 telephone contacts with the family to support them to contact the relevant agency! The telephone case management/care coordination service collects data from the service provider on appropriateness of referral, outcome and any changes in service provision.



Could this be a potential model for New South Wales?

In NSW, with most recent funding for service development going to NGOs and Medicare, important ways of linking community based paediatrics with health and other children's based services are needed. Such a model of telephone referral, triage, case management and case monitoring would evidently be a cost effective way of drastically improving the services for children especially those with special needs with minimal cost. The Child Wellbeing Units within DET, Health and Police are one such example of how telephone case management can be utilised for the benefit of child protection and hopefully local service planners will follow the evidence-based literature that reports on this model and enable a system that connects all child health needs and services across the state.



a note from David Dossetor...



Clarifying concepts of disturbance, disorder and mental illness in children and adolescents with 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.

How do you tell whether a child is going through a normal challenge of life, has a behavioural disturbance, a mental disorder or a mental illness? The dictionary describes "disturbance" as "a temporary change in average environmental conditions that cause a pronounced change in the ecosystem" whereas "disorder" is "a physical or psychological malfunction". This definition suggests disturbance is a temporary affair and at the other end of the spectrum disorder assumes a biological malfunction of the brain. It is less straight forward to apply this definition of disturbance in mental health functioning to a minority population whose functioning is in many ways different to those in mainstream due to their intellectual disability.

The recent experience of editing a book on "mental health of children and adolescents with intellectual disability" (Dossetor, White & Watson, in Press) has highlighted how complex and confusing concepts of mental disturbance and disorder are. There are differences in the nature of disturbance in different populations and a diversity of interpretation according to who is doing the defining, what profession and what sort of interventions they represent and what is the strategic purpose of their agency. Accordingly

the way the patterns of disturbance, mental disorder and illness in people with an intellectual disability, or children and adolescents with intellectual disability is different and complex compared with the mainstream population. I shall try to give some insight into some of the ways a child psychiatrist with a special interest in intellectual disability thinks about these issues.

Confusing Language

Adding to problems of understanding these problems, the language is often ambiguous and a source of confusion and even conflict. For example "Learning Disability" means different things on different sides of the Atlantic. In UK it is the term used for Intellectual Disability; in the USA it is the term for Specific Learning Disorders which may or may not be in the presence of Intellectual Disability. I am unclear where Australia stands in relation to these trenchant positions. Dual diagnosis means intellectual disability and mental health problem in USA and UK, and mental health and drug and alcohol problems in Australia.

In interagency work the terminology used often implies an obligation rather than a concept. For many people Mental Disorder means that mental health services or psychiatrists have to "sort" the problem out. Challenging Behaviour suggests that disability services or psychologists have to "sort" the problem out. Yet most dictionary definitions equate "emotional disturbance" with "mental disorder".

Other dichotomous ways of thinking include: "if the patient can't talk then they can't have a mental disorder". A more scientific way of saying this is that subjective mental phenomena cannot be reliably be elicited below the age of 7 years or an IQ of 45, and therefore diagnoses that depend on subjective mental phenomena cannot be reliably identified. But there is little agreement on how mental disturbances are different in the earlier stages of mental or intellectual development.

How broad or narrow is mental ill health?

Some clinicians limit mental disorder to a few defined mental illnesses such as depression, bipolar disorder, schizophrenia and certain anxiety disorders, as defined by criteria in the International Classification of Diseases (ICD10) or Diagnostic and Statistical Manual (DSMIV) (Moss, 2000). But in children and adolescents with intellectual disability ADHD and Autism are the most common conditions. Possibly most controversial is whether or when is Disruptive Behaviour Disorder a concern to mental health services? They are generally not considered a core focus of child and adolescent mental health services due to the lack of effective treatments and the lack of resources.

We mustn't forget that 'Intellectual Disability' is classified as a disorder of delayed or arrested development, but both human rights models and mental health services define this brain disorder out of scope for health or mental health services. Conversely diagnostic overshadowing has prevented people from looking for mental disorder and attributing all disturbance to the intellectual disability. Yet longitudinal epidemiological research suggests that mental disturbance, that is disturbance of emotions or behaviour in addition to the level of intellectual disability, occurs in a third to a half of people with intellectual disability (Tonge & Einfeld, 2000). However the best predictor is that they were disturbed before, i.e. that disturbance of any sort when it occurs is a pretty persistent co-occurrence of intellectual disability. Disturbed behaviour is therefore a significant part of the challenge of dealing with children and adolescents with intellectual disability adding to problems for the individual, the family and all community child orientated services.

To my knowledge no study has looked at defining how much functional impairment in this population is due to the intellectual disability and how much is due to an additional mental disorder. Conversely some specialist mental health advocates assert that people with an intellectual disability have the same mental disorders as those of any other population group and therefore have the same rights of access to services. But those with intellectual disability have marked increases in mental disorder. Doesn't this mean they actually need much greater access to mental health services, or does this raise questions about the types and validity of mental disorders in those with intellectual disability?

Do mental disorders differ in those with intellectual disability?

There is paltry consideration to differences to presentation according to level of intellectual disability, and there has been little attention to epidemiological findings of disturbance in children and adolescents compared to the studies in adults with intellectual disability. Empirical mental health diagnostic studies in adults indicate completely different diagnostic practices in intellectual disability on different sides of the Atlantic (Dossetor, White & Watson, in press). Not only are there different diagnostic models but limited research in reliability and validity on these diagnoses in this population. Most of this research is in adult populations. The most common mental health diagnoses of childhood with intellectual disability of ADHD and Autism are hardly considered in adults even though they are often described as disorders that persist into adult life.

There are debates over what 'adult' mental disorders can occur in children of average intellect and to what extent they have a different group of disorders such as Attachment Disorders (which implies an environmental corollary). So to what extent do these specific diagnoses of childhood also apply to children with intellectual disability, or even to adults with intellectual disability because of the ways their mental development is

more 'child-like'. There is a limited research base showing that children with intellectual disability do have attachments but in both populations the linkage to subsequent mental disorder is not clearly established.

Historically psychiatric diagnoses were derived from doctors bringing scientific methods into the Victorian asylums where magistrates had admitted people so disturbed that they could not fend for themselves. Studying these people led to the establishment of most of the mental health diagnoses by a mixture of diagnostic fashion, research and a consensus committee process of the World Health Organisation or American Psychiatric Association to achieve a common language and a consistent approach incorporated as described in the diagnostic manuals of ICD10 or DSMIV (version V currently out for consultation). Defining these diagnostic criteria enabled the diagnosis and treatment of the same conditions earlier in our community without the need for admission. Nowadays admission to mental health services is generally for a brief period of medical assessment and treatment and subsequent care, support and rehabilitation is best managed in a community setting.

If one examines the general population of children and adolescents for mental disorder by using a general definition of mental disorder such as "disturbance of emotions or behaviour sufficient to cause persisting distress and causing handicap in other areas of function, out of keeping with cultural expectation" then this includes a broader range of disturbance than that by the defined diagnoses above. For example a reliable and predictive psychometric scale such as the Developmental Behaviour Checklist finds that approximately 40% of children, adolescents and adults with intellectual disability have significant emotional or behavioural disturbance but this does not readily convert to psychiatric disorder, opening the debate of what is behaviour disorder versus mental disorder.

The duration of disturbed behaviour is another factor influencing the term used. All children have periods of disturbed behaviour such as tantrums, or anxiety. Mental illness is indicated by a severity and persistence of change from a previous stable state. For example a change in affect such as undue sadness that lasts for at least 2 weeks. It often also includes vegetative or biological changes such as in appetite and weight or cognitive capacity. However what determines positive recognition of a mental disorder or illness is the co-occurrence of certain features to fulfil features of a syndrome or recognisable constellation of symptoms. For example depressive disorder is diagnosed by the presence of other associated features of the syndrome, such as loss of affect, guilt, anhedonia, irritability, diurnal variation of low mood, altered appetite, loss of energy, early morning waking, reduced memory and concentration etc. The diagnosis of a mental illness implies that the disorder has a momentum of its own to persist and is not purely

a reaction to circumstances. The diagnosis of a syndrome, such as depression, also predicts what the approach to treatment should be. Standard evidence based treatment is therefore cognitive behaviour therapy and or antidepressants.

Conversely assessment and intervention approaches to challenging behaviour is linear in nature: that is to say it is not so much a case of identifying and counting symptoms, but starting with a single key symptom and looking for environmental factors that predicts that behaviour. As such it is often seen to provide a communicative function.

On these grounds, child psychiatric disorders are in between adult mental disorders and challenging behaviour: their descriptions are syndromal but assume multifactorial causality. This includes a wide range of factors: biological/genetic, temperament/personality, psychological, social, family, community (Dykens, 2000). It has been shown that those with cognitive impairment have greater rates of adverse social risk factors and even higher rates of adverse life events (Emerson, 2004). Both child mental disorders and challenging behaviours are now viewed from a bio developmental psycho social cultural framework and brought together with a formulation.

Mental Disorder and Developmental Considerations

In emergency health services many people are brought for assessment under the mental health act whose behaviour reflects a short lived severe behaviour, rather than a persistent syndrome. These people are referred to having 'a mental disorder' that may be stress/circumstance related, or part of a longer standing maladaptive style of functioning or personality, rather than 'a mental illness'. There is limited evidence based treatments for these mainstream presentations of people with mental disorder, but mental health clinicians may be involved in short term crisis management, and may have some involvement in helping others to minimise future crises. The similarity of these presentations of mental disorder, such as recurrent self harm or short lived bizarre behaviour, and Challenging Behaviour in people with an intellectual disability, is that they may both have chronically maladaptive patterns of coping, but they also are at a higher risk of having a psychiatric disorder.

There are however differences in such mental disorder presentations in children and adolescents. In paediatric emergency services for the under 14, presentations for aggression is at least as frequent as those for self harm, but by 16 years police will tend to deal with aggression, and self harm remains the assessment responsibility of medical services. These differences are partly because younger children have limited insight and understanding and adults and families have the major responsibility for their welfare and the way they grow up. Whereas by the age of 16, the assumption is that you have full capacity for insight and autonomous responsibility for

such maladaptive behaviour. The social norm is that with adulthood, aggression is seen as bad or criminal.

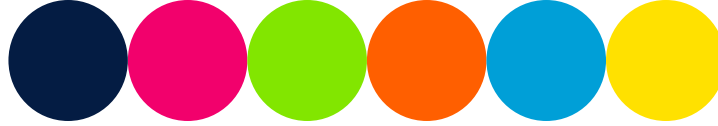
The question arises therefore to what extent should limited skills of sensory integration, arousal modulation, attention, communication, social reciprocity and insight affect the way people with an intellectual disability are treated. It has to be said that the law works on the assumption that people with an intellectual disability have the same capacities and responsibilities as the mainstream population according to their age. This is not only a biological falsehood, but it clearly also influences mental health diagnostic and treatment practices. There is an increase in the rate of diagnosis of schizophrenia and other psychoses and also problems of the reliability of these diagnoses. Indeed it is my view that young people with autism in intellectual disability are at significant risk of being diagnosed as having a psychotic illness in mainstream mental health services, if their supportive environment fails to modify the stresses of their world and they become persistently mentally disordered.

The identification of depression in children is more difficult than adults, and more difficult in adults with intellectual disability. The diagnosis of associated psychiatric disorder in the context of severe behaviour disturbance in intellectual disability is difficult. Such diagnoses are often not best assessed by emergency services. There are therefore major gaps in mainstream adult and child mental health services for optimally helping these complex cases.

Environmental Deficits

The World Health Organisation has defined the distinction made between impairment, disability and handicap in those with intellectual disability: the biological deficit, the skills deficit and the loss of social access and valorisation. This has led to the suggestion that the handicap is dependent on the environmental match to enable social access despite a skill deficit. A simple example is wheel chair access to community amenities reduces the handicap of someone who cannot walk. How much further can this environmental matching be expected for mental disorders for example for a young person with ADHD, who may need increased space and opportunity to let off steam and increased routine structure. Further to what extent can a specially enriched environment improve development in those with intellectual disability or autism?

The contention of the clinical working group that researched the Dossator, White and Watson book is that having a developmental perspective is a primary key to understanding disturbed behaviour in children and adolescents. The severity and type of behaviour disturbance is most related to developmental age or stage, and only secondarily related to chronological age. This is recognised in law in terms of both children and those with intellectual disability having limited capacity for understanding right from wrong, let alone being able to take responsibility for their



behaviour. It is of interest that the most common diagnosis in adolescent mental health units is of an adjustment disorder of emotions and/or behaviour which may be acute or chronic. This diagnostic bias implies that clinicians see environmental pressure or deficits as causal in the mental disturbance even of teenagers. Yet this thinking is seldom applied to people with and intellectual disability, who frequently have major environmental needs (even if they cannot be met). In a similar vein of causal thinking, the empirical evidence suggests skilled parenting has the best effect in improving childhood behaviour in children and adolescents with intellectual disability.

The most obvious differences in mental health diagnoses in children and adolescents with intellectual disability is the increase of the co-occurrence of Autistic spectrum disorder (ASD) (approximately 50%) and ADHD (approximately 30%), or the occurrence of ADHD in the presence of ASD (80%). The presence of either of these problems in children and adolescents with intellectual disability is a frequent cause of behaviour disturbance. Yet both the treatment of ADHD and Autism in this context is more difficult. In Australia, general paediatrics have taken the health lead in treating ADHD. The funded designated lead intervention service for Autism is an NGO, ASPECT, although developmental paediatrics has a significant role in early assessment. It is my contention that in those with intellectual disability that a developmental model of mind development is probably more helpful for understanding ADHD and ASD than a medical model. This then focuses on building and reinforcing mental skills over a persistent period of time rather than solely relying on medical treatment.

It is the co-occurrence of developmental disorders and genetic linkages that suggest underlying commonality of developmental processes. The developmental nature of disorders in children and adolescents with intellectual disability leads to the need for a wider treatment team than is traditionally used in mental health: not just psychiatrists, psychologists and social workers/family therapists but speech therapists, occupational therapists, physiotherapists and special educators. The more complex the problem, the greater the need for this diversity of assessment and therapy skills. This wider range of professional skills also generates a wider range of causal explanations or hypotheses for disturbed behaviour which is key to understanding and improving persistent and complex disturbance.

The range of professional skills and services
So what skills are needed to assess and treat what sort of problem? The first emphasis is supporting the skill base of families who need to have additional and special skills for the special emotional/behavioural needs of children and

The developmental nature of disorders in children and adolescents with intellectual disability leads to the need for a wider treatment team than is traditionally used in mental health

adolescents with intellectual disability, with help for community integration and the burden of care. The next level of help for such behavioural/developmental/challenging behaviour needs is specialist advice of a disability skilled psychologist. This may lead onto to further need to assess what other allied health services and special education are needed. In parallel to this is the need to consider physical health, especially in the ways it can contribute to disturbance. Developmental mental disorders of ADHD and ASD are best assessed by paediatric specialists and they have significant skills in the psychotropic medications that may be needed. Mental Health has a role specifically in the discrete mental illnesses outlined above and assists in the crisis management of mental disorder. However complex problems of unclear challenging behaviour/mental or developmental disorder/mental illness need cross agency collaboration of professionals and skills to offer the best outcomes. This includes mental health specialists who have a special interest in intellectual disability. In the NSW context it is clear we have clinicians with good quality skills with sustained learning, but we lack a service structure for collaboration and specialist mental health services for children and adolescent or adults with intellectual disability. Often the private sector is the most available substitute but this is not sufficient.

Behavioural phenotypes and individual difference

The study of behavioural phenotypes highlights a growing complexity and sophistication to our understanding of emotional and behavioural disturbance, and illustrates that different mechanisms can apply to different symptoms in the same patient. For example in those with Prader Willi Syndrome the incessant food seeking may relate to intrauterine starvation affecting hypothalamic function, the obsessive features are related to developmental stage and the ADHD type behaviour relate to problems of executive function, such as deficits in attention switching capacity. In Williams syndrome different types of anxiety are thought to have different mechanisms: fear of noise such as thunder is associated with hyperacusis, fear of heights is associated with clumsiness and poor coordination, and general anxiety disorder is associated with family genetic risk and parental reinforcement. Family stress has been shown to be predicted by aggression and

attentional problems in the child with intellectual disability and protected by a child's social, empathic and kind spirited qualities.

Conclusions

These sorts of findings indicate that the diagnostic concepts and individual diagnoses are only partial guides to understanding any presenting disturbance. Ultimately up-to date informed clinicians are needed to bring to bear an understanding of potential external environmental factors and also internal and biological factors. This can have a bearing on how best to use our therapeutic skills to best advantage whether this is for a challenging behaviour, a developmental or mental disorder, or a mental illness.

Ultimately it is an open question as the extent that the mental disturbance of children and adolescents with intellectual disability can be resolved. However there is a diverse cadre of clinicians who believe in bringing the best state of scientific and professional understanding to these problems, with a belief that it is possible that, despite mental health problems, children and adolescents with intellectual disability and their families can achieve "a good enough" quality of life. Nonetheless there is good grounds to suggest that treatment and care has improved over the last 20 years, whereby children with intellectual disability are not sidelined to long term hospitalisation and institutionalisation.

This essay also suggests that the use of terms to describe mental disturbance, disorder and illness is changing and developing over time. There remain major gaps in our understanding, but clinical and scientific approaches are shaping the language, terminology and skills. As Sir Archibald Garrod (1857-1936) physician at Great Ormond Street and St Bartholomew's Hospital said: "Practicing medicine without textbooks is like sailing the oceans without charts".

See page 10 for the list of references.

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