

Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities: *An Educational Resource*

Volume Seven, Issue Two, 2016. ISSN 2203-6687, SHPN CHW 160415



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The aim of this Journal is to improve the mental health of children and adolescents with intellectual and developmental disability through enabling academic debate, research and commentary on the field.

Description and purpose

This journal is a modification of the previous newsletter; a vehicle of expertise about mental health information of children and adolescents with intellectual and developmental disability. As a product of CHW School-Link, this journal is supported by School-Link and a collaborative effort with a multi-agency editorial group from the Statewide Behaviour Intervention team of the Department of Aging Disability and Home Care, NSW Family and Community Services, and NSW Department of Education. We are extremely proud to present these ideas and invite you as authors to help develop this field and the knowledge base to help support children and adolescents.

On our Website:

www.schoollink.chw.edu.au

The website will be playing a crucial role in the information that CHW School-Link can provide to you.

- The collection of previous and current editions is located there with the ability to download articles separately.*
- An invitation for contributions can be found on the website with instructions for authors.*
- Upcoming training at conferences, workshops and other professional development opportunities will be continuously updated.*

Jodie Caruana

CHW School-Link Coordinator
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Coordinators Welcome.

The 4th of August 2016, was National Aboriginal and Torres Strait Islander Children's Day (Children's Day). This is a time for Aboriginal and Torres Strait Islander families to celebrate the strengths and culture of their children and an opportunity for all to show their support. Each year the Secretariat of National Aboriginal and Islander Child Care (SNAICC) produces and distributes resources to help organisations, services, schools, and communities celebrate.

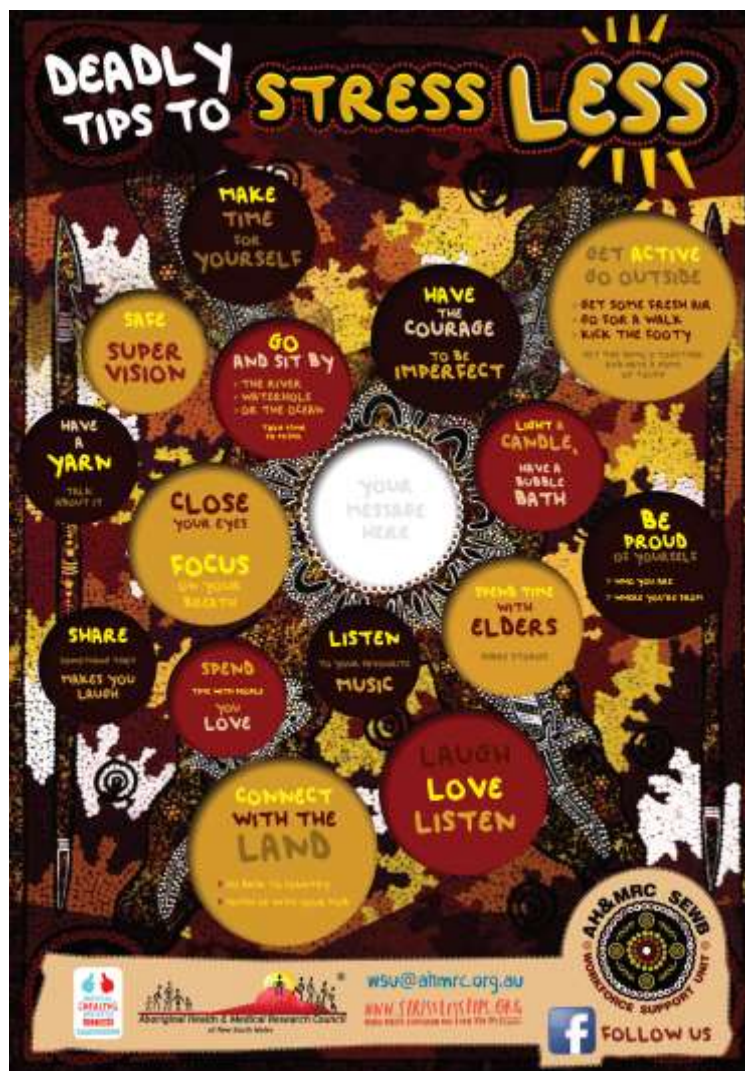
The theme for Children's Day 2016 is *My Country, Our Country, We All Belong* and is all about helping kids feel connected and proud in culture. It's all about ensuring all our kids feel like they belong, which is such an important foundation in positive mental health and wellbeing.

October is Mental Health Month with the 2016 theme of Learn & Grow. The theme carries a simple but important message – that each of us learn about our mental health (or our students') and by doing so grow. By learning we are empowering ourselves and others to take an active approach towards good mental health and wellbeing. You can find resources here: <http://mentalhealthmonth.wayahead.org.au/>

An opportunity to *learn and grow* is by accessing our Jessica resources online. These resources aim to increase awareness of the mental health of children and adolescents with an intellectual or developmental disability in a school environment. We travelled NSW last year and the resources are finally ready for your access and use. To find out more about the Meet Jessica resources simply head to page 26. We have great pleasure in announcing that the Meet Jessica project is the 2016 cross sector collaboration mental health matters award recipient as awarded by the Mental Health Association of NSW.

Enjoy reading this edition of the journal and please send any feedback or your own contributions to schoollink@chw.edu.au

Jodie Caruana
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Source: WayAhead Mental Health Association of NSW



Source: Kidsmatter

Engaging learners with Complex Learning Difficulties and Disabilities (CLDD).



Reviewed by Associate Professor
David Dossetor

*The Children's Hospital at Westmead
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Child Psychiatrist with a Special interest in Intellectual Disability

Engaging Learners with Complex Learning Difficulties and Disabilities (CLDD).

Carpenter B, Edgerton J, Cockbill B, Bloom T, Fotheringham J, Rawson H and Thistlethwaite J. Routledge: Abingdon, Oxon; 2015. www.routledge.com/education. Aus\$75. Review by David Dossetor

Commentary: I have provided considerable detail on this book, as it represents an interdisciplinary and empirical approach to understanding and helping children and adolescents with complex developmental and mental health problems but starting from an educational framework. I am the first to acknowledge that understanding such kids is difficult and our approaches often need to be individualised. Innovative approaches that build developmental benefits are clearly of interest to all those that work with children with CLDD. It also strikes me the engagement processes are gaining in relevance in research processes to understanding ASD and other complex cases. The seven dimensions of engagement have a face validity. Certainly engagement is going to be central to any relationship, whether it is with the physical and conceptual world or the emotional and human attachment world. I

am reminded of a few children that come to my clinical service after enthusiastic treatment with Applied Behavioural Analysis (ABA), who have lost all motivation to engage. While recognising the evidence base for ABA, such a performance-orientated intervention may sometimes overlook engagement processes and even **damage a child's capacity for engagement and motivation. A child's engagement is such an important early step in child development, which is so slowed up in children with CLDD.**

This book gives an important overview in describing the way special education is changing in first world countries. For me it provides a methodical framework with principals of scientific enquiry that (special) educators and associated clinicians can work together around. This is an influential approach which is gaining currency but it remains an experiential/ individualised framework based on practice-based evidence rather than evidence-based practice (ie randomised or control studies). Yet, clinical activity with this population is so often limited in reliability and predictive validity. Perhaps the greatest contribution of this text is providing an approach for educators to develop advanced



skills in promoting child special education and development. The cheapest service development and progress for helping children with CLDD must be through individualised promotion, development and testing of expertise in schools, with support from child orientated community partners. As a guide to the education of the most difficult children it is a provocative and essential read.

Introduction

This is the latest development from the CLDD group (Dossetor, 2012). Dame Philippa Russell leads the foreword quoting her 7-year-old autistic grandson: **‘it’s very difficult to be me, I don’t really understand myself; I don’t always know who I really am!’ That is: if we feel lost, it is likely the child does also.**

Technology has created a new generation of children with special needs. All too often school experience is the lead-in to future rejection. Schools need to transform their responses to the learner from the standardised to personalised learning. Professor Michael Rutter said we need to understand how these children learn, and work collaboratively to enable resilient children. Resilience requires: a sense of self-esteem, a belief in **one’s self**-efficacy to deal with change and adaptation, and a repertoire of social problem approaches. For **parents, help comes from unexpected places ... ‘it takes a village to raise a child’... with creative solutions** and a can-do positive school ethos. This book offers a wide repertoire of problem solving approaches for schools with **‘partnerships of care’ with all professionals, which can create for many ‘a springboard for life’.**

Chapter 1: Sue Williamson describes the approaches to children with SSAT (The Specialist Schools and Academics Trust or The Schools Network) Ltd CLDD led by Barry Carpenter as an inspirational piece of research, integrated with practice (www.complexld.ssatrust.org.uk), developed by a multi-disciplinary research group. **“Every child can succeed and needs to be fully engaged in learning” with new pedagogical tools.** 4 themes are highlighted: dialogue with neuroscience, transdisciplinary approaches, student engagement with personalized learning, and partnership with families. The UK Special Educational Needs (SEN) and Disability Code of Practice 2015 enshrines CLDD project elements: integrated work across professions that promote choice and diversity for children and adolescents with disability and their families. SSAT focuses on our most vulnerable students. SSAT acknowledges a strong international collaboration centered across UK but including the Antipodes.

Chapter 2: The Engagement for Learning Framework: **“we are guilty of many faults, but our worst crime is**

“This book gives an important overview in describing the way special education is changing in first world countries”

abandoning children, neglecting the fountain of life. **A child cannot wait: to him we cannot answer ‘tomorrow’, his name is ‘today’” (Gabriel Mistral, Chilean Literature Nobel Prize winner).** The project aims to explore and identify effective teaching and learning strategies for children with CLDD. This also includes a group whose **needs fail to be recognised. Teachers say ‘I have never taught a child like this, especially in a mainstream setting, nothing works consistently’.** **These children include those: with premature birth, advanced medical interventions in infancy, parental substance and alcohol abuse, or rare chromosomal disorders.** They may have co-occurring diagnoses, such as dyslexia, ADHD, tuberous sclerosis and ASD, compounded by sensory perceptual issues, exacerbating mental health problems or require invasive medical support such as supported nutrition, assisted ventilation and rescue medication. **Stage 1:** The project built expertise by identifying schools that showed excellence in SEN in **‘cognition and learning’, ‘communication and interaction’, ‘emotional and behavioral difficulties’ and/or ‘physical difficulties’.** **Stage 2:** the approaches were trialed in other special schools in UK and internationally. **Stage 3:** the resources were trialed in primary and secondary mainstream schools.

The CLDD engagement for learning framework is downloadable from the SSA Trust website and includes: briefing packs, the **Engagement Profile and Scale** an observation and assessment resource; the **Inquiry Framework for Learning** starter questions towards learning solutions in 12 areas in: communication, emotional well-being and motor skills etc. Attention or engagement is the most important predictor of successful learning, even more than IQ. **Learning doesn’t take place without engagement for learning.** It is about constructing learning readiness, making knowledge, understanding and skills desirable so they **‘thirst to learn’.** **Engaged learning extends post-school chances and is in the gift of educators.** Engagement is an umbrella of a group of related ideas: The Engagement Profile and Scale uses 7 indicators: **Awareness** (conscious response), **Curiosity** (thirst/desire), **Investigation** (activity to find out more), **Discovery** (light bulb moment), **Anticipation** (based from previous experi-

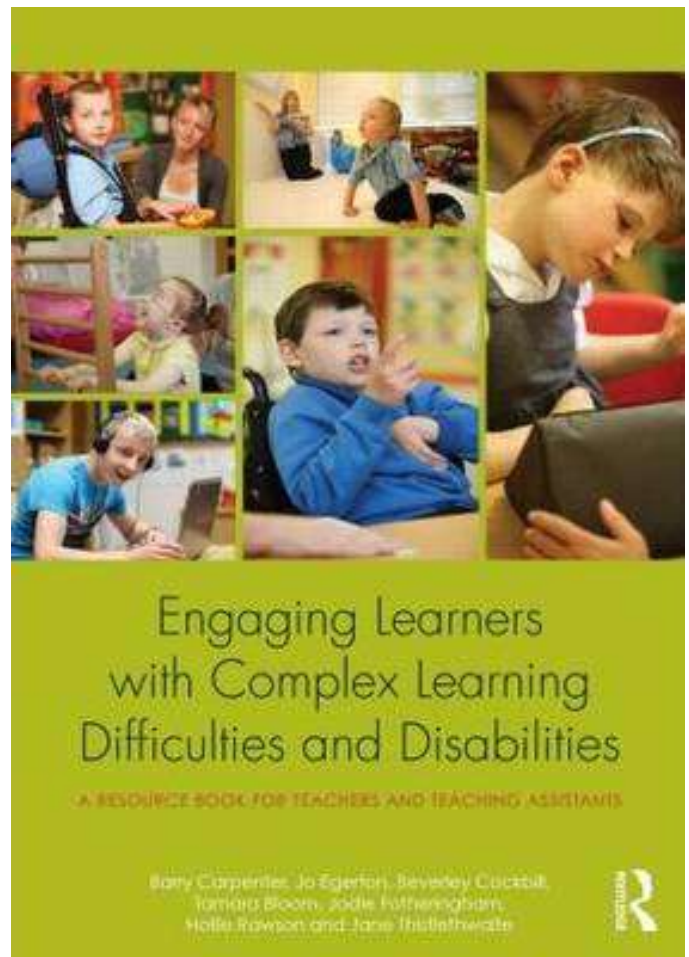
“Training parents to enhance children’s emotional literacy and social competences reduces aggression and strengthens literacy”

ence), **Persistence** (determination), and **Initiation** (self-directed request or initiation). Can be scored 0-4 for each dimension and gives a total score of engagement out of 28.

Most hard-to-reach learners have some interest in or out of school. Others may be distracted by their environment and need reasonable adjustments. The book then looks at approaches to multiple perspectives to expand understanding which requires a culture of innovation and expanding inquiry, to construct personalised learning pathways: in this way children-who-fail can succeed.

We are facing a **new generation of children**: Despite the principal of equal opportunity of education, this century is meeting children with new profiles of **learning needs, with children with ‘different brain functioning’**. **Michael Guralnick described: the cognitive development of 780 million children worldwide are affected by biological, environment and psychosocial conditions.** In addition, the growing stranglehold on our children of poverty, violence and stress contributes to risk of disability. These contribute to the rise in emotional and disruptive behaviours. Training parents to enhance **children’s emotional literacy and social competences reduces aggression and strengthens literacy.** These skills can also be taught during circle time using child-sized puppets. Vulnerability may be the only unifying concept in this homogenous group driven by disadvantage, deprivation and disability. This increased complexity needs new skills in personalised learning. **Susan Greenfields (Chief Scientist UK) described ‘the mind is the personalisation of the brain through unique dynamic configurations of neuronal connections, driven by unique experiences’.** **Frith added: ‘Education is concerned with learning and neuroscience in concerned with understanding the mechanisms of learning’ which needs ‘a pedagogical reconciliation’ through evidence-based innovative practice.**

Research has consistently found that **Engagement in learning** is a primary reason why some schools are **better than others**. **‘Without engagement, there is no deep learning, effective teaching, meaningful outcome, real**



attainment or quality progress’. Many educators see engagement as foundation for effective learning in **children with disabilities.** Teachers have to **‘penetrate the mask of disengagement’.** Engagement is difficult to define but it involves **‘the intensity and emotional quality of involvement in learning’**, not just time on task. Meaningful engagement involves a connection between a child and their environment for sustainable **learning.** **Special needs children can’t do this for themselves.**

The Engagement profile can be used dynamically to work out what will increase attention with what motivation. There are a range of examples: eg Harry with Mod ID, ADHD, OCD, ODD, speech and language difficulties. The Engagement profile indicated engagement only in cooking, and with the use of puppets, both of which were introduced to the classroom, and enabled wider communication through interest in what others were doing in the classroom, leading to participation in a wider curriculum. Alfie a 4 year old with profound and multiple learning disabilities with epilepsy and physical difficulties. **Engagement profile showed he would ‘self induce sleep’ in class, especially during cooking lesson.** He was animated with prosocial babble with the sound of pouring water. Excessive stimulation in the classroom and light and sound was overwhelming him. This led to a progression over weeks of: washing hands in a bowl, peeling a banana, mixing icing sugar, changing the sensory environment and his washing his hands in

the water each time he looked tired. This progressed on to communication with singing which led to making a banana sandwich, all leading to better engagement with teacher. Examples like these demonstrate how an examination of engagement and what a child likes to do led to better engagement in learning.

Chapter 6 looks at the family's perspective on the life of their CLDD child with their own emotional, often traumatic, experiences, including the struggles of getting an educational placement to meet their needs and being held responsible for the behavior problems at school. Eg. Adam 7 year old, in mainstream school lacked a sense of social appropriateness. Engaging with the family the school found this to be secondary to birth prematurity and brain damage affecting his social skills and responded with pastoral mentoring, teaching why certain behaviours were unacceptable, instead of the previous negative disciplinary approach. Mencap reported that 8/10 families with a child with a disability are at breaking point. When we talk of parents as partners, in these families it can mean grandparents, aunts, siblings, neighbours and other agencies helping support the family. **"In my son's twelve short years, I have dealt with 12 psychologists, 6 psychiatrists, 7 speech therapists, 3 social workers, numerous teachers, tutors and home support workers. Despite this array of professionals, he still ends up getting suspended from his special needs school and sent home to Mum: who else is expected to do the job nobody else can manage!?"** Addressing family needs involves: inclusiveness with whole family; encouraging fathers' involvement; demonstrating listening and regular communication eg emails; providing opportunities

to meet; providing information; encouraging participation, eg in training staff. Many problems need tackling at home and in school, such as good sleep routines affecting school performance. Families usually know most about what interests their child has that can enable engagement. Partnership skills involve: active listening, prompting and exploration, empathic responding, summarising, enabling change, negotiating, problem solving. **There is guidance on engaging 'hard to reach' families with special issues of feeling stigmatised, worries about confidentiality, problems of access, understanding disinclination to reveal themselves, as well as language and cultural issues and lastly persistence.** Structured conversations can establish a **shared narrative of a child's problems.**

Chapter 7: "Collaborating with other professionals: together we can achieve more". Bringing specialist skills into the classroom can aid engagement and individualised learning; eg. training teaching assistants to work closely with a visiting allied health professional, who can provide the information conduit between professional and class teacher. An alternative is using computer aided teaching to bypass a language problem as a stepping stone to improved engagement, rather than his previous escape activities and disruptive behaviour. Success in a foreign language, Spanish, helped English and enabled a growth in self confidence that a pupil became able to read aloud in class. **Transdisciplinary focus requires 'targeted eclectic flexibility' with simultaneous assessment of the child, intensive ongoing interaction between the professionals involved and role release to help one another deliver intervention.** The pleasure of using music led a profoundly disabled



boy to develop a communication system with improved posture, eye gaze and pointing to learn cause and effect, and finally words with contributions from a physiotherapist, a music therapist and a speech therapist. With different degrees of professional knowledge and subspecialty skills, research skills can be brought to bear on a complex case: this requires an openness, a common language and room for ever further examination and enquiry to enable engagement.

Chapter 8 ‘Mental health and children with CLDD: a ticking time bomb’ refers to the growing epidemic of childhood depression and other mental health problems. The British Medical Association reported a rise in prevalence from 10% to 20% of children with and without disabilities in any one year. The rate in children with learning difficulties is over 36%, or over 6 times **more likely than in peers that don’t have a learning difficulty** and they are likely to have multiple disorders. In mild ID it is 1/3 and below IQ of 50 it is 1/2. ASD is a major risk factor. For FASD it rises to 9/10. They suffer the same spectrum of mental illness, and yet they have the same right to positive mental health, which is a basis for a quality of life for all children. Wellbeing includes: self-esteem, optimism, a sense of mastery and coherence, the ability to initiate and sustain mutually satisfying person relationships, ability to cope with adversity, and belief in one’s own worth and of others. **‘The emotional wellbeing/mental health CLDD project development phase’** which looked at 59 children in 12 special schools, indicated a high level of educator concern. The children were categorised into 4 groups: those who received help from MH clinicians (9), those who did not but were in need of it (6), those whose behaviours indicated concerns about emotional wellbeing (EWB) (13), and those with no MH concerns (although medical problems may still be important). It is difficult to distinguish between EWB and MH. They often had more than one presenting problem and in up to 6 different areas. MH, ADHD and ASD were the three main difficulties identified in a mainstream school. A focus in engaging learning approaches improved MH and EWB in many cases often complementing the work that MH clinicians were doing. MH is still a poorly defined issue for many education staff who need sufficient knowledge, training and support

to: promote psychological wellbeing, identify early indicators of MH problems, and provide positive support for recovery from severe MH problems. Picking up early signs depends on a strong sense of what is normal functioning for a student, systematic recording of change, and an awareness of uncharacteristic behaviour. MH problems can be indicated by changes lasting more than 2 weeks, that generalises to different settings, and extreme behaviour, which should be supported by close contact with parents. Schools need to establish a positive MH ethos, including prevention, promotion and early intervention. This should be supported by policies and curriculum eg on social inclusion, health and exercise, approaches to injustice, discrimination, including bullying and abuse, and school criteria for identifying MH/EWB problems. A significant literature identifies what sustains MH in schools and what PPEI programs can be helpful. The prominent **government message that ‘mental health is everyone’s business’** applies to all educational settings including special schools.

Chapter 9: School-based ‘enquiry gives you wings’ in engaging children with CLDD. There is a time when every educators experience runs out and they need flexible and imaginative approaches. The CLDD project

“Schools can establish a positive MH ethos, including prevention, promotion and early intervention”



approaches can provide skills and confidence to tackle problems. At this point in time we are into a second generation of research on understanding complex kids with a practitioner-led evidence base. A formal approach to enquiry avoids intuition and human fallibility **and supporting treatments that don't work. An Action Research Spiral increases influence based on formalised enquiry and evidence. The 'Accessible Research Cycle' may require multiple cycles of planning an intervention, implementing, observing the outcomes and reviewing and modifying it.** This may start with a basic questioning approach to one selected child but this can develop on to a class and then have implications for wider organisational approaches. 88% of schools that used the CLDD Project reported improvements in professional ethos and practice benefits. The appendices have various resources. Consent from parents and child may be an important part of engagement processes. Consideration of ethical standards and guidelines are part of building communities of practice **and enquiry. The "Inquiry Framework for Learning" is a content-free web-based tool to support educators which includes learning-focused questions around 12 areas of enquiry: engagement for learning; communication/interaction; identify/self-advocacy/independence; behaviour for learning; sensory perception/processing; health/physical wellbeing; teaching/learning; EWB/MH; motor skills; improving life chances; social skills; and environment.** This provides a broad basis from which to start an enquiry. It can help to have a reflective colleague or mentor but inquiry is the basis of continuing professional development. School-based enquiry needs prioritisation and resourcing and senior leadership teams and leads to cultural change which inspires and empowers staff. Alignment with academic or university staff can be helpful. These **approaches can teach both 'what to do' and why.**

Chapter 10: "Envisioning the future: the engagement for learning framework" enables educators to become leaders of learning and in turn extend the CLDD approaches and knowledge. Jane Thistlewaite from Positive Paths International, New Zealand, describes how experience with the engagement process enables **greater skill in appreciating elements of a child's environment and people that can impact on how they engage and learn.** For example, you may learn about a **child's high preference items through engagement in the garden such as a coloured bucket, starting with functional engagement progressing on to an engagement diet and to an engagement passport.** Another child with ASD was able to participate by having adhesive tape around his desk to help him self-focus. Neil Jordan, a music therapist in NZ has trained 60 staff in the CLDD framework, including video-analysis as an extra tool. In one school the approach is included in



another program such as TEACCH or Floortime to test out the sequential benefits of such an approach. The Engagement Framework has been described as a liberation of intrinsic motivation, unlocking curiosity, increasing the participation of the child, empowering learning and helping the move from vulnerability to resilience.

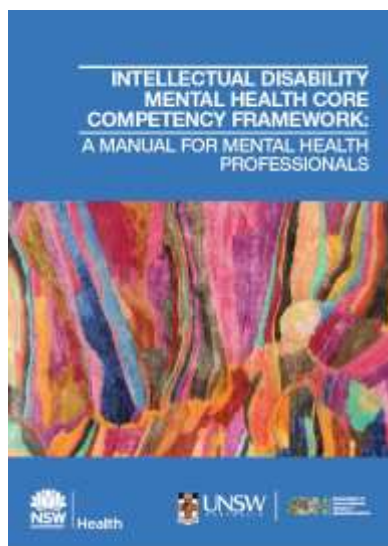
Reference:

Dossetor, D. A review of: Educating children and young people with fetal alcohol spectrum disorders: constructing personalized pathways to learning. Blackburn C, Carpenter B, Egerton J. 2012. CHW School-Link Newsletter 2012 Vol 3 (3/4)18-19.
www.schoolink.chw.edu.au

Intellectual disability mental health core competency framework: a manual for mental health professionals

*Launch Review by Hebah Saleh
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The Intellectual Disability Mental Health Core Competency Framework: A Manual for Mental Health Professionals describes the **specific skills and attributes required by mental health professionals for the provision of quality services to people with an intellectual disability**. It outlines the necessary approaches to clinical practice when working with people with an intellectual disability and identifies the core competencies that mental health professionals require to work in this area. The Framework also includes a self-assessment tool to help professionals determine their current skill set and guides readers to resources that support professional development in intellectual disability mental health.

The Framework was developed in consultation with key stakeholders, and was funded by Mental Health-Children and Young People, NSW Ministry of Health.

Who is the Framework for?

The Framework has been developed for **mainstream mental health professionals**. It is beneficial to professionals who provide mental health services within hospitals, government and non-government community services, and private practices. The framework is also useful for people who work in service management, service development, education of mental health professionals and quality improvement.

Aims of the Framework

By supporting professionals within mainstream mental health services to develop core competencies in intellectual disability mental health, the Framework aims to:

- increase the capacity of mental health services to meet the needs of people with an intellectual disability
- Ensure the provision of high quality mental health assessment and treatment to people with intellectual disability and
- Increase access to services and reduce service barriers for people with an intellectual disability

How to use the Framework

Mental health professionals can use the framework to:

- make reasonable adjustments to clinical practice to assist in better assessment and management of mental health problems in people with an intellectual disability
- assist in undertaking a self-assessment of current skills and knowledge
- inform a professional development plan, or
- guide you to available relevant resources, education, and training material.

Service managers, service developers and people responsible for quality improvement could use the framework:

- to review current capacity of services and workforce in the area of intellectual disability mental health,
- for the professional development of your staff,
- to inform education and training plans, and
- to guide recruitment of appropriately skilled mental health professionals

Official Launch

In the lovely grounds of the Prince of Wales Hospital, the official launch of the intellectual disability mental health core competency framework took place on the

30th of March 2016. An introduction by Beth Kotze announced the Honorable Pru Goward who opened the session to launch the framework.

Professor Julian Trollor gave an overview of intellectual disability and people with mental ill health, discussed the risks and lack of choice for this population and the multiple barriers to quality healthcare that includes a lack of specialised services, the lack of content in training which leads to a lack of awareness whilst agencies not collaborating about patients has major implications across services.

People with Intellectual Disability (ID) are twice as likely to be admitted and stay twice as long in hospital; number of visits are higher with longer consultations that are more complex.

There are a range of resources available to improve mental health and intellectual disability (MH+ID):

- The guide
- Idmh e-learning
- This competency framework; this manual supports mental health professionals to assess and respond to MH+ID with a means of self assessment of current skills and knowledge and is for everyone in MH to make adjustments to clinical practice.

Arahni Soht shared a Lived Care experience where she described some barriers and positives regarding her experience of her son Shai who had an early psychotic episode at age 18. Although they initially felt like there was nowhere to go and he was placed with other adults who were neurotypical, some positives included a special nurse, recovery in rehab unit, and eventually Shai was able to access urban space at double bay.

Shai's private unit used talking and creative therapies where he was discharged after three weeks.

Jim Simpson from the NSW Council for Intellectual Disability (*NSWCID*) gave an overview of the agency, its 60 years of experience and their barriers to advocacy that mainly consist of a lack of communication between the patient and the professional with not enough collaboration across agencies.

Some policies outlined included: CRPD UN, 2006. People with ID have a right to a high standard of healthcare. The National Disability Strategy (COAG, 2011) mental health services have to raise their game and include people with ID and the National roundtable (2013) which brought together psychiatrists from around the country, senior representations from around the country and advocacy groups. Strategic plan developed by community relations commission with common elements of drivers

- Equitable access to MH services
- Skilled treatment
- Training of health professionals
- Specialists to back-up mainstream
- Collaboration between service systems

David Coyne discussed Stronger Together initiatives including the Criminal Justice Program, Integrated Services Program, and the two ID chairs and the Memorandum of Understanding.

Associate Professor David Dossetor gave an insightful overview of children and young people with MH+ID. He began with an overview of clinical diagnostic disorders and prevalence in ID which highlighted the need for collaboration in supporting children and young people with severe problems. He discussed the evidence of treatment through the Training Curriculum Project which had a focus on children, common language, skill building and a great overview of clinical adjustments for interviewing and traps for caring.

Selina Thomas and **Billie Dong** presented a case study using a strength model and recovery approach with an emphasis on changing assessment tools and goal identification whilst identifying the family and support.

For more information about the Framework and to download please visit

<https://3dn.unsw.edu.au/IDMH-CORE-COMPETENCY-FRAMEWORK>

Pictured: Jim Simpson, Julian Trollor, Arahni Soht, Billie Dong and David Dossetor



The Role of Occupational Therapy in Behaviour Support Work

Lucinda Mora, Senior Clinical Consultant, Statewide Behaviour Intervention Service, Clinical Innovation and Governance, ADHC, FACS

Susan Heiler, Behaviour Support Specialist, Behaviour Support Team, Quality and Reform Unit Sydney, South Western Sydney and South Eastern Sydney Districts, ADHC, FACS

With the introduction of the National Disability Insurance Scheme (NDIS), the disability service sector is changing. There is much energy being invested in describing how best to meet the needs of children and young people with Intellectual Disability and Mental Health (IDMH) and complex behavioural difficulties and this article seeks to explore one aspect of this.

Behaviour Support (BS) is a clinical sub-specialty in intellectual disability. This type of input is required when behaviour is of such an intensity, frequency, or duration as to threaten the quality of life and/or the physical safety of the person or others and is likely to lead to responses that are restrictive, aversive or result in exclusion (Banks et al, 2007).

As behaviour is complex and may present across different environments and activities there is a need for multiple professionals to be involved in BS. Positive Behaviour Support (PBS) is an evidence-based approach that aims to increase a person's quality of life, and decrease the frequency and severity of behavioural difficulties (Disability Services Commission, 2012). The holistic and strengths based perspective of Occupational Therapy (OT) and its specific skill set will strengthen this work.

There are currently few OTs working solely in PBS in Australia. Some have specialised in PBS, whilst most provide consultative input to other disciplines. OTs however, are in a position to lead this work and provide positive BS with additional training and specialist supervision.

What is occupational therapy (OT)?

Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation (Occupational Therapy Australia, 2016). Occupation is everything people do to occupy themselves, including looking after themselves (self care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity, including play) (Law, Polatajko, Baptiste, & Townsend, 1997, p 34), as well as the things people do to rest, the purposeful pursuit of non-activity (Chapparo & Ranka, 1997, p6). As Iwama (2010) states the magnificent promise of occupational therapy is to enable people from all streams of life to engage and participate in activities and processes that they value.

A key component of OT work in PBS is assessing an individual's sensory processing style and developing strategies for self-regulation. The scope of OT practice, however, goes beyond this domain. OTs are trained to look at multiple factors influencing a person's performance of tasks, activities, routines and roles across multiple environments. They examine how biomechanics, cognition, sensory-motor; intrapersonal and interpersonal factors facilitate or limit a child's occupational performance. They have the capacity to prescribe specialized equipment and promote meaningful engagement which may contribute to the reduction of behavioural difficulties (Perez, Carlson, Ziviani & Cuskelly, 2012).

There are many similarities between OT and PBS. Both draw upon social, behavioural, psychological, educational and biomedical theory, and use a combination of evidence based practices, formal strategies and clinical reasoning to determine the best outcomes for a person with ID. The language and key concepts in





PBS, that is, ecological strategies, positive skill development; focused support, situational management (reactive strategies) and systems change (La Vigna & Willis, 2003) are comparable to OT constructs relating to person, occupation and environment congruence. A case study has been developed to illustrate the role of OT in PBS.

Case study:

Emma was a 14-year-old adolescent with a moderate/severe ID and an undiagnosed mood disorder. She would scream, scratch herself, bang her head against walls, car doors, hard objects and people and no one understood what this was about. Emma also grabbed, pinched, scratched and hit others. As Emma was volatile, her family, respite carers and school did not feel safe taking her out into the community and her respite options became limited. She presented with physiological arousal dysregulation which heightened during her menstrual cycle.

Emma was referred to the team for assistance with managing her self-injurious behaviours and restricted lifestyle. Initially the psychologist completed a behaviour assessment. The psychologist observed behaviours they thought were of a sensory and communicative nature and referred to Speech Pathology and OT for assessment. The speech pathologist and OT discovered that Emma had a long history of undiagnosed ear infections. It became clear that during periods of high levels of self-injury, Emma had an ear infection. This meant that staff could take her to the doctor for the treatment of the infections.

The OT also asked staff to collect data on the arousal levels and mood state of Emma over a 4-week period. **This data was supplied to Emma's psychiatrist who diagnosed Emma with a mood disorder and prescribed appropriate medication.**

When combined with observations and interview, the **OT discovered there was much damage to Emma's hearing and that she sought intense movement (vestibular) and joint (proprioceptive) input to regulate herself. As a result Emma couldn't participate in stationary activities without having some movement or joint input.** She also disliked having haircuts, being dressed; standing in lines and having other people too close to her. When Emma engaged in these activities, **her arousal state escalated, and she felt a 'pain-like' response to these activities. Observations of Emma's physical and emotional developmental milestones equated to that of a 3-year-old, which meant the interventions, had to accommodate this.** A safety plan (see table on page 14) was developed which reflected the arousal information obtained.

The team provided interaction guidelines (see page 15) that outlined how to respond to the communication, sensory and BS needs of Emma.

The OT, in collaboration with Emma and her support system, identified ways for Emma to engage in meaningful occupation. This included going out to eat at local cafes, taking her dog for a walk, going to the local trampoline facility, going for bushwalks and beach walks. All the BS strategies were used during **these activities. Emma's behaviour was not eliminated;** however, there was a reduction of frequency and intensity in her crisis behaviours. Her quality of life improved as her support network became familiar with her needs and provided appropriate support.

Conclusion

In conclusion, OT can offer a unique and valuable perspective to PBS, with its emphasis on promotion of health and well-being through occupation, and its specialist tools in facilitating occupational engagement. The changing landscape that is disability service provision **enables a perfect opportunity for OT's to develop their role in this area.**

Safety Plan for Emma	Early Warning Signs	Escalation	Crisis	De-escalation	Recovery
Behavioural Indicators	Paces, flaps objects, grabs all at once	Pacing more furiously, moaning, crying, banging objects, grabbing and pinching people	Screams, scratches herself, bangs her head against walls, car doors, hard objects and people Grabs, pinches, scratches and hit others	Removes herself Mouths objects	Paces
	Offer a drink/bottle of water Offer a movement activity, e.g. walk or swing on porch chair Direct her to the backyard where she could get leaves Give her space Offer ice to crunch	Offer walking Offer TV or tablet Lead Emma to the outdoors guiding her physically with one hand on her back and on arm Reassure Emma - “its ok” Give her lots of space and maintain in line of sight Give Emma a choice of something to chew, e.g. chewing gum, ice Provide leafy twig which was visual input that calmed Emma	Remain in outdoor area when possible When raining, use designated inside quiet area Provide Emma something to chew, e.g. chewing gum, ice	Offer or redirect to a preferred activity Go inside/or remain in quiet area Direct to cushions to lie down and relax Provide her something to chew Provide ipad to look at favourite videos	Re-commence with typical daily routine activities using visual supports and key word signs
Client Focussed Carer Focussed Response Strategies Apply in situations where Emma appears agitated or stressed	Use a slow voice with a low pitch Use three word sentences Point and verbally prompt Emma outside “Outside now Emma” Use gentle physical prompt if Emma needs more direction	Remain calm Inform other staff what is happening Maintain personal safety, be at least 3 metres away, in line of sight Use one word sentences ‘gentle’ with the key word sign Use actions/ gestures/ pointing to direct him Avoid offering choices Administer emergency psychotropic medicine as protocol	Keep something between Emma and yourself, e.g. table Maintain personal safety e.g. - monitor from 5 metre distance in line of sight - limit interaction	Stay alert and continue to monitor Provide first aid/ medical attention if Emma had hurt herself	Monitor for signs of re-escalation Use single words with key word signs and physical guidance as appropriate

Things I need & like	Things I don't like	How can you support me
To be kept calm and at a just right level	When I become upset and agitated	Be familiar with my behavioural indicators and ways to keep me calm
A quiet open place to pace and calm down	Visually and auditory busy places	Read my signals try not to let me get too upset as it is hard for me to calm down
Activities that provide body awareness information e.g.: swimming, banging objects, crashing onto crashmat, rocking in a chair	Activities requiring balance Being told to stop banging	Try to incorporate the physical activities throughout the day
People using firm / deep pressure when touching me	People using light touch	When interacting with me always use firm touch. I also need deep pressure input regularly throughout the day
Crunchy foods and things that I can chew on Regular snacks and drinks	Being hungry / thirsty	Use the foods I like at mealtimes and provide regular crunch and chewy snacks throughout the day. Provide me with water in a clear plastic pop-top bottle that I can access freely.
People using simple language, key word signs and gestures	When people use lots of words When I get too many instructions at once	Use simple language with key word signs and gestures. Only give me one instruction/piece of information at a time. Show me how to do things so I know what you expect of me.
I like to fidget with and look at lots of different things but they usually only hold my attention for short time	Always having to do what others want me to do	Rather than hand me an object to play with stand near me and use it yourself e.g. model how to use it, then put it down I can pick it up and use it if I choose to Ensure I have access to items around the house that I can safely fidget with
To have a routine and knowing what I can do next	Waiting for the routine to happen	Use a visual routine and 'Now and Then' board to help me understand what happens next. When it is time to transition to the next activity, tell me the current activity is finished, use the finished key word sign and tell/show me what is happening next.

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Treatment of Neurodevelopmental Disorders: Targeting Neurobiological Mechanisms.

Edited by Randi Hagerman and Robert Hendren,

Oxford University Publication, 2014

*Reviewed by Meenakshi Rattan, FRACP, General Paediatrician, Academic Fellow,
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Randi Hagerman is a regular visitor to Australia and has an international reputation as a clinician, researcher and lecturer in the Fragile X field. This book represents a new phase in her career as the director of the MIND Institute at the University of California Davis. As such it represents a new frontier in approaches to and research in developmental and psychiatric disorders.

Targeted for both psychiatric and paediatric audiences: it reinforces that symptoms of neurodevelopmental disorders need to be described in the context of brain developmental trajectory which in turn improves our understanding and capacity to address them. It also attempts to link the advances in neuroscience research to clinical practice, calling for an interactive partnership between clinicians, researchers and families for the ongoing success in the management of neurodevelopmental disorders. This book captures advances in molecular biology and targeted treatments for major psychiatric and neurodevelopmental disorders over thirteen chapters.

The overview describes the process of neurodevelopmental formulation which forms the basis of the therapeutic interventions. These interventions can enhance developmental progression, improve environmental

interactions, reverse neurobiological dysfunction and prevent sensitisation. The imbalance of the neurotransmitters GABA and glutamate, and their complex neuroanatomical pathways is the background to explain the pathogenesis and treatment strategies. Newer techniques as WES (whole exome sequencing) and WGS (whole genome sequencing) have been used to trace mutations, deletions and duplications which are seen in more than half of the patients of autism with intellectual disability. The identification of pathways that are affected by these mutations gives insights into understanding major psychiatric and neurodevelopmental processes. The neurodevelopmental process is explained in terms of synaptogenesis and myelination, whilst epigenetics explain the influence of environment on gene expression. For example changes in epigenetic markers such as histone acetylation and DNA methylation secondary to environmental exposure to smoke, air pollutants, metals, and organic chemicals results in conditions such as cancer, asthma and metabolic disorders. More detailed description of epigenetic processes follows, described under different sub-headings including immune etiology of neurodevelopmental disorders, oxidative stresses and mitochondrial dysfunction. High levels of cytokines even during intra-uterine periods are associated with schizophrenia and major depressive disorders. Similarly there is a link between oxidative stress or mitochondrial dysfunction and disorders like Down's syndrome, Alzheimer disease, Fragile X, schizophrenia, depression, ASD etc. The description of biomarkers in diagnosis of disease risk, targeted treatment and their outcomes is interesting although the examples feel repetitive at times. These aetiologies do not follow a sequence to highlight broader framework but come across as disjointed and fragmented. The theory of mind and developmental sequencing seems to be lost at times in complex descriptive genetic processes.

The major disorders as Autism, schizophrenia, depression, ADHD, Rett syndrome, Cardio-facio-cutaneous syndrome, Tuberous sclerosis, Fragile X, Angelman's syndrome, Down syndrome, Phenylketonuria, muscular dystrophies are described in the next thirteen chap-



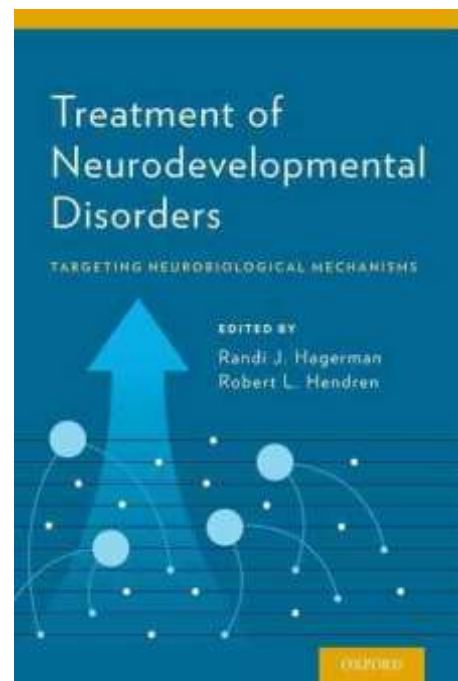
“Behavioural phenotypes provide important models for understanding the biology of mental mechanisms”

ters. Each topic starts with an introduction of prevalence and clinical features. The neurobiological abnormalities and epigenetics are highlighted followed by use of biomarkers in the diagnosis. The associated comorbidities are mentioned in these contexts. The management is described under current available options, followed by newer targeted treatments and future prospects. There is a useful, comprehensive and relevant summary at the end of each topic. All available treatment options including non pharmacological options are discussed for each disorder. References are current and relevant to the text. Of interest, Mazurek et al (2013) reported aggression in 53% of cases of ASD at some time which is higher if there are associated medical co morbidities highlighting the need of comprehensive screening to look for associated issues.

In the last chapter, the authors bring forward the novel concept of merging current research into clinical practice. The translation of advances in understanding of the neuroanatomical and neurochemical basis of major psychiatric and neurodevelopmental disorders anticipate a new area of targeted treatment options which are currently being successfully trialled in animal models and human cohort studies. It also touches on a few promising potential areas for the future such as stem cell therapy.

While emphasising the potential of newer options to reverse the neurobiological dysregulation caused by **mutations, the authors don't minimise the role of advances in educational technology and digital aids in providing comprehensive patient care.** This is important for strengthening partnerships with the families in optimising care. It also summarises common abnormalities that occur across different disorders. At the end of the last chapter, all the important concepts that can be translated into clinical practice are summarised.

This book is of interest to paediatricians, allied health, geneticists and child psychiatrists, in fact all involved with disability services as the concepts discussed are viable and relevant across different faculties. The ethical, legal and political implications of such new therapies will need to be worked through, as well as more clinical studies and trials. The authors emphasise the



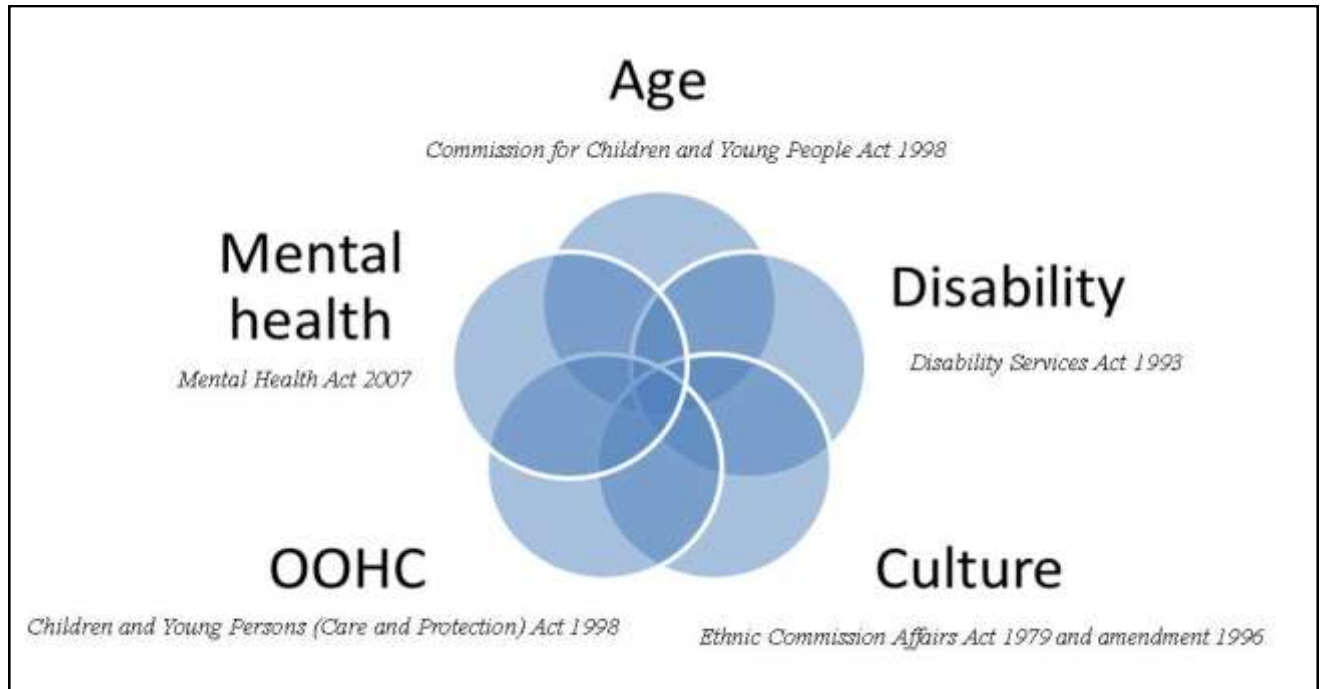
importance of clinician support to enable the potential of such therapies to become a reality. In the absence of any local experience, most of the targeted treatments which have promising results in animal models raise ethical issues for their suitability for current patient cohorts. Further studies will also need to look at long term safety profiles before they are suitable and applicable to clinical practice.

This book aims to bring current neuroscience to understanding and treating neurodevelopmental and psychiatric disorders. With the presentation of so much detailed research observations it is difficult to find a coherent story. It raises the question as to whether risk markers could ever become the basis of treatment and a substitute for, or significant contribution to diagnostic classification.

There is no doubt that behavioural phenotypes provide important models for understanding the biology of the mental mechanisms. I recently saw a 12 year old boy with temporal lobe epilepsy, severe ADHD, some features of ASD, mixed emotional and conduct problems, motor coordination disorder, encopresis, and specific learning difficulties. Such a multidimensional disorder is not so unusual, but the next time I met him, he had been diagnosed with 16p.11.2 microdeletion, and the behavioural phenotype, which was first described in 2010, fitted my clinical description remarkably. The biological marker added meaning and coherence to this clinical picture. It may be that by collecting different biological mechanisms that each new behavioural phenotype will accumulate understanding of mechanisms of the mind which could create a whole new biology of mental development and disorder. We have to **accept that this book represents ‘a work in progress’** and as such an interesting, novel and potentially important approach to keep informed about.

Insight into a mental health review tribunal

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This article is based on an observation of a Mental Health Review Tribunal (MHRT) of an 11 year old boy under the NSW *Mental Health Act of 2007*. Some details have been changed to protect the identity of the child.

What is a MHRT?

In NSW, a Mental Health Review Tribunal is a court-substitute tribunal where court like judicial power has been given, instead of purely administrative power of other tribunals (Rice & Day 2014 p.433-4), **Advantages of the 'quasi-judicial power' that is held by the *Mental Health Act 2007***, include that they are not as costly or as time consuming as a court process (p.433).

Like an onion this case revealed multiple layers of vulnerability and clearly illustrated how the influences on mental health come from various bio-psycho-social domains, as diagram 1 (above) illustrates. The first layer was his age: a minor under the age of 16; the second layer involved his mental health episode of psychosis, bipolar disorder and experience of childhood trauma; the third, his level of disability Autism Spectrum Disorder and an intellectual disability; the fourth layer his guardianship status, as the parental responsibility lay

with the minister as he was a child in Out of Home Care (OOHC); and the fifth layer was his cultural background being from a non-English speaking background.

Who is involved?

There are numerous professionals present at an MHRT. Firstly there is a tribunal panel. This consists of a Magistrate who chairs the meeting, a Psychiatrist, and one other, in this case a Social Worker. The role of the tribunal panel is to determine whether the patient is mentally ill and for whom no other care is appropriate (*The Mental Health Act 2007* s.38-1).

The second group consisted of hospital ward staff: the treating psychiatrist, social worker, nurse, and registrar. **Their roles were to 'give evidence about the need for the client to be on a legal order' (MHRT p.1).** Turunen *et al*, suggest that psychiatrists prioritise medical rights over civil rights as the right to receive treatment with serious mental health problems, even when not asking for it, dominates (2001 p.39). In this particular case the side effects from the psychotropic medications the child was taking needed to be monitored daily, highlighting the pressing need for research into medication for children.

As the child was under the guardianship of the Minister, the third group of professionals present was the OOH representative from NSW Department of Family and Communities (FACS). The main role of FACS was to ensure that the least restrictive practices were being made and the best interests of the child were being addressed.

The fourth group of professionals included a lawyer from The Mental Health Advocacy Service and his assistant. Their role was to advocate for the best interest of the child and in this instance they supported the **medical team's application**.

The final group present was the child and his support person, his long term foster carer, who also supported **the medical team's application as she felt she could not manage the child's acute mental illness at home**. His support person was able to voice her care related concerns. The child was unable to communicate verbally during the proceeding.

Mental health legislation can be discriminatory as it imposes significant limitations on liberty and autonomy of those who have a mental illness (Rice & Day 2014 p.283). Therefore it is fundamental to gain input from various representatives in the room. Rees acknowledges the skills and insights that this multi-member panel bring to the decision making process **and the role of the tribunal in safeguarding 'the foundational human rights of freedom of movement and freedom of bodily integrity' (2003 p.42)**. The array of participants reflect the commitment to the quasi-judicial process and the reflection of the involuntary treatment as a last resort, as the *UN Principles for the Protection of Persons with Mental Illness* outline (Rice & Day 2014 p.274).

Structure of the MHRT

The MHRT comes under the *Mental Health Act 2007* of NSW and under a civil as opposed to forensic jurisdiction. The order that was discussed in the observed

“The array of participants reflect the commitment to the quasi-judicial process”

MHRT was a review of the Involuntary Patient Order S.37, as the initial 3 months of the original order was due to expire and the treating medical team were seeking an additional 3 months for continued treatment. The tribunal was held at the treating hospital, with the MHRT three member panel participating over video conference. The whole process took about 90 minutes. Paperwork is submitted several days before a tribunal, with verbal updates given on the day, followed by more paperwork after the event.

All participants of the MHRT tribunal were professionally dressed in appropriate attire without appearing too formal. The majority of conversation was in plain English, with a concerted effort to avoid medical jargon to make the process accessible. This is congruent with how Freckelton (2003) refers to language and questioning being straight forward and not complex. Similarly *The Mental Health Act 2007* stipulates that Tribunal meetings are to be held with as little formality and technicality as the act permits (S.151.1).

Photo 1: Example of a panel. Source: MHRT 2013.

Protocols that I observed were the use of 'your Honour', when talking to the Magistrate and not speaking unless you were asked a question or asked to speak. At the end of the tribunal, the panel gave the carer and the child the opportunity to ask any questions or offer any additional information.



Is the MHRT open to the public or closed?

The Mental Health Act 2007 (NSW) states that 'The proceedings of the Tribunal are to be open to the public (S.151.3)'. An exception to this is if the Tribunal is concerned about the welfare of a person or if another person present requests, the Tribunal could order that the proceeding occur in private, or partly private and/or restrict the publication of the report, evidence or any other documents given to the Tribunal (S.151.4a-d). According to Nettheim, cases involving juvenile persons, marriage disputes or the guardianship of children need to be closed to the public (1984 p.25). There needs to be a balance between transparency and respect for the privacy of the child especially with acute mental illness, determining who is fit to attend and who can access documentation.

Epilogue

The extra 3 months were granted pending a second opinion from an independent psychiatrist. This was gained and the child spent some time in hospital at which point the extension on the Involuntary Patient Order S.37 was ceased. The child is back with his carer and is still on medication. The staff commented that this stay in hospital was pertinent to his recovery. He is still being treated for his mental illness but has stabilised.

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Rice, S. & Day, A (eds) 2014. *Social Work in the Shadow of the Law*.

Turunen, S., Välimäki, M., & Kaltiala-Heino, R. 2010. Psychiatrists' views of compulsory psychiatric care of minors. *International journal of law and psychiatry*, 33 (1), 35-42.

Reading List

Euser, S., Alink, L.R.A, Tharner, A., van Ijzendoorn., and Bakermans-Kranenburg, M.J. (2016). The prevalence of child sexual abuse in out-of-home care: Increased risk for children with mild intellectual disability. *Journal of Applied Research in Intellectual Disabilities*. Vol 29, Pp. 83-92.

Unfortunately the prevalence of child sexual abuse for children with intellectual disability was significantly higher for children in out-of-home care, but also in the general population.

Fletcher, R.J., Barnhill, J., McCarthy, J. and Strydom, (2016). From DSM to DM-ID. *Journal of Mental Health Research in Intellectual Disabilities*. Published online 16th June 2016.

A new edition of the DM-ID, probably the most important publication on psychiatric diagnosis of individuals with IDD, will be published later this year. An article about the reasons for publishing the DM-ID and some of the highlights of the new edition. *To link to this article use the following address:*

<http://dx.doi.org/10.1080/19315864.2016.1185324>

Gilroy, J., Donnelly, M., Colmar, S. and Parmenter, T. (2016). Twelve factors that can influence the participation of Aboriginal people in disability services. *Australian Indigenous HealthBulletin*. Vol 16, Iss 1, Pp. 1-10.

This is an interesting discussion with many factors that play a role in access to disability services. It may be a great article for including in service reform. In addition, the Australian Indigenous HealthBulletin is a great resource for further reading.

Health of Indigenous peoples: Fetal Alcohol Spectrum Disorders (FASD). Cochrane Library Australia Special Collection. (Accesses July 2016).

Access the link here: [http://www.cochranelibrary.com/app/content/special-collections/article/?doi=10.1002/\(ISSN\)14651858\(CAT\)Freeaccesstoreviews\(VI\)indigenoushealthFASD](http://www.cochranelibrary.com/app/content/special-collections/article/?doi=10.1002/(ISSN)14651858(CAT)Freeaccesstoreviews(VI)indigenoushealthFASD)

This Special Collection is one of a series focusing on health of Indigenous people, with a focus on Australia, Canada, and New Zealand. There is a plethora of research based on women, pregnancy and post partum care.

Young, H., and Garrard, B. (2015). Bereavement and loss: Developing a memory box to support a young woman with profound learning disabilities. *British Journal of Learning Disabilities*. Vol 44, Pp. 78-84.

This is a good case study of working with a young woman to work through the loss of her brother. Although used with a young woman, the use of the memory box could be adapted for all ages. It is a great practical idea for use in therapy.

Below are a few of the references of the abstracts presented at the World Congress of the International Association for the scientific study of intellectual and developmental disabilities held in Melbourne, Australia in August 2016. I have selected from the sessions that I attended and really enjoyed. For a full listing of presentations, see the *Journal of Intellectual Disability Research*, Volume 60, part 7 and 8, 2016. Pp. 625-627

Hertz-Picciotto, I. (2016). Autism and other developmental disabilities: State of the science in environmental exposures and prenatal windows of susceptibility.

A complete eye-opening presentation discussing the real risks of exposure to food contaminations and other chemicals.

Leach Scully, J. (2016). Disability, Identity and Human Flourishing.

This lecture was a great dialogue about ethics, disability and individual identity, especially with the advent of more advanced prenatal and postnatal care.

Saxena, S. (2016). Intellectual and developmental disabilities: Global challenges and opportunities.

The current work of the world health organisation was highlighted including an exciting Parent Skills Training Manual that will eventually be free for use across the globe.

Reflections of a paediatric fellow on child neurodevelopmental psychiatry

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As a general paediatrician, child psychiatry always intrigued me. The myth that it is a distinct subspecialty from paediatrics was disrupted after I had the opportunity to work in the Neurodevelopmental Team of the Department of Psychological Medicine at the **Children's Hospital at Westmead, towards the end of my training.** It was a period of revelations and learning in personal and professional development that I want to share with others. I realised that principals of general paediatrics and child psychiatry work intricately together and in many ways complement each other. I was exposed to concepts and experiences which made a permanent imprint and will always influence my professional practice. A number of key experiences stand out.

The central concept is recognising and supporting the development of the mind in childhood, evidenced by the development of theory of mind and the ability to modulate emotions according to developmental age and stage. This is the context for supports and interventions for children and adolescents with neurodevelopmental disabilities. With the development of theory of mind, children learn to match their arousal levels,

emotions and thoughts with their primary caregiver and other adults. These are the foundations of developing social skills and indeed reciprocity in emotions, thought, relationships and flexible creativity with others, particularly peers. In children with autism spectrum disorder or intellectual disability, the delayed development of theory of mind and social reciprocity leads to delay in the emotional regulation and skill, and relationship building (Baron-Cohen, 1991).

One of the most critical parents skills is to teach children non-violent ways of engagement (Szalavitz & Perry, 2010). Empowering parents and counselling against coercive parenting styles (Patterson, 1982) goes a long way in keeping everyone involved safe and is also a cost effective way of managing aggression in the disabled child. Giving way to aggression reinforces such maladaptive behaviours. Calm persistence of intervention is a key measure of caring. It is helpful to encourage parent participation in training programs as **early as possible before a child's behaviour patterns** and perception of self has developed a sense of permanency which will then require more intensive, pro-



longed interventions (Eldevik et al, 2009; Centre for Reviews, 2015). Safety and behaviour support interventions for children with intellectual disability and aggression is a crucial long term investment which cannot be underestimated. Medications can facilitate but at no point replace them as aggression is not a psychiatric disorder in itself. Parents still carry the basic responsibility of teaching the child emotional and behavioural regulation and need to learn for themselves the strategies to be able to do that.

The evidence-based behavioural interventions supported by professionals reduce the aggression and also allow other development-enhancing therapeutic interventions including emotional and behavioural social skill training to be effective. It also prevents establishment of long term negative/maladaptive patterns of affect and behaviour later such as disruptive behaviour, depression and anxiety and personality (Whatson L, Corfield D, Owens B, 2011). That children with neurodevelopmental disorders need skilled developmentally sensitive parenting is part of ensuring the wellbeing of all family members but also fosters their positive interaction with the intellectually disabled child. Effective regulation of the emotions and behaviours is arguably the most important ingredient for a better quality of life and facilitates overall educational and social development (Ali et al, 2015). Teaching aggressive children with disability to develop skills to settle themselves with self-soothing strategies such as using sensory toys and a low stimulating environment (including **limiting screen time**) can necessitate **assess to a 'calm or sensory room' which can provide a place of safety** (Sutton, 2011). I have seen how these approaches reduce the need, often for frequent emergency services, call outs and requests for hospitalisation and enable a greater chance of these children being accepted in **society. It is tragic witnessing a family's desperation** when the size of their disabled child means they no longer have control or safety to teach them further, relinquishing their care to the state and access to group homes (Dossetor, 2016). A universal approach to enabling such optimal early development through parenting skills may arguably be the most important approach to preventing adult mental illness, which means it needs to be something that paediatrics and primary care take responsibility for.

I was also impressed with the impact of the Developmental Psychiatry Interagency Tertiary Clinic and Partnership (colloquially called the DPC) which is a novel collaborative approach which brings together specialised skills of paediatrics, child psychiatry, disability, education to support young intellectually disabled children with emotional dysregulation and behavioural issues. This model of assessment and intervention de-

“The central concept is recognising and supporting the development of the mind in childhood”



“the prevention of mental health has not received the attention that its growing impact demands ”

depends on the collaboration of interagency expertise and interdisciplinary approaches with medical and allied health staff, specialised in intellectual disability enabling multifaceted interventions to achieve better outcomes. It is not only a model of excellence using subspecialty skills but I feel sure it is a highly cost effective alternative strategy for dealing with complex patients and supporting the families who are at the end of their tether (Bernard, S. 1999).

Preventive approaches in mental health especially in children with neurodevelopmental disorders are still at a nascent stage. After 20 years research, there is now enough evidence to suggest that preventive strategies for heart diseases, hypertension, diabetes and infectious diseases have established cost effective ways of reducing morbidity and mortality. Despite significant impact of mental health problems in children and adolescents and in turn adults, the prevention of mental health has not received the attention that its growing impact demands because scientific and medical research and funding in this area has been limited as it

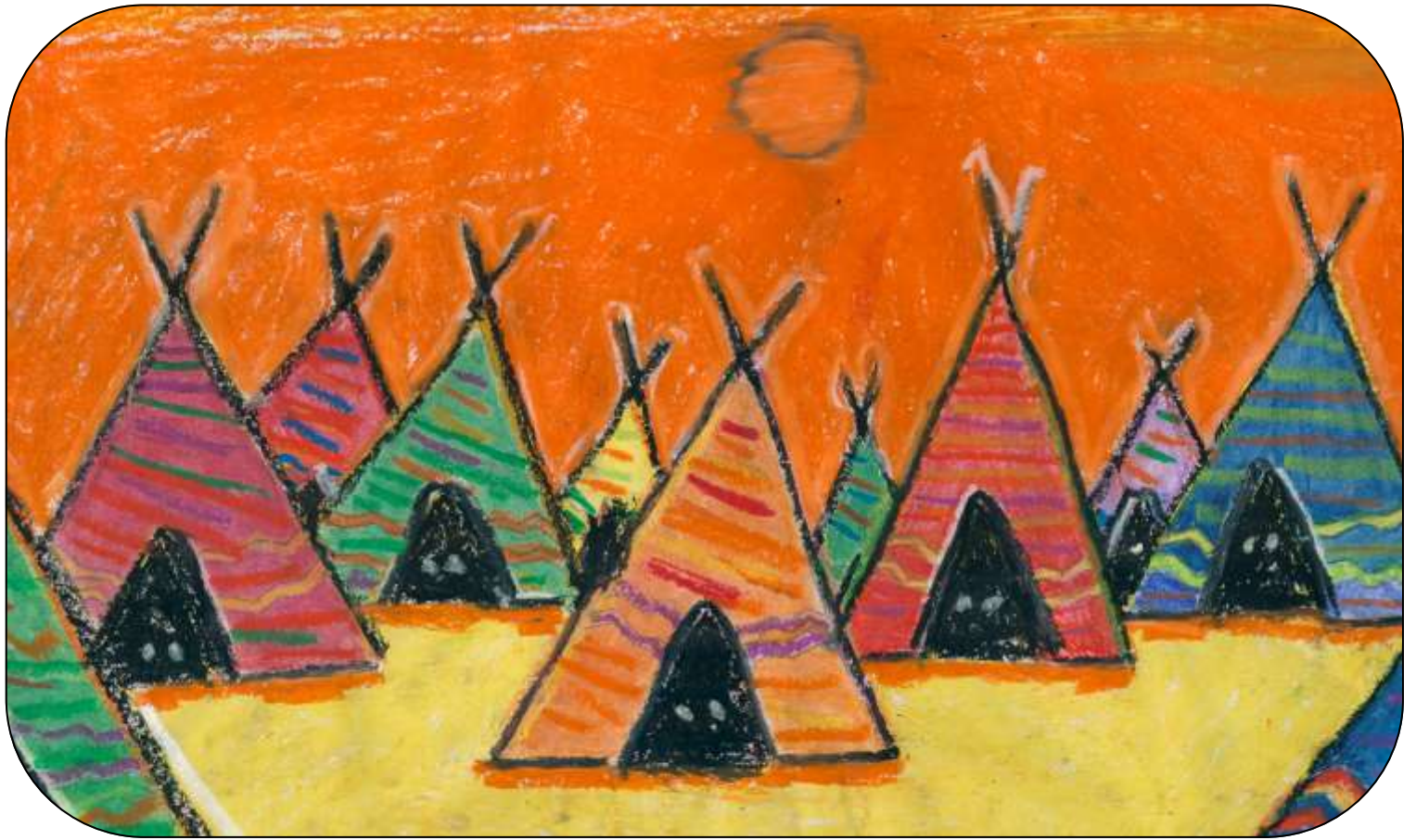
lacks status compared with other medical specialities. The lack of priority and initiative has contributed to a paucity of effort to develop better models of preventive mental health. However, neurodevelopmental disorders may be at the core of the problem with the increased risk of associated other psychiatric co morbidities and conversely major mental illness have been reconceptualised as neurodevelopmental disorders. Early detection and intervention for these is as important as any other medical problem (Durlak, J. A., & Wells, A. M. 1997) and intervention studies are showing high levels of cost effectiveness (Dossetor, 2013). It calls for increased education and awareness regarding disorders of the development of the brain and mind. I feel that the key to this is understanding the neurodevelopmental processes and skills in developing capacities of human reciprocity.

Early and middle childhood is the most important time and stage of the development of the brain and the mind, and where building resilience and hopefulness **is possible**. **As they say ‘our children are our future’**. The political and community interest in preventive mental health is reaching a critical time. I feel the prevention of mental disorders and the promotion of emotional wellbeing and resilience may be the most important area of epidemiology for the future of mankind. The clinical and research partnership between paediatrics and mental health is a critical building block and the time to act is now. Problems of neurodevelopment may have been the Cinderella of health and mental health, but I suspect that helping these children provides the key to unlocking our understanding of developmental processes of the brain and mind more broadly.

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Meet Jessica: A road trip around NSW

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Meet Jessica Report

The School-Link team at the Children's Hospital at Westmead travelled across NSW to engage a discussion about the mental health of children and adolescents with Intellectual and Developmental Disabilities (IDD) in mainstream settings.

In 2014, there were 8000 students in the public school system in NSW with a confirmed diagnosis of Autism Spectrum Disorder (ASD) and approximately 15,000 students with an intellectual disability (DEC, 2014). Previous research has suggested that up to 40.7% of these children and young people experience mental health problems or disorders (Einfeld and Tonge, 2006).

An increasing number of students with a disability are attending regular classes in mainstream school settings. The Australian Bureau of Statistics (ABS) report that 65.9% of children with a disability attended regular classes in mainstream schools, compared to 24.3% who attend special classes within mainstream schools and 9.9% who attend special schools. These figures are consistent for students with mild intellectual disability and/or ASD.

This has seen a growing need to modify existing programs and environments to include all students from a variety of disabilities and mental health capacities. The School-Link team from the Children's Hospital at

Westmead presented a two hour workshop in every Local Health District (LHD) across NSW in term 3 & 4 of 2015. This included a short animation written in collaboration with the Department of Education, NSW Public Schools and the Statewide Behaviour Intervention Service, Clinical Innovation and Governance, Ageing Disability and Home Care, Department of Family and Community Services, about a student in a school setting. The animation titled meet Jessica was then used to initiate further discussion, reflection and learning amongst participants. The animation was supported by a PowerPoint presentation and activities.

The CHW animation workshop aimed to further assist primary and secondary school staff:

- to understand that students with an intellectual or developmental disability (IDD) are more likely have additional mental health problems and challenging behaviours.
- to identify students within their classroom who may need help (what to notice).
- to build on existing strategies for supporting students in the classroom.
- to know where to direct students who need additional assistance.



Bandaged Bear on the road in Broken Hill, NSW



The Three Sisters, Blue Mountains, NSW

“Amazing collaboration and shared learning processes with participants”

The workshop and resources were presented as a train the trainer session to enable participants to replicate the session back in their schools and workplace settings to share the awareness of mental health and IDD for children and adolescents. The resource pack is now available on the School-Link website www.schoollink.chw.edu.au.

Key Outcomes

Key outcomes of the animation road show included 1200 registrations from participants across NSW comprising of:

- 28 workshops across all NSW Local Health Districts
- 380 schools
- 50 NGOs
- Several ADHC and CAMHS staff
- A participant informed package that discusses mental health and intellectual and developmental disability of children and young people
- 2016 cross sector collaboration mental health matters award recipient

ent as awarded by the Mental Health Association of NSW

There were some tremendous lessons learnt from organising and implementing such a detailed road show. There was amazing collaboration and shared learning processes both logistically and with participants.

- Various levels of knowledge amongst participants
- Scarcity of services in regional and remote areas
- NSW is a beautiful and diverse state

Future Directions

Now that the presentation and script and implementation resources are available, we hope that there will be an exponential impact in the number of people who will see the Meet Jessica animation and use the pack-



Street Art in Lismore, NSW

age for useful discussion with colleagues.

The animation presentation and accompanying resources are now available at www.schoollink.chw.edu.au/workshop-resources/

Acknowledgements:

The animation and road show was a collaborative process that took much effort from many agencies and colleagues, the Children's Hospital at Westmead School-Link team would like to thank:

- Statewide Behaviour Intervention Service, Clinical Innovation and Governance, Ageing Disability and Home Care, Department of Family and Communities
- NSW Department of Education
- NSW School-Link Coordinators
- Workshop Venues
- MHCYP



Bandaged Bear on the road to Gundagai, canola fields, NSW



Bandaged Bear with Jodie Caruana, School-Link Coordinator, Blast Furnace Park, Lithgow NSW



Bandaged Bear at the Big Golden Guitar in Tamworth NSW

The beautiful artworks in this journal are taken from the participants of the **Operation Art project** at the Children's Hospital at Westmead. You can find out more at <https://www.artsunit.nsw.edu.au/visual-arts/operation-art-2014>

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