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

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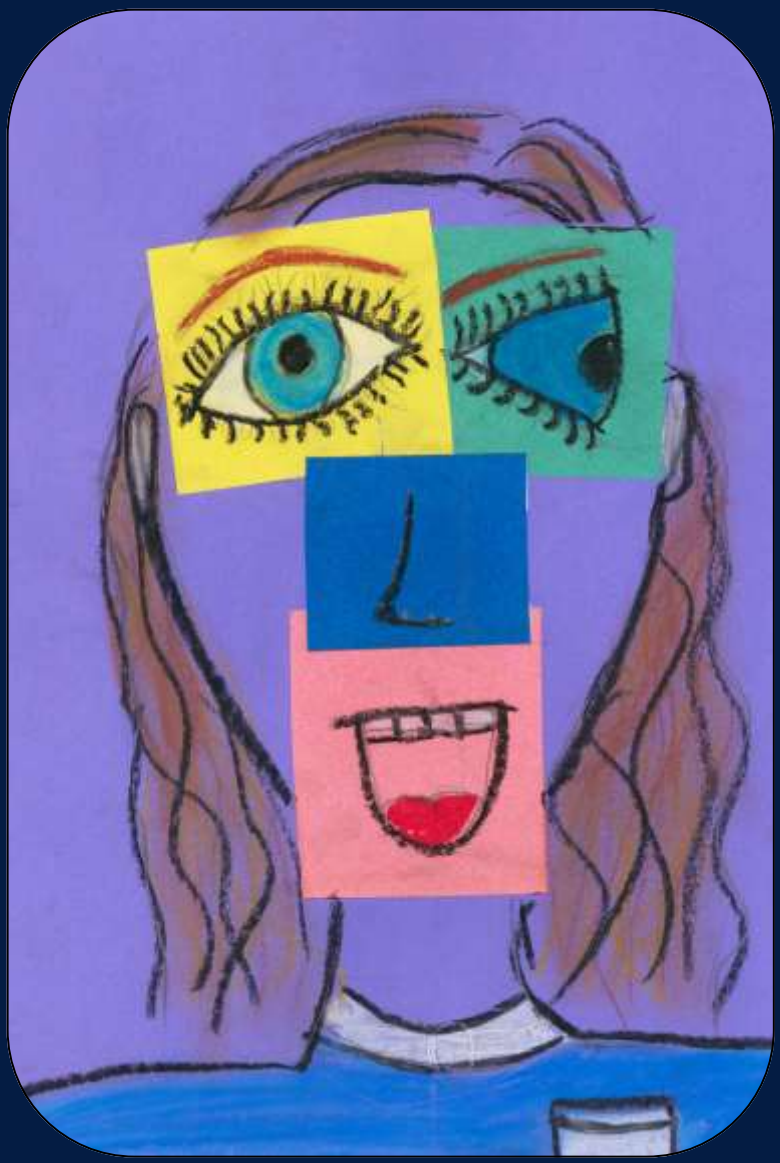

School-Link Initiative, Department of Psychological Medicine, The Children's Hospital at Westmead

Contents

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 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 Practice and Service Innovation team of The Benevolent Society, and the 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.*

Editorial

Jodie Caruana

CHW School-Link Coordinator
The Children's Hospital at Westmead

www.schoollink.chw.edu.au

Dear subscribers,

Welcome to the issue 1 for 2018.

Thankyou to those who completed our School-Link survey earlier this year. We had over 100 people complete the survey which has helped inform the professional development activities that we are currently planning, in conjunction with our partners in education and disability. To read more about the results of our survey please see page 12.

Dr Deepa Singhal completed a paediatric psychiatry fellowship within our Department of Psychological Medicine here at CHW, and along with psychiatrist Dr David Dossetor, they reflect on their 25 child cases of behavioural phenotypes, providing us with their valuable clinical insights.

Did you know that there are almost one million people in NSW who provide unpaid care and support to family members or friends with a disability or other condition? Our interview with Barbara Lewis, Manager of the Carer Support Service at Royal Northshore Hospital highlights the important support available for carers and her career journey (pg 22).

Judy Longworth provides a detailed description of the medication guanfacine and compares this to clonidine in treating ADHD (pg 24). If you are looking for a summary of the latest developments concerning mental health and intellectual disability, look no further than David Dossetor's recap on presentations from the European Association for Mental Health in Intellectual Disability (pg 28) or our 2018 research article reading list (pg 17).

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

Happy reading!

Jodie Caruana

School-Link Coordinator
The Children's Hospital at Westmead.

Behavioural phenotypes: The changing role of the neurodevelopmental psychiatrist; genetic simplification only serves to illuminate complexity.

Dr Deepa Singhal and Associate Professor David Dossetor
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The authors reflect on the importance of understanding behavioural phenotypes based on the first author's six month fellowship in dual training in Child Psychiatry and Paediatrics, in the Developmental Neuropsychiatry Team in the Department of Psychological Medicine at the Children's Hospital at Westmead.

The team at the Children's Hospital at Westmead provides a tertiary/quaternary service for psychiatric disturbance in the developmental context of Autism and/or Intellectual Disability. The team provides opinions to paediatricians and child psychiatrists who continue to case manage the referral, as a measure of their special interest, with priority given to the paediatricians of the Children's Hospital at Westmead.

Behavioural problems first need assessment and treatment by disability services, now funded through the National Disability Insurance Scheme (NDIS), which now means that behavioural support services are generally not provided until an annual review of the NDIS package has recognised the need for intensive and multidisciplinary support or a review is requested mid-plan. Conversely, there are many cases that have failed to improve despite input from behaviour support, psychology, speech therapy and occupational therapy. In those with more severe disturbance, a psychiatric assessment is required, and often these cases also need child mental health skills in family and relationship assessment. This is a vexed area, as while there is clinical consensus on the prevalence of multiple psychiatric diagnoses in these cases, the lack of communication skills in the young person can lead to diagnostic overshadowing, attributing disturbance to the developmental disability, and difficulties in reliability of diagnosis. However, one hears of many cases with clear psychiatric disorder being refused a psychiatric service, which is unethical, immoral and illegal under the Disabilities Inclusion Act, 2014 (https://www.adhc.nsw.gov.au/about_us/legislation_agreements_partnerships/nsw_disability_inclusion_act) and Disability Discrimination Act, 1992 (http://www.pwd.org.au/student-section/key-pieces-of-legislation.html#dda1992) .

Although sometimes the behaviours relate to emerging mental health issues, sometimes they are related to physical health issues, and need close collaboration,

and even to be led by a general paediatric, neurology or other subspecialty paediatric service. At times, problems arise related to a long standing behavioural pattern getting worse with onset of puberty and growth spurts. Regardless of the cause, these issues have enormous impact on the parents and family well-being. Often we need to support parents to navigate the NDIS and sometimes even the empathic appreciation of the adverse predicament can have a huge effect on families' well-being and capacity for survival. In the presence of longstanding severe disturbance, families really value even moderate improvements, as it can make continuing to care for their child a bit longer possible, e.g. in helping sleep disturbance or reducing the severity and frequency of violent behaviours.

Paediatric training and exposure to developmental paediatrics confirmed an interest in Autism and intellectual disability for the first author; Dr Singhal. However this term's experience has determined her future subspecialty career pathway in developmental neuropsychiatry. During the term, we came across a series of cases with behavioural phenotypes, some were textbook descriptions and some were extremely rare with their own unique challenges. This increased Dr Singhal's curiosity in the concept of behavioural phenotypes and describing the experience. The definition of behavioural phenotypes can be described as "behaviour, including cognitive processes and social interaction style that is consistently associated with, and specific to, a syndrome which has a chromosomal or genetic aetiology" (Skuse, 2000). Such syndrome-based patterns of behaviour provide insight to the biological underpinning of the human behaviour. How the genes influence protein production, proteins influence the neurophysiology, and neurophysiology influences the behaviour in a trickle down sort of a chain reaction. This sequence is made more complex by the growth of epigenetics, ie. attempts to understand what turns a gene on and off in the course of development and the environmental contributors to epigenetics. As a result, study of these minority populations of behavioural phenotypes takes one to the cutting edge of neuropsychiatry and the gene revolution.

In a 6 month period we saw around 25 cases with different behavioural phenotypes. With the rising awareness of the severity of psychiatric disorder in young people with neurodevelopmental disorder, any of these can present to a mainstream child and adolescent psychiatry service. Conversely, the speed of development in genetics leads to identifying new genetic disorders and new behavioural phenotypes at such a quick rate that it is a common event to be referred a new disorder that we haven't previously heard of.

"Families really value even moderate improvements, as it can make continuing to care for their child a bit longer possible"

While some conditions, such as Fragile X, Prader Willi, tuberose sclerosis or complex epilepsy, may have the benefit of specialist syndrome-based clinics, often supported by a parent group, such a notion for all behavioural phenotypes in the resource-poor public mental health system is fanciful. However, equity of access means that those with ASD/ID need 3-4 times greater access than a mainstream population. Accordingly, any child or adolescent mental health clinician may need to be prepared to consult to the mental health problems of a well-established or a newly recognised behavioural phenotype. No psychiatrist can keep up to date with this rate of change, and a search on Google before seeing a new behavioural phenotype can quickly arm you with a global case series of health and mental health vulnerabilities. Although such special knowledge may make a clinician feel disarmed, especially if the family come bearing several of the latest scientific articles, as psychiatrists, we bring a range of skills to formulate and make diagnostic sense of severe mental health scenarios.

In this article we aim to provide some clinical insights, partly from newer scientific reports from developmental neuropsychiatry and partly based on some case examples. Of the 25 behavioural phenotype cases we managed over the six months, some are comparatively common ones that all mental health clinicians should be aware of, such as:

- Fragile X (CGG repeats in X Chromosome, most common inherited cause of ID) (www.fragilex.org.au)
- Down syndrome (trisomy 21), (a case presented with developmental decline secondary to Catatonia due to Major Depression (JMHCAIDD, 2017, 8 (1): 4-10),
- Noonan's syndrome ('male Turner's Syndrome') with autosomal dominant genetic defect (mostly causing mutations in the Ras/mitogen activated protein kinase),
- Velocardiofacial sydrome (22q11.2 deletion) associated with marked increased rate of psychosis in adolescence/adulthood predicted by cognitive decline; also increased ASD, anxiety and ADHD in childhood, (JMHCAIDD, 2014, 5(2): 4-7)

“All these conditions have raised rates of anxiety and ADHD”

- Williams syndrome (deletion on chromosome 7q), cocktail party chatter, sound sensitivity and visual-spatial problems, and provides models of different types of anxiety eg thunder storms vs fear of heights.
- Fetal Alcohol Spectrum Disorder, complex uneven developmental problems with major self-regulation problems and ODD and major depression in adolescence. (School-link Newsletter 2012. 3(2): 2-5.)

All these conditions have raised rates of anxiety and ADHD. Amongst those that are less common syndromes and scenarios were:

- Kleefstra syndrome (intellectual disability, limited or absent speech, hypotonia, microcephaly, characteristic facies and childhood obesity),
- Sanfilippo syndrome or Mucopolysacharidosis type III, a lysosomal storage disease that may present with severe hyperactivity in the context of a slow developmental fatal decline
- 18p deletion (intellectual disability, behavioural problems and distinctive facial features) (see Euan’s story in JMHCAIDD, 2017, 8 (2))
- 16p11.2 deletion (may have mild ID, language delay, ASD and motor impairments)
- Merosin deficient muscular dystrophy (a severe congenital muscular dystrophy; can lead to problems with contractures, sleeping and breathing and feeding)
- Landau-Kleffner syndrome (rare complex epilepsy, progressive loss of speech, ADHD, often with severe intellectual disability); could night time epilepsy in a teen that is difficult to assess with EEG be causing sleep disturbance that generates other major psychiatric disturbance?
- Kluver-Bucy syndrome (neuropsychiatric rather that genetic): compulsive eating, hypersexuality, hyperorality, visual agnosia and docility from bilateral lesions of medial temporal lobe and amygdala
- New behavioural challenges in post stereotactic surgery for complex epilepsy, with resultant lobectomy, hemispherectomy, corpus callosectomy mostly in context pre-surgical complex developmental disorders.

Below we present some brief case summaries with learning points.

A case that confirms that describing complex mental health co-morbidity has a value.

A 13 year old apparently compliant boy presented with mild-moderate learning difficulty, autistic rigidity, behavioural issues and major attentional problems. He was a day dreamer (not due to absence seizure). He appeared to be lacking motivation, yet showed significant planning skills in his antisocial behaviour eg stealing from his grandmother, significant violence to her and outrageous lying eg late for school because ‘his aunt had died’. He also had some subtle unusual facial and physical features. He lived with his grandmother, who was his main stable carer. We diagnosed and treated his ADHD with a range of medications, but he continued to be antisocial despite a good care environment. His mother had a similar history of school problems and strange asocial and impulsive behaviours, for example she still disappears for six months at a time without warning. We also treated his mother for her ADHD to try and help her and improve her influence on him. We organised a genetic microarray and he was found to have a 16p11.2 microdeletion. The gene testing helped clinicians and custodial grandparent to have an explanation of the features of his presentation. The genetic testing and behavioural phenotyping provided an explanation on “why he was the way he was.” Knowing the genetic cause of his presentation had a huge positive impact on family and they “did not need to feel guilty or feel they were doing something wrong”. Further, the behavioural phenotype was characteristic of the above mixture of learning problems, ADHD, and ASD features and oppositional behaviour. This affirmed that the multidimensional psychiatric diagnosis was an accurate description. Nonetheless he continued to cause problems and some sexual inappropriate behaviour led to his expulsion from school. His uncle subsequently provided him with a positive relationship, daytime supervision and sheltered employment. His grandmother benefitted from toughening up on her behavioural management skills with good effect, reducing the need for some of his medications. This was a good example of the positive impact of a behavioural phenotype, adding meaning and explanation to behaviour that didn’t fit the socio-cultural environment.

A rare complexity:

FLVCR1 gene mutation is autosomal recessive, one of five reported cases in the world literature. The presenting six year old girl had severe intellectual disability, was still learning to sit up, unable to feed self or otherwise fend for self, growth retardation (10kgm); retinitis pigmentosa and blindness; peripheral neuropathy and

inability to feel pain; sensory ataxia from degeneration of posterior columns of spinal cord; scoliosis, camptodactyly, achalasia and gastrointestinal dysmotility, needing supplementary feeding by a gastric peg, and sensitivity to most foods causing frequent diarrhoea. She was referred because of self-injury of biting her fingers, leading to loss of her teeth, largely managed with arm splints. She also had sound sensitivity leading to waking at night. She was managed by five teams: general paediatrics, neurology, gastroenterology, brain rehabilitation and palliative care. She is loved by remarkable parents who give so much attention. She communicates needs with blowing raspberries, responds to sensory input with cuddles and music, and has a vocabulary of over 100 words and can make choices. Psychotropic medication may still have a role in sleep management (clonidine) and could contribute to reducing self-injury (naltrexone).

A rare clinical predicament led to a new approach to medical decision making:

A nine year old girl with PCDH 19 mutation, a rare (approximately 150 cases identified but with many different identified mutations and deletions of this gene on X chromosome at q22.1) congenital complex epileptic condition in girls with developmental delay and behavioural difficulties including autism, aggression, stripping and self-injury. The patient was severely intellectually retarded, with limited language, mainly echolalia. She needed multiple admissions for uncontrolled complex seizures/status. She had tried multiple antiepileptic medications singly and in combinations (including newer treatments such as ganaloxone, rufinamide and cannabinoids) and psychotropic medications (including stimulants, major tranquilisers, mood stabilisers and melatonin) to help with her intense agitation and sleep disturbance. Her mother was very involved in her care and has been to the bi-annual syndrome specific conferences in the USA. The mother wished to withdraw the girl from all anticonvulsants, because they appeared ineffective and she was concerned they made her behaviour worse. Her neurologist was concerned there was an increased risk of sudden death in epilepsy on no anticonvulsants. This difference of opinion in a clinically unusual situation led to a multidisciplinary review, led by the department of medical ethics. This enabled the consideration of opposing legal concerns of informed consent versus clinical responsibility to act in the best interests of the child. Balancing the issues of quality of life for the child, versus the risk of no anticonvulsant led to an agreement to treat seizures only when needed with Midazolam and has been associated over time with an improvement in the frequency and severity of the seizures but not the behaviour disturbance.

Both hormones and pharmacology have a psychological benefit in Prader Willi Syndrome (PWS)?

A 15 year boy with PWS , mild intellectual disability, ADHD and anxiety was having difficulty in mainstream education, and was troubled by explosiveness in school and school refusal. He also had social disinhibition and social immaturity, rigidity and perseveration. A change of school routine or teacher could make him so distressed that he would leave his class and could not be persuaded to return. His diet was managed actively with restricted access to food, not just for him but also his younger brother who had Sotos' syndrome. He was helped by moving to a support class, where he was able to show greater relative competence and confidence. He wasn't helped by two different SSRIs, clonidine made him sleepy, both risperidone and quetiapine were helpful but led to problems with weight gain. He got significant benefit from a small dose of propranolol of 10mg, but higher doses made him feel dizzy. His weight and appetite has been most significantly been helped by growth hormone injections but now he has stopped growing in height, he is now only entitled to growth hormone on a private script of $800/month. He is due to start testosterone injections for bone health and density.

Could this complex case be Smith Magenis syndrome?

A 13 year boy presented with early onset of severe violence in context of brain damage of prematurity, bor-

derline intellectual disability, ASD and difficult to treat complex partial epilepsy. He had a psychiatric inpatient admission for acute suicidality and violence at 10 years of age, but because of his age he was 'not entitled' to psychiatric service follow up! He presented with problems of anger, mood regulation, and auditory and visual hallucinations which appeared to be mood related. He would get quite paranoid and misinterpret social situations. He also got flashbacks of traumatic experiences. He had a preoccupation with violence, despite his parents' efforts to modify his media access. His mother has Aspergers and a strong maternal family history of bipolar disorder and actual suicide. There was no contact with father who had history of ADHD, gambling and substance abuse. His behavioural phenotype, facial appearance and his self-injury of pulling off his toe nails to eat them raised a question of Smith-Magenis syndrome. Initial gene probe was negative, but we are checking for less frequent gene subtypes. His management has stabilised with excellent parenting skills and behaviour management from a school for emotional disturbance. NDIS has funded occupational therapy, emotion-based social learning, socialisation through 'Jedi training camp' and learning the piano. Medication for ADHD, anxiety, sleep disorder and mood instability included: mirtazapine at night, carbamazepine, clonidine day and night, risperidone and PRN quetiapine. Working with cases of Smith Magenis syndrome emphasises the importance of behavioural management plus active multimodal management approaches to create the art of possible.

A child psychiatrist/mental health clinician should be familiar with the most common behavioural phenotypes, but here are some of valuable specific characteristic clinical features that have been described by researchers in recent years.

- 15% of people with Down syndrome have autism, which makes them a challenge to care for.
- As young people with Fragile X become older, their developmental trajectory slows and they have an increased risk of being diagnosed with autism; carriers can have Tremor/Ataxia syndrome with memory problems.
- People with Prader Willi syndrome have problems of shifting attention which leads to increased aggression, and the need for careful warning processes for change of routine.
- Any neurodevelopmental disorder increases your risk of catatonia.
- Young people with Smith Magenis syndrome have increased rates of autism and autistic spectrum features, but also have a strong attachment to their primary carer and separation anxiety contributing to greater violence to parents than other adults.
- Self-injury in people with Cornelia de Lange's syndrome is usually caused by the inability to express pain, e.g. from gastro-oesophageal reflux, dental/sinus pain. (A frequent challenge in those with non-verbal Autism).
- There is an awareness of high rates of ADHD in all people with neurodevelopmental disorders, but Developmental Coordination Disorder has less attention paid to it, but can add increased functional disability and dependency especially for independence skills.
- Angelman's syndrome (Happy Puppet Syndrome) includes unusual laughter which is exaggerated by the environment, and seeking of attention and affection especially in the presence of adults. Genetic disposition provides survival advantage to illicit care and can be modified by change in environment.
- In PKU (Phenylketonuria) early intervention with a phenyl alanine diet prevents intellectual disability, but later childhood/teens levels of phenylalanine can contribute to features of ADHD. Phenylalanine in the diet of a mother with PKU can also cause problems for a genetically normal fetus.
- Behavioural Phenotypes illustrates different types of self-injury with different genetic disorders, such as eating lips in Lesch Nyhan syndrome (related to receptor hypersensitivity); Cornelia De-Lange syndrome (pain related to gastro-oesophageal reflux); Smith Magenis syndrome (putting objects in orifices) or tearing off toe nails. One still has to look for psychiatric co-morbidity, for example unrecognized anxiety or depression e.g. in Fragile X.

"A child psychiatrist/mental health clinician should be familiar with the most common behavioural phenotypes"

Will the genetic revolution make psychiatric disorder redundant?

These scenarios and cases provide diagnostic, management, medicolegal and ethical learning points. They illustrate some of the complex co-morbidities and aetiologies. New genetics syndromes present new or unique clinical situations, some of which require novel approaches. In the context of such novelty psychiatrists/mental health clinicians bring a range of integrative skills to diagnosis and formulation that are helpful and insightful. This includes medical/psychiatric

knowledge, family, parental and relationship assessment skills and attention to co-morbidity, plus psychopharmacological experience. These cases, while benefitting from genetic research, still depend on traditional approaches to child and family assessment. Behavioural Phenotypes have become an established part of child neuropsychiatry but recent developments provide more detailed understanding of the clinical aetiologies, often for different symptoms in the same genetic disorder and appreciating greater individual differences.

Some argue that the new Diagnostic and Statistical Manual (DSM), although increasingly reliable, lacks biological validity. Some are quick to say that the DSM will soon be redundant, to be replaced by a 'disruptive technology' research approach of the Research Domain of Criteria (RDoC) a project from the US National Institute of Mental Health, based on genetic/biometric data (https://www.nimh.nih.gov/research-priorities/rdoc/index.shtml).

In 2013, NIMH director, Thomas Insel, published a blog post critical of the DSM methodology and highlighting the improvement offered by the RDoC project. The RDoC approach is based on the biology as well as the symptoms and not be constrained by the current DSM categories. "Mental disorders are biological disorders involving brain circuits that implicate specific domains of cognition, emotion, or behaviour. Each level of analysis needs to be understood across a dimension of function. Mapping the cognitive, circuit, and genetic aspects of mental disorders will yield new and better targets for treatment." RDoC dimensional **psychological constructs (or concepts),** relevant to human behaviour and mental disorders, are measured using multiple methodologies and as studied within the essential contexts of developmental trajectories and environmental influences. Constructs are in turn grouped into higher-level **domains of human behaviour and functioning** that reflect contemporary knowledge about major systems of emotion, cognition, motivation, and social behaviour. The major RDoC research **domains/constructs**:

- **Negative Valence Systems**

Fear, Anxiety, Loss, Frustrated, Non-reward

- **Positive Valence Systems**

Reward learning, Reward valuation, Habits

- **Cognitive Systems**

Attention, Perception, Declarative Memory, Working Memory, Cognitive control

- **Systems for Social Processes**

Attachment formation, Social Communication, Perception of self, Perception of others

- **Arousal/Modulatory Systems**

Arousal, Circadian rhythm, Sleep and wakefulness

The domains are tentative: "It is important to emphasize that these particular domains and constructs are simply starting points that are not definitive or set in concrete. Methods used to investigate and understand constructs (termed "**units of analysis**") can include molecules, genes, cells, neuro-circuits and behaviours, self-reports and paradigms." In these terms schizophrenia can be seen as an information processing disorder, prioritising the importance of motivational, cognitive and social dysfunction. So far, there is no indication whether these approaches will be helpful to anyone.

Remember the limitations to genetic explanations

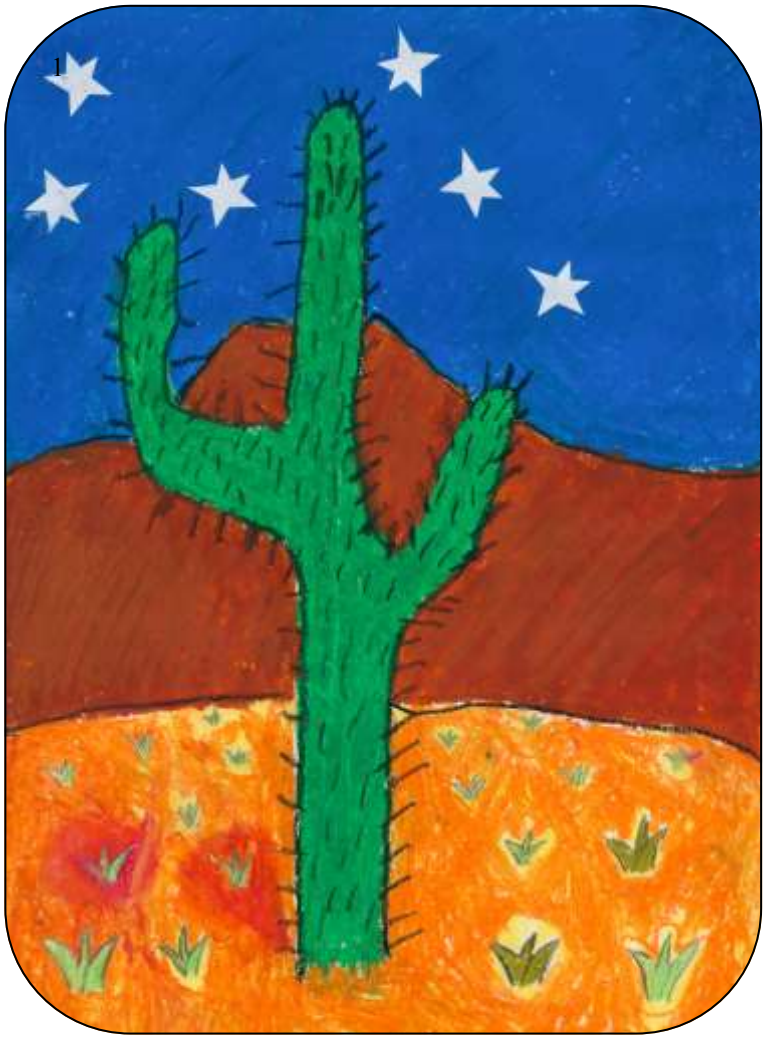
6-Pyruvoyltetrahydropterin Synthase *(6-PTS) Deficiency* is one rare behavioural phenotype series managed at the Children's Hospital. *This* autosomal recessive disorder causes malignant hyperphenylalaninemia due to tetrahydrobiopterin deficiency. This enzyme is necessary for the creation of Serotonin, Dopamine and Noradrenaline, which are arguably the 3 neurotransmitters involved in all psychiatric disorders. Commonly reported symptoms are truncal and appendiclar hypertonia, bradykinesia, cogwheel rigidity, generalised dystonia, and marked diurnal fluctuation. They become confined to bed, immobile and unable to communicate. Other reported clinical features include difficulty in swallowing, oculogyric crises somnolence, irritability, hyperthermia,
and seizures. Chorea, athetosis, hypersalivation and sudden death have also been reported. Treatment involves substitution with neurotransmitter precursors (levodopa, 5-hydroxytryptophan), monoamine oxidase inhibitors, and tetrahydrobiopterin. Response to treatment is remarkable, with patients resuming normal intellect and daily competences, although long-term and functional outcome is variable and remains uncertain.

One case from the series was referred to the Developmental Psychiatry Team, because of the violent behaviour in the context of moderate intellectual disability. Lengthy assessment and treatment concluded that the behavioural phenotype was not the cause of the violence but that is was due to the deficits of behaviour management, style of parenting and marital problems. Accordingly, even in context of an overwhelming biological factor, environmental factors can be the primary determinant of psychiatric disorder.

Could we be throwing the baby out with the bathwater? Is this rush of enthusiasm for genetic biases and explanations of 'life's rich tapestry' instead of the patience needed to build an understanding of the family context, leading paediatricians to be less inclined to consider family relationships, and parental mental health in their comprehensive clinical assessments? Even worse, does this biological theoretical practice bias, at the risk of neglect of the social context, lead in some cases to excessive medicalisation of dysfunction or even factitious disorder and potentially medical child abuse?

Conclusion

The cases presented confirm the value of the current diagnostic system. Indeed our capacities to be helpful confirms its predictive validity. The tried and tested model of case series of behavioural phenotypes illustrates the importance of applying clinical descriptive research. Currently, child psychiatry services are overwhelmed, with a shortage of, and inadequate training and recruiting of, psychiatrists. At the same time, political emphasis is on client-led adult recovery services. These changes indicate a downgrading of the importance of science and medicine in Mental Health. The study of psychiatric disorder has been a revolution of understanding and helping people with such disorders and enabling them to return to the mainstream of society. In particular, people are seldom institutionalised due to the advances of psychiatric treatment. Scientific methods include the progressive delineation of subtypes and validity of psychiatric disorder over time,



> “Both paediatrics and child mental health clinicians need to continue to collaborate”

just as in any medical specialty. There is an essential need for further research into these disorders which can be seen as central importance to the future of human flourishment and quality of life. Disruptive research attempts should not be the excuse to lower its priority in health. This article confirms that genetics provide important additional information to the human predicament. However, such science progressively moulds our clinical understanding, rather substituting it.

We would suggest that there needs to be a greater appreciation of the validity and importance of neuropsychiatric disorder and its importance to helping our patients. Take for example Tuberose Sclerosis which is a common genetic disorder appreciated by all paediatricians. On top of the physical health problems, Tuberose Sclerosis Neuropsychiatric Disorder occurs in 90%, most of which are not identified by routine clinical consultations. Petrus DeVries and colleagues (www.tscinternational.org/) have identified, using the ‘TAND checklist’ (TS associated Neuropsychiatric Disorder), that these neuropsychiatric disorders are only assessed or treated in 20%. The ‘TAND checklist’ developmental assessment include assessment of key developmental milestones, and common, key psychological symptoms e.g. anxiety, depressed moods, mood swings, aggressive outbursts, tantrums, self-injury, language problems, repetitive behaviours, rigidity/inflexibility, over/hyperactivity, concentration problems, restlessness, impulsivity, problems of eating or sleeping. The common neuropsychiatric disorders found are: ASD (25-50%), ADHD (30-50%), Anxiety Disorder (30-60%), Depressive Disorder, Obsessive Disorder and Psychotic Disorder.

This routine assessment of young people with Tuberose Sclerosis assesses for intellectual level and learning problems in reading, writing, spelling and mathematics. It identifies neuropsychological problems in memory, attention, dual tasking, visuo-spatial skills, executive skills in planning, organising, flexible thinking, and orientation for time, place and person. These dimensions should be considered in the context of the level of family stress and relationships. They argue that the ‘TAND checklist’ should be part of routine management for every case.

Such a multidimensional neuropsychiatric approach is a model that is applicable for any brain-based or genetic behavioural phenotype. Accordingly, both paediatrics and child mental health clinicians need to continue to collaborate, follow the growth of skills and knowledge in neuropsychiatric disorder, and work to make clinically valid multidimensional approaches become mainstream paediatrics.

Additional reading on behavioural phenotypes from the CHW School-Link Newsletter and the Journal for the mental health of children and adolescents with intellectual and developmental disabilities.

Dossetor D, Behavioural Phenotypes: A Window into the Mechanisms of the Mind. CHW School-link Newsletter 2011; 2(1): 2-4.

Dossetor D, Conference Review: Translating Genetics to Phenotype: the Society for the Study for Behavioural Phenotypes Research Symposium. CHW School-link Newsletter 2012 3(1): 10-11.

Skuse D. Behavioural Phenotypes: what do they teach us? Arch Dis Child 2000; 82: 222–225.

Wurth P. Report on the Society for the Study of Behavioural Phenotypes Conference. CHW School-link Newsletter 2013; 493-4: 8-10.

Wurth P. Notes from the 19th Society for the Study of Behavioural Phenotypes (SSBP) International Research Symposium. JMHCAIDD. 2016; 7(3-4):14-20.

Wurth P. Society for the Study of Behavioural Phenotypes (SSBP) 20th International Research Symposium. Linked here to the School-Link website. www.schoollink.chw.edu.au

Children's Hospital Westmead School-Link Satisfaction Survey 2017

Results compiled by Kim Eisler

The Children's Hospital Westmead School-Link (CHW-SL) Satisfaction Survey was distributed by email to all contacts on the CHW-SL Data Base in December 22 2017. It included 12 questions with several focusing on the professional development needs and preferences of our colleagues. Other questions sought to understand the effectiveness of the CHW-SL Journal in providing information and education to those working with children and young people with an Intellectual or Developmental Disability.

The survey was completed by 109 respondents. Individual comments were contributed by 67 participants. These were overwhelmingly positive or as one responder said "I think the journal is awesome. I enjoy reading it and it is a great resource."

The results of the Survey are summarised below.

Question 1: What state are you from?

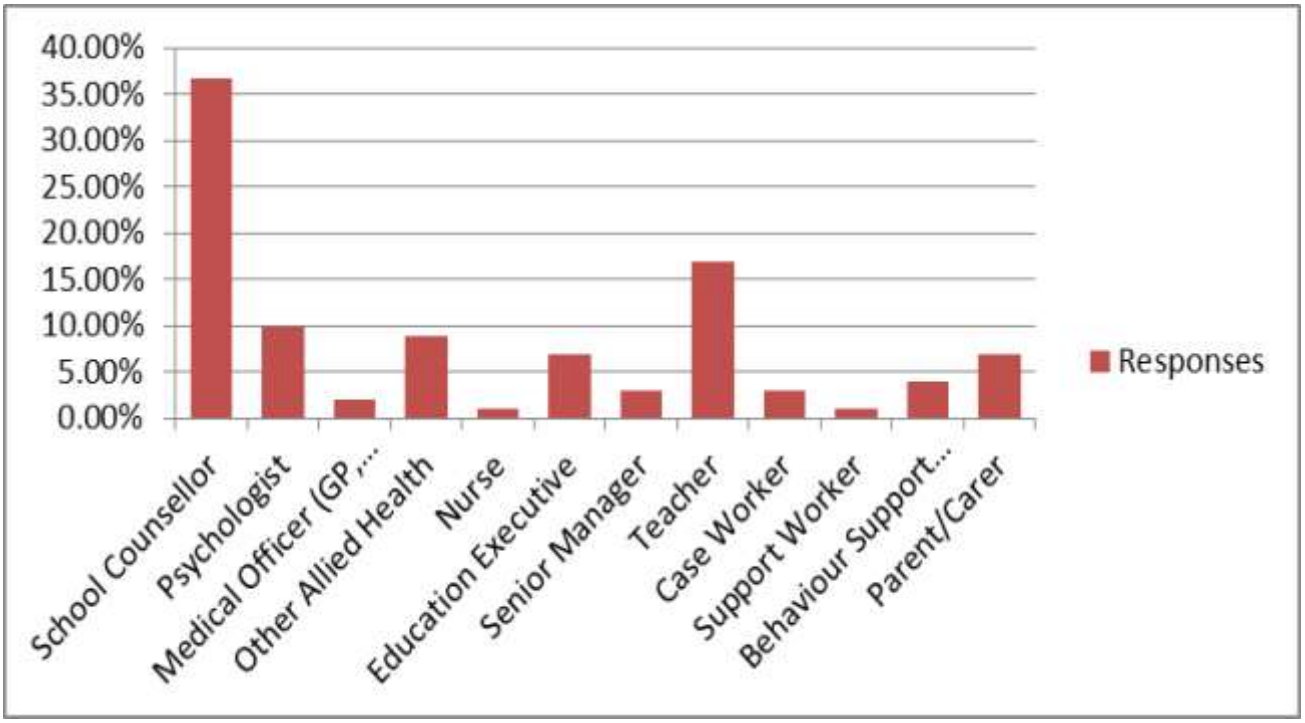
There were 103 respondents to this question and they all indicated that they were from NSW. Six individuals skipped this question.

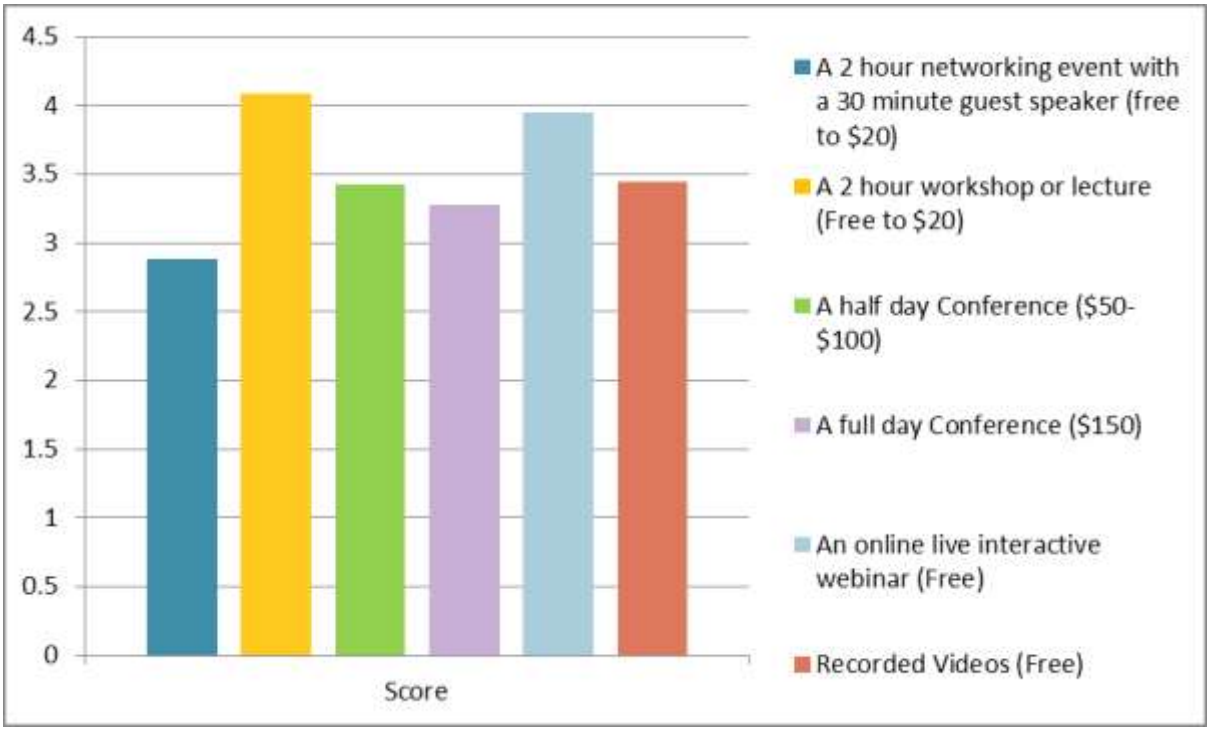
Question 2: What is your occupation?

As indicated in the graph below School Counsellors made up the largest group of respondents with 36.63% of the total 101 individuals who answered this question. Teachers comprised the next largest group at 16.83%, followed by Psychologists, 9.9%, and allied health professionals, 8.91%. A significant number of parents and carers completed the survey, 6.93%, and Education Executives were 6.93% of respondents. Representatives from other occupations included behaviour support practitioners, nurses, medical officers, senior managers, case and support workers. Eight people skipped this question.

Question 3: Please rate the following professional development (PD) activities in order of preference from 1-6?

A total of 108 individuals responded to this question and indicated their preferred activity was a 2 hour workshop or lecture. This was closely followed by online live interactive webinars. Those surveyed also had a strong interest in recorded videos and a half-day conference. Attendance at a networking event with a guest speaker was the least preferred.



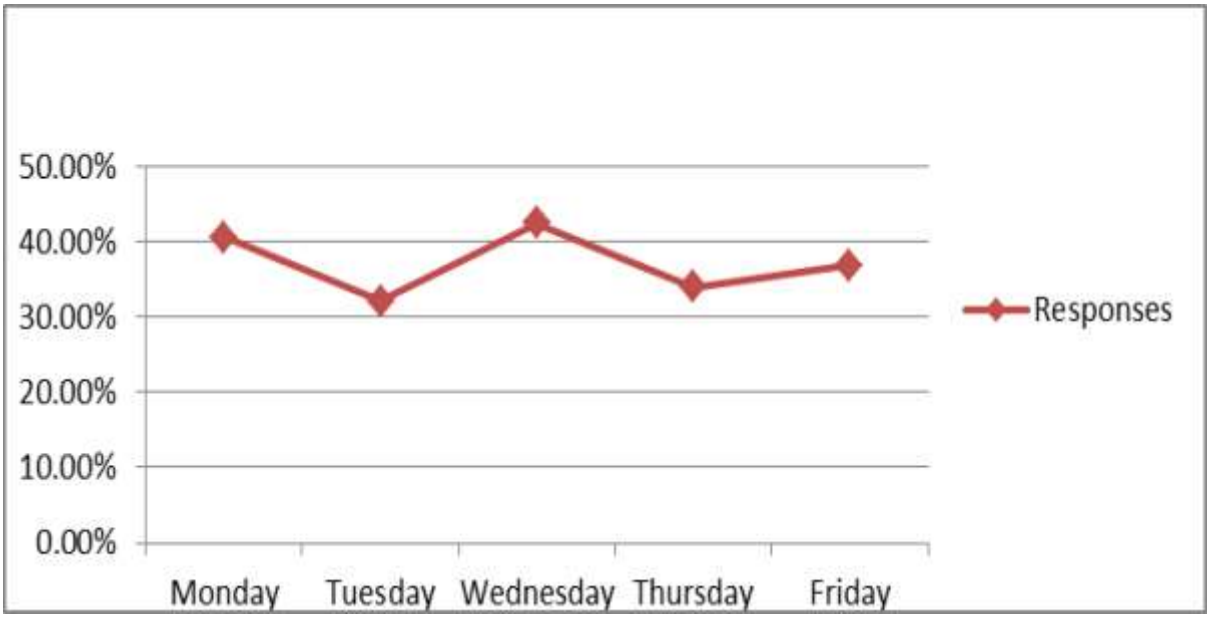


Question 4: What is your preference for the time of year of the workshop/conference?

Of the 108 individuals who answered this question a significant majority of respondents, 87.96%, indicated that they had a preference for professional development to occur during school terms. 12.04% preferred activities to occur during holiday periods.

Question 5: What day of the week is best?

As the graph below shows responses showed that Wednesday was the most preferred day for professional development to be held. This was closely followed by Monday as the next most preferred option. 106 respondents answered this question.

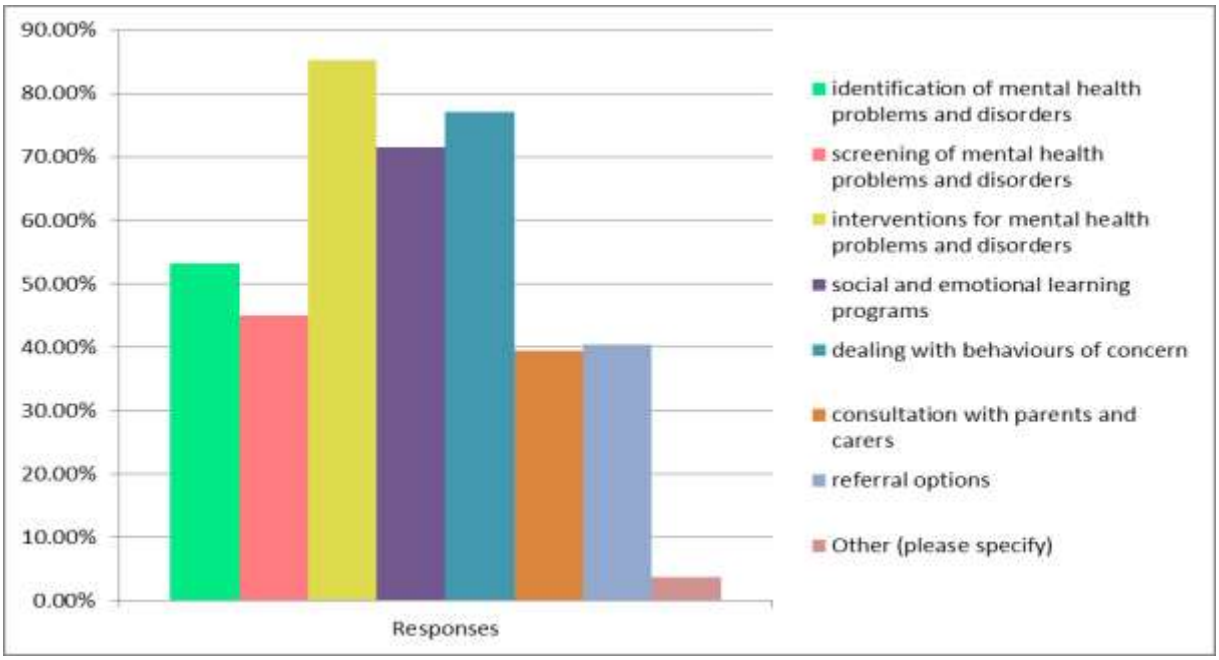


Question 6: What is your preference for the time of day for a workshop/webinar?

All participants answered this question and the majority of those answering the survey opted for PD that occurs during school hours (66.97%) with after school between 3 -5pm the next preference (31.19%).

Question 7: What topics would you be interested in learning more about concerning the mental health of children and adolescents with an intellectual or developmental disability?

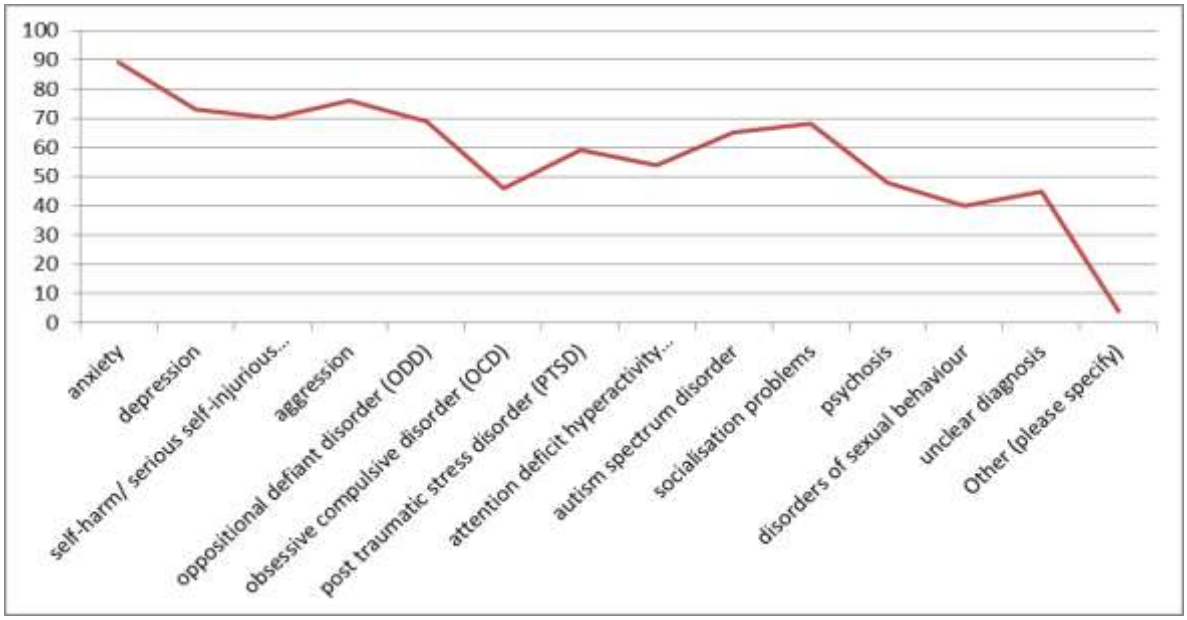
As signified by the following graph, survey participants are most concerned with learning about interventions for mental health problems and disorders. There was also significant interest shown in PD that covered dealing with behaviours of concern and social and emotional learning programs. A number of those surveyed indicated that they would also be keen to learn more about Identifying and screening for mental health problems. Referral options and working with parents/carers had the least appeal.



Question 8: Which of the following topics are you interested in concerning children and adolescents with an intellectual or developmental disability?

All respondents answered this question and they demonstrated a range of interests covering the cross-section of the Survey's items. While anxiety was of interest to 81.65% of individuals; depression, self-harm and self-injurious behaviours, aggression, oppositional defiant disorder and socialisation problems all scored over 60%. Unclear diagnosis and psychosis was of least concern.

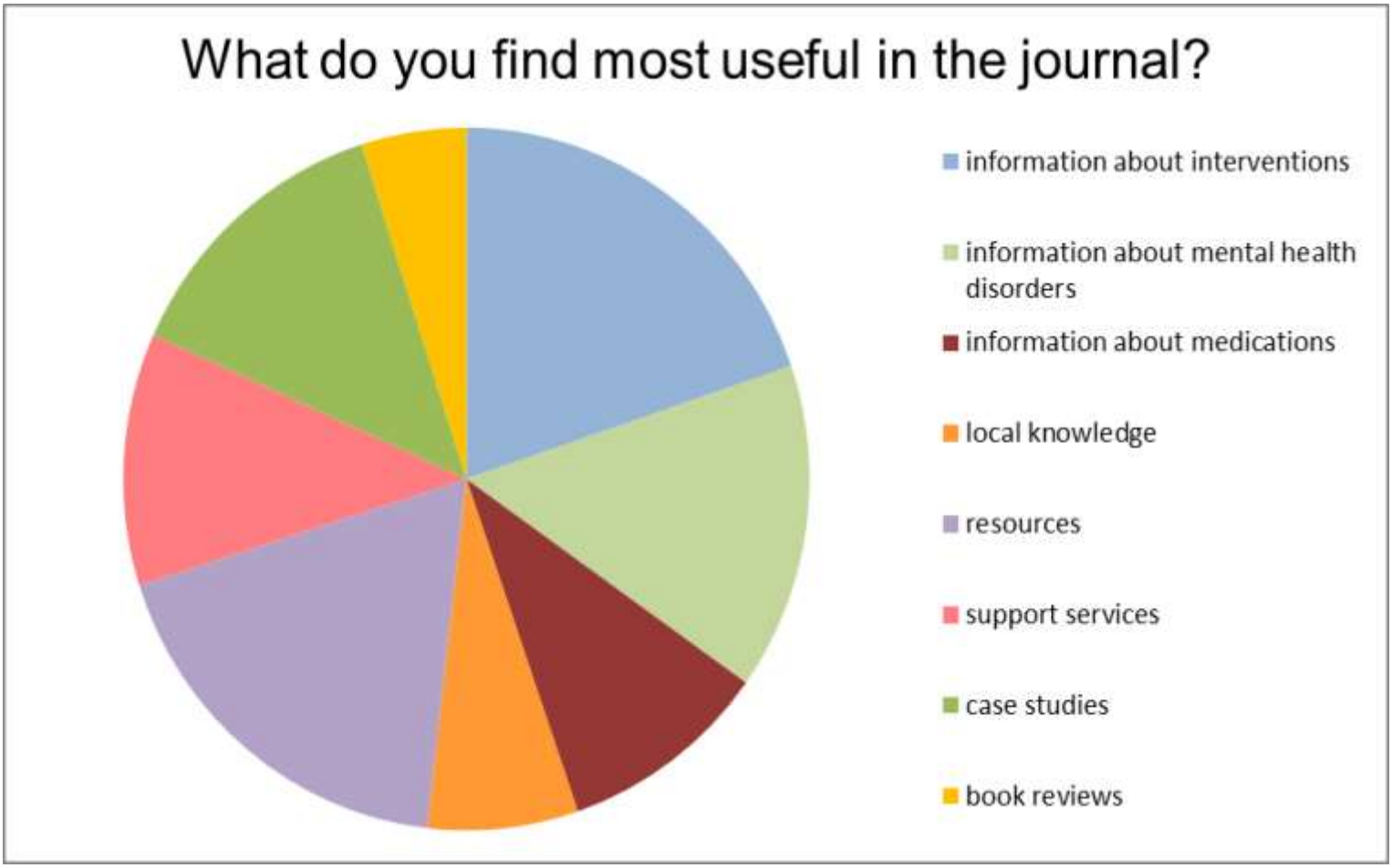
Suggestions for 'other' PD included "working with the education sector" and "residential assessment for complex MH cases".



Question 9: What do you find most useful in the journal?

Information about interventions and resources were identified by respondents as the most useful aspect of the journal with a score of 86.79% and 80.19% respectively. As shown in the graph below information about mental disorders, support services and case studies were also very popular.

This question was answered by 106 of the109 surveyed. While some of those who commented noted that they do not read the journal other comments included; “Evidence based practice and critically appraised research” and “Love all of it!”.



Question 10: How can the journal be improved?

Comments were received from 67 individuals with the overwhelming majority indicating that they thought the journal was “really good already”. Some responses dealt with practical considerations such as “font.type face can be very challenging” and “keep information brief with links to further reading”. There were also suggestions about access such as “Easier access to a printed copy, happy to subscribe and pay for it”

A small number of the comments addressed the content with recommendations to add “More strategies/ activities/resources to support students” and “overviews of research”. One suggestion was to include “Specific case studies and successful strategies used”.

Many of those surveyed gave very positive feedback such as “I find this journal extremely satisfactory and provides a wealth of pertinent information that is meaningful, relevant and user friendly.” While another respondent stated that it was “A thoroughly professional journal, updates and renews my knowledge and skills / keeps me abreast of current research and interventions.”

Question 11: How likely are you to recommend the journal to your colleagues?

Almost 95% of the 107 individuals who answered this question said they were very likely (57.94%) or likely (36.45%) to recommend the journal to their colleagues. 4.67% gave a neutral response and one individual (0.93%) signified that they would not recommend it.

Question 12: Do you have any other suggestions on how CHW School-Link can assist in supporting the mental health of children with an intellectual or developmental disability?

Responses to this question came from 52 individuals; of these almost half said they had no suggestions or gave very positive feedback on the "wonderful work" CHW School-Link was doing. The other comments received focused on some common themes as outlined below.

A number of respondents suggested providing more localised information or support. For instance to "ensure training options include options for families/ practitioners who live outside of Sydney and other major centres." Another comment noted "As a regional NSW person I think any access to something online is really helpful with local hub meetings an option."

There were submissions recommending that information could be kept up to date with "regular information through emails" and "Ensure that information and links about referral options remain up-to-date." Another individual proposed that it would be useful to "Create a database of resources for links/contacts/ services".

Several comments advocated for more PD opportunities and improved access for parents to the journal and support generally. Another of those surveyed wrote "I think to do more advocacy, education and support for teachers, principals and teacher's assistants in mainstream and special education. Implementing evidence based programs in schools to support the needs of children with IDD and their families." It was also suggested that an "Interactive website for professionals across disciplines to pose specific questions about problematic cases." would be of benefit.

To view the survey results in full please go to www.shoollink.chw.edu.au

Reading List

Lucinda Mora, Kellie van Sebille & Lloyd Neill (2018): **An evaluation of play therapy for children and young people with intellectual disabilities.** *Research and Practice in Intellectual and Developmental Disabilities,* DOI: 10.1080/23297018.2018.1442739 https://doi.org/10.1080/23297018.2018.1442739

Children and young people with intellectual disabilities are more likely to experience emotional, behavioural, or mental health difficulties, including a combination of these health problems. There are risks that existing interventions may not be accessible or effective for this group. This program evaluation explored the effectiveness of child-centred play therapy, a developmentally appropriate mental health intervention, for a single group of 42 children with intellectual disabilities aged 4 to 16 years with emotional, behavioural, or mental health difficulties. The intervention was provided by seven therapists trained in the same play therapy protocol and procedures. Parents rated children's emotional and behavioural difficulties before and after play therapy using the Strengths and Difficulties Questionnaire. Statistically significant improvement to children's prosocial skills, emotional and behavioural difficulties, and the impact of these difficulties on everyday life was found at the completion of child-centred play therapy. Children with high-priority referral needs were found to have made greater levels of change. However, with increasing severity of difficulties, children required more time in therapy. A higher level of play therapy training predicted greater prosocial skill development for children and a reduced impact of difficulties on their daily life. This evaluation demonstrated that play therapy may be an effective intervention to use with children with intellectual disabilities and emotional and behavioural difficulties, and warrants further consideration for research and practice by the disability and mental health sectors.

Jones, L., Gold, E., Totsika, V., Hastings, R. P., Jones, M., Griffiths, A., & Silverton, S. (2018). **A mindfulness parent well-being course: Evaluation of outcomes for parents of children with autism and related disabilities recruited through special schools.** *European Journal of Special Needs Education*, *33* (1), 16-30.
https://www.tandfonline.com/doi/abs/10.1080/08856257.2017.1297571

Parents of children with intellectual disabilities and/or autism have been shown to experience higher levels of distress than other parents. Despite such data having been available for several decades, the evidence base for psychological interventions to support parental well-being is small. Recent data suggest that both mindfulness and acceptance processes are associated with decreased psychological distress for parents of children with intellectual disability and/or autism. In addition, some controlled evaluations of mindfulness-based interventions for these parents have resulted in positive outcomes for mothers in particular. In the present study 18 mothers and 3 fathers were recruited via special schools who then attended a Mindfulness Based Well-Being for Parents (MBW-P) group over eight weeks. Parents completed questionnaire measures before and at the end of the course. Statistical analysis showed significant reported increases in mindfulness and self-compassion, and reduced general stress. Parents also reported reductions in anxiety and depression, although these changes were not statistically significant. No significant reductions in their child's behaviour problems or increases in the child's prosocial behaviour were found. Parents also reported high levels of satisfaction with the course. These preliminary data suggest that further research studies testing the effectiveness of the MBW-P course are warranted.

More articles on the next page...

Teague, S. J., Newman, L. K., Tonge, B. J., & Gray, K. M. (2018). **Caregiver Mental Health, Parenting Practices, and Perceptions of Child Attachment in Children with Autism Spectrum Disorder**. *Journal of autism and developmental disorders*, 1-11. https://link.springer.com/article/10.1007/s10803-018-3517-x

This paper investigates the role of caregiver mental health and parenting practices as predictors of attachment in children with intellectual disability/ developmental delay, comparing between children with ASD (*n* = 29) and children with other developmental disabilities (*n* = 20). Parents reported that children with ASD had high levels of anxiety and stress, and attachment insecurity in children (less closeness and more conflict in attachment relationships, and more inhibited attachment behaviours) compared with children with other developmental disabilities. Children's attachment quality was associated with parenting practices and the presence of an ASD diagnosis. These results highlight the bidirectional nature of the quality of caregiving environments and attachment in children with ASD, and also provide a strong rationale for targeting children's attachment quality in early interventions.

Ng, J., & Rhodes, P. (2018). **Why Do Families Relinquish Care of Children with Intellectual Disability and Severe Challenging Behaviors? Professional's Perspectives.** *The Qualitative Report*, 23(1), 146-157. Retrieved from http://nsuworks.nova.edu/tqr/vol23/iss1/10

Relinquishing care of a child with developmental disabilities can be a traumatic experience for parents. The aim of this study was to explore the perception of professionals regarding the relationships within families and service systems that contribute towards the relinquishment of children with Intellectual Disability (ID) and challenging behavior. Fifteen disability professionals were interviewed from a variety of disciplines, each having been involved in supporting a family while they relinquished care. A constructionist grounded theory approach was used for analysis, with data interpreted through a systemic lens. An accumulation of factors led to relinquishment, including the cumulative isolation of mothers within the family and within informal and professional networks of relationships. These findings must be understood in the context of societal discourses that both pathologise and overburden mothers with caregiving roles for children with disabilities. Interventions need to focus assertively on whole family involvement and repair, and on community development, if relinquishment is to be prevented.

Kalb, L. G., Hagopian, L. P., Gross, A. L., & Vasa, R. A. (2018). **Psychometric characteristics of the mental health crisis assessment scale in youth with autism spectrum disorder**. *Journal of child psychology and psychiatry*, *59*(1), 48-56. https://onlinelibrary.wiley.com/doi/full/10.1111/jcpp.12748

Background
Youth with autism spectrum disorder (ASD) exhibit high rates of psychopathology. These symptoms can pose a risk of injury to self or others when the child is in crisis. Despite this danger, there are no instruments available to identify those with ASD who are at risk or actively in crisis. This study examined the psychometric properties of the Mental Health Crisis Assessment Scale (MCAS), a 28 item parent report measure.
Methods
The MCAS was administered to the parents of 606 children and young adults (aged 3–25 years, M age = 13 years, SD =5 years) enrolled in the Interactive Autism Network, an online registry of families raising a child with ASD. The MCAS asks parents to rate the severity of various emotional and behavioral symptoms exhibited by their child. The parent then selects the behavior they perceive as the most dangerous behavior and rates the acuity of as well as their efficacy in managing this behavior. The MCAS was tested for internal consistency, construct validity, criterion validity, and convergent validity.
Results
The MCAS demonstrated strong internal consistency (Total Scale Cronbach's α = .88). The exploratory and confirmatory factor analyses suggested that a two factor (acuity and behavioral efficacy) model fit the data well, providing evidence of construct validity. Criterion validity, which was assessed by comparing the MCAS to clinician determination of crisis, indicated high levels of agreement (ROC = .85). Strong positive relationships emerged between the MCAS and measures of family distress (r = .56), parental stress, and frustration (r = .48), and use of emergency psychiatric services (OR = 24.2, 95% CI: 8.6–68.2), indicating convergent validity of the measure (all $p < .05$).
Conclusions
Results of the psychometric analyses suggest the MCAS appears to be a promising tool that can measure mental health crises in youth with ASD.

Dew, A., Dowse, L., Athanassiou, U., & Trollor, J. (2018). **Current representation of people with intellectual disability in Australian mental health policy: The need for inclusive policy development.** *Journal of Policy and Practice in Intellectual Disabilities*. https://onlinelibrary.wiley.com/doi/abs/10.1111/jppi.12239

People with intellectual disability in Australia experience poor mental health, are underrepresented in mental health policy, and encounter major barriers in accessing mental health services and treatments. This study interrogated the current representation of people with intellectual disability and recommended strategies to enhance the inclusion of intellectual disability in mental health policy. A policy analysis framework was developed that included context, stakeholders, process, and content. Nine pieces of Australian mental health legislation and 37 mental health policy documents were analyzed using the framework. Fifteen of the 37 documents included mention of intellectual disability with limited attention to the specific mental health needs of people with intellectual disability and mental illness. Only two documents identified specific strategies or measurable actions and targets to improve the access of people with intellectual disability and mental illness to mental health services. The documents' strengths that may be applied to develop inclusive intellectual disability mental health policy included being values-based, recognizing diversity, taking a life-course approach, focusing on workforce development, and ensuring checks and balances. An inclusive approach to the development and implementation of intellectual disability mental health policy will best meet the mental health needs of individuals with intellectual disability. An inclusive policy approach will be based on a sound evidence-base and include a comprehensive understanding of the context in which the policy is developed; consultation with key stakeholders including people with intellectual disability and mental illness, their family and carers, and those who work with them; cross-sector collaboration and workforce training. An inclusive approach to the development and implementation of intellectual disability mental health policy using an integrated knowledge translation approach will address the current lack of attention to the important area of how to best meet the mental health needs of individuals with intellectual disability.

Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2018). **Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review.** *Journal of Mental Health Research in Intellectual Disabilities*, *11*(1), 69-102.
https://www.tandfonline.com/doi/abs/10.1080/19315864.2017.1408724

Background: It is well established that people with an intellectual disability have high rates of mental health problems, yet rates of uptake of services do not match need. *Aim*: To identify the current literature pertaining to the barriers and facilitators to access to mental health services for people with an intellectual disability. *Method*: A systematic search identified English-language articles that addressed barriers or enablers to access, mental health services, and intellectual disability from 2005 to 2016. Results were synthesized according to Gulliford et al.'s four dimensions of access: availability, utilization, relevance and effectiveness, and equity. *Results*: Barriers and enablers were identified across all the dimensions. Organizational barriers, lack of services, and poor-quality services related to deficits in knowledge were among the barriers discussed in the literature. Facilitators included emphasis on interagency collaboration, and training and education. Substantial gaps were also identified, particularly in relation to the lived experience of these barriers. *Conclusions*: Further research and evaluation across all aspects of access to mental health care for people with an intellectual disability is needed.

Kezia's Story

NDIS

"I'm able to go to work without worry and Maria can too. We've built up a great support network and thanks to the NDIS life is so much better now compared to before." Kezia's Dad Aldrin.

So caught up providing the best care for nine-year-old daughter Kezia, who has profound disability, Aldrin and Maria Dias could not visit family overseas and found it increasingly difficult to see friends or even leave their home.

But now, as part of the National Disability Insurance Scheme (NDIS) trial in Perth Hills, Mr Dias cannot believe how good life is compared to two years ago, not only for Kezia, but also for he and his wife.

Receiving appropriate equipment and funding for two support workers has been life changing.

"After eight and a half years I finally got to visit my family and friends in India," Mr Dias said.

"With Kezia, we were spending all our time, all our life, looking after her. What we didn't realise was her care was consuming us, we weren't living life for ourselves," he said.

"Now my wife and I can enjoy activities together, and we feel confident leaving Kezia because we know she is in safe hands."

Feeling there was no option but to give up their own lives to provide Kezia with adequate care, Mr and Mrs Dias felt confined to their home with no significant help in sight.

"We had our eyes and ears on Kezia 24/7," Mr Dias said. "If she woke up before 1am, Maria would go to her and if she woke up around 3, 4 or 5am, I would go to her – we took shifts," he said.

Prior to the NDIS, the family received some respite for Kezia but were told there was a long wait for additional support.

"The help we got prior to the NDIS was good but it was on a much smaller scale and very limited," Mr Dias said.

"But now, with the NDIS, we've been able discuss and address Kezia's needs, and ours, and work out a plan which has really helped to improve all of our lives," he said.

"I self-manage Kezia's NDIS plan. This means I'm in control of her supports and I can employ who works with my daughter, what supports she needs and where those supports are delivered. The NDIS is much more streamlined and the equipment we've been able to receive has been such a help.

"Before the hoist came, the carers had trouble shifting Kezia but in the past six months (with the hoist) it is much easier."

NDIS, Accessed April 2018

https://www.ndis.gov.au/Keziasstory.html

National Disability Insurance Scheme

iNDISpensable

Complaints and Feedback Process

NSW GOVERNMENT

There are different types of complaints that can be made and different processes to follow depending on the type of complaint a person wishes to make. An advocate can help a participant choose the right type of complaint and how to prepare for the process.

NDIA decisions

The best way to register a concern is to complete the short online complaints form at: www.ndis.gov.au/about/contact-us/feedback-complaints/complaint-form.html or contact the local NDIA office. If a persons is still unhappy they can ask for a NDIS manager to review their complaint. If still unhappy they can contact the Commonwealth Ombudsman:

1300 362 072

- Make a Complaint using their online form www.ombudsman.gov.au/making-a-complaint
- Post: Commonwealth Ombudsman, GPO Box 442, Canberra ACT 2601

Service provider concerns

If a person has concerns regarding their service provider their should in the first instance talk to them. they can seek help from a Support Co-ordinator or carer.

If they are still not happy, they can contact the NSW Ombudsman:

1800 451 524

nswombo@ombo.nsw.gov.au

Concerns regarding NSW Healthcare professionals can be made to the Health Care Complaints Commission at any time.

Consumer concerns

If a perosn is not happy or satisfied with a product or service they have bought they should contact NSW Fair Trading

13 32 20

www.fairtrading.nsw.gov.au

Useful links

Want to know more about the NDIA/NDIS feedback and complaints procedure? Follow these links:

disabilityadvocacyfinder.dss.gov.au/disability/ndap/

www.ndis.gov.au/about-us/contact-us/feedback-complaints

Agencies that can help resolve a complaints can be found here:

www.advokit.org.au/review-and-complaint/complaints-about-ndis-funded-services-and-supports/

The National Disability Insurance Agency (NDIA) welcomes feedback. The National Disability Insurance Scheme (NDIS) is the new way of providing support for Australians with disability, their families and carers.

www.health.nsw.gov.au (GR) 170628 11/17

Interview with Barbara Lewis

Manager, Carer Support Service
Northern Sydney Carer Support
Royal North Shore Hospital

Your career pathway to date

I have been very blessed in the places that I have worked in. I started off as a consular officer with the British embassy in Spain. It was at that point that I started counselling: when supporting people affected by car accidents or other incidents that brought them into the Embassy for assistance. Then I went off to the BBC world service where I was exposed to working with people who had left war torn countries. When I came back to Australia, I worked with the ABC in News and Current Affairs, and I think probably, in a nutshell, I would put my career pathway as very strong social policy – a belief that we support people in our community. As a result I have put myself through university and degrees that have led me to this point. I started with the Carer Support Service when it was being established by NSW Health back in 2004, and I have been chipping away ever since. I am blessed to walk beside carers everyday who have different journeys, a variety of things that make their journey complex; from parents of a child with an intellectual or physical disability through to husbands and wives who's partners have motor neuron disease or are frail aged or have dementia. It's a very varied role but what I like about it is I am able to inform good social policy in Northern Sydney Local Health District in terms of the recognition and engagement of carers as partners in care.

Tell us about the Carer Support Service

It is a state-wide service funded by the Ministry of Health and you will find us in all the Local Health Districts across NSW. Our role is to ensure that health services are able to 'think patients - think carer'. When we use the term 'carer' we are really establishing that that term is applied to a family member, partner, or friend. Carers are not support workers and are not employed in the role to provide care and support. We help with guidance and the best analogy is walking side by side. We are not there to take over a carers life or to fix all of the problems; but we certainly try and help facilitate what they need.

What are the main aspects of supporting carers?

Every carer would say something different, we work to empower, care and connect carers in Northern Sydney. We like to think that we are empowering carers to have a voice, we show them care and consideration and we connect them to the information or services that they need to access. The biggest thing that anyone can do is listen, and appreciate that there are many views and many responses and many reactions to life experiences and there is no one easy answer. There are a variety of different journeys and different hurdles as no two people have the same issues.

What are your main projects?

One project is improving the hospitalisation of people with an intellectual disability, but it is also about improving the primary health components of care so they don't get to the point where they need to access hospital at the point of crisis. If, for example, a client/patient and their carer are connected to a Psychiatrist early enough with good health care and medication in place, it doesn't end up being a hospitalisation for an injury that was due to frustration and certain behaviours. Since the closure of the government disability provider ADHC, there has been a considerable extra pressure on carers as a result. Cross agency collaboration remains a key component for positive patient care, with sensible ways of communicating and facilitating care, as after all, all professionals want the best circle of support around an individual child and their family.

How has the NDIS improved caring for a child with IDD?

At this moment in time I haven't experienced many families that have said it has improved their ability to care for their child. It does appear that those who previously had no support are now receiving some funding. I do fear that many families are still struggling to put it all together.

What challenges does the NDIS bring for carers of a child with an IDD?

One challenge I am noting is that carers probably had access to services in the past that might have been cheaper but are now more expensive, sometimes

> “We help with guidance and the best analogy is walking side by side”

there is not enough money in the plan to cover all the needs of the child. Accessing services and being very clear on what a carer wants for their family member is really important. I also note that sometimes carers are struggling to find the right service providers, and good support workers to provide care. It is also difficult for different businesses to bring the care together, eg. a behaviour support plan done by one business, relies on being able to train staff from other organisations, this is difficult to achieve.

Where can carers go for additional support?

There are some considerable changes that are going to be bought about by the Federal Government such as asset testing the carers allowance. In the past, carers were not asset tested which will have an impact on the health care card. There will be a lot of changes over the next year or so. I urge carers in Northern Sydney to keep an eye on our website www.nscarersupport.com.au. If carers are stuck they can always contact our service for help. Alternatively, there is the *Carers Gateway* and Carers NSW as peak providers. On the ground there are Advocacy Services that will be there to assist.

Some fun Questions: Favourite book

I actually have two books. The first is by Mary Delahunty and is called *Public Life, Private Grief* and that is a fabulous book. Mary Delahunty was a member of the Victorian government at the time that her husband passed away. So that was a lovely story about her family’s journey. Then the other one that I love is *Tales from the Political Trenches* by Maxine McKew, which was written after she left Federal Government. Maxine was one of the key people within Kevin Rudd’s team that was instrumental in social policy reforms, which sadly, at the moment we are seeing being discounted. It felt at the time that we were going to see really good social policy - and that was from the National Apology to the stolen generation through to the NDIS, which of course was from the government at the time.

A weblink that you would like to share

Beyondblue and Blackdog because they are both wonderful resources for people to quietly access in their own homes and be able to look at how they can manage their own levels of stress and anxiety. Or even if you are just feeling a little bit blue, there are a lot of self-managed care approaches rather than having to sit in a room with a clinician. And of course our Carers website, www.nscarersupport.com.au

One thing you always take on holidays

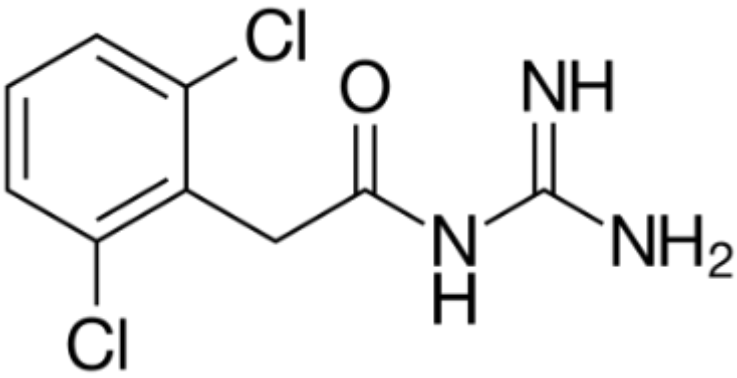
My pillow! My pillow has even travelled to Paris and wherever! Nothing like putting your head on your own pillow at the end of the day.

Is there is anything else that you would like to add?

I think that we really need to emphasise the importance of a community around carers and recognise, respect and value them as partners in care. That is across all sectors whether it is health, education or community support. The caring journey is tough, it doesn’t matter what type of journey it is, it is a tough one. We need to really have that respect in place.

The Medicine Cabinet: Guanfacine

Judy Longworth
Department of Psychological Medicine,
The Children's Hospital at Westmead



Guanfacine is an alpha 2 receptor agonist which has been in use as an antihypertensive in the immediate release form, from the 1980s in the USA. It is currently licensed in Australia as an extended release preparation for use in the treatment of ADHD as monotherapy or adjunctive therapy in children and adolescents 6-17 years. It primarily works on the alpha 2A receptor postsynaptically, (clonidine a similar medication works on alpha 2A, 2B and 2C and imidazole receptors). Guanfacine is significantly stronger affinity for the postsynaptic receptors than presynaptic whilst clonidine has stronger affinity for presynaptic. (See previous edition of MHCAIDD: Vol4, Issue 3/4, 2013)

The preparation (Intuniv®) is an extended release preparation and thus will not be able to be crushed, chewed or broken and should be swallowed whole and this is the preparation that will be on the Pharmaceutical Benefits Scheme (PBS). The Pharmaceutical Benefits Advisory Committee (PBAC) has approved it for listing on the PBS but the actual date at the time of writing is unknown but will be available until that date a private script could be utilised. It is available in 1mg, 2mg 3mg and 4mg strengths and boxes of 28 tablets.

Description of drug mechanism of action

Unlike clonidine, guanfacine acts only on the alpha adrenergic 2A receptor post synaptic primarily in the prefrontal cortex of the brain. This has been postulated as contributing to improvements in impulsivity, hyperactivity and inattention by the increase in noradrenaline release in the synapse without impairments to the dopamine neurotransmission. Treatment with a selective alpha 2A agonist would lead to increased signal via direct stimulation of postsynaptic receptors, resulting in increased ability to sit still and focus[1].

Side effects

In the clinical trials for licensing the main adverse effects were somnolence (strong desire to sleep), fatigue, abdominal pain, irritability and sedation[2]. Incidence of abdominal pain increases with dose but fatigue does improve. Other adverse effects would include a drop in blood pressure (hypotension) as well as dizziness, dry mouth, constipation and weakness[3] .

Other adverse effects that have been identified in the trials include weight gain, loss of appetite, wetting oneself, feeling or being sick, diarrhoea, indigestion or constipation, slow heart, beat low or high blood pressure and rash.

Dizziness and drop in blood pressure can be helped by not getting up from the lying position too quickly. Dry mouth can be relieved by sucking on ice. Taking guanfacine with food but not a fatty meal can also help with the nausea and feeling sick.

Drug interactions

Guanfacine is metabolised in the body by CYP 3A4 (most prolific of the drug metabolising enzymes) and thus when strong inhibitors of the enzyme such as fluoxetine, fluvoxamine and ketoconazole are also given then the clearance of guanfacine will be reduced causing the blood levels of guanfacine to raise.

Inducers of 3A4 such as the antiepileptics - carbamazepine, oxcarbazepine, phenobarbital, phenytoin, primidone and high dose topiramate as well as St John's Wort especially those products with high levels of hyperforin will cause the guanfacine levels to rise and increase the risk of adverse effects[4].

Clinical trials in children

There has been several clinical trials conducted both placebo controlled trials and against comparator

atomoxetine. These trials have been used to support the application to PBAC for PBS listing as well as helping to extend the patent of the preparation in the USA.

Biederman trial was a multicentre USA double blind placebo controlled fixed dose escalation study in children 6-17 years. During 2003, a total of 365 patients were recruited to either placebo, or doses of 2mg, 3mg or 4mg and showed significant improvement in the Attention-Deficit/hyperactivity disorder rating scale IV (ADHD-RS-IV)[2]

Hervas study compared guanfacine to placebo as well as atomoxetine. The study was held over 58 sites in 11 countries from January 2011 to May 2013. Optimal dose of guanfacine used as 0.05-0.12mg/kg/d and the dose of atomoxetine was to a target dose of 1.2mg/kg/d. The total number in the study was 404 screened and 338 patients were randomised into 3 groups and 80% completed the study. There was a statistically significant improvement from baseline of the primary measure the ADHD-RS-IV. Although not designed for head to head study there was a greater mean change from baseline with guanfacine than atomoxetine[5].

Wilens trial for adolescents aged 13-17 years with a diagnosis of ADHD in a multicentre (48 USA sites) double-blind placebo controlled randomised study. Total of 314 adolescents (at least 25% female) entered the trial and received dosing 0.05 to 0.12mg/kg/d up to $\leq$ 7mg daily. Optimal response as with the other trials reduction of $\geq$ 30% from baseline in the ADHD-RS-IV for which there was a statistically significant improvement. As well as looking a functional gains through parental report for which there was no statistically significant difference between placebo and Guanfacine in the 2 key secondary domains of functioning – learning and school domain and family domain as measured on Weiss Functional Impairment Rating Scale –Parent report (WFIRS-P) at 13 weeks[6].

Open trial of 25 children with mean age of 9.03 years with a diagnosis of pervasive developmental disorder DSMIV who had failed treatment with methylphenidate in a multisite 8 week placebo-controlled trial. Primary measure was parent-rated hyperactivity subscale of the Aberrant Behavior Checklist (ABC) for both teacher and parent ratings. Dosing ranged from 1mg to 3mg/ daily using the immediate release preparation so dosing was in two to three divided doses. 39% improvement over baseline in the parent reported ABC hyperactivity subscale and this is compared to similar study using risperidone for more serious behavioural problems. Main adverse effect was sedation in 28% and irritability (moody, tearful and easily frustrated) in 28%

"Improvements in impulsivity, hyperactivity and inattention by the increase in noradrenaline release in the synapse"

of the population and 3 patients withdrew due to irritability. Effects on blood pressure and pulse were modest and appeared to diminish over time[7].

The Pediatric Psychopharmacology Autism network study in use of guanfacine ER in 62 subjects (85% boys) aged 5-14 years over an 8 week trial in 5 USA sites. Aberrant behaviour checklist –hyperactivity scale was the primary outcome measure. Statistically significant results in the hyperactivity subscale of the ABC scale and also hyperactivity scale in the ADHD rating scale in favour of guanfacine[8].

Why it might be used

- Guanfacine may be used instead of clonidine to ensure better control over the day as well as being less sedating.
- As adjuvant medication for psychostimulants to ensure proper sleep at night when doses are given earlier in the day and also extending the hyperactivity control without affecting the sleep.

Benefits

Single daily dose
Can be used with or without psychostimulants
Only licensed for patients 6-17, what happens to adult stabilised on it?

Problems

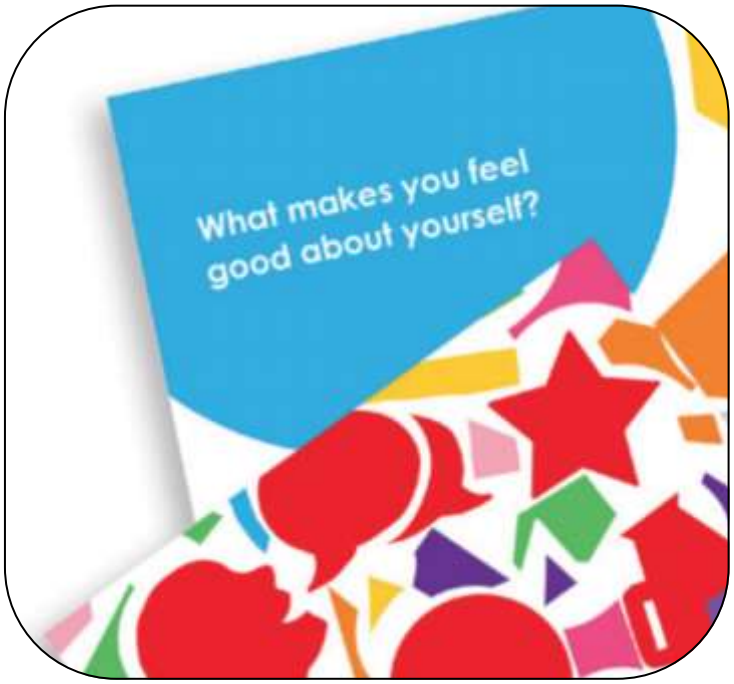
Cost
Until listed on PBS there could be considerable expense in using the medication.

To be taken with water, milk or other liquid at the same time each day either day or night, should not be chewed, crushed or broken and not to be taken with a high fat meal.

References:

1. Stahl SM ed Stahl's Essential Psychopharmacology Neuroscientific basis and practical Applications 4th ed 2013 Cambridge Univ Press New York
2. Biederman J, Melmed RD, Patel A, McBurnett K, Konow J, Lyne A, Scherer N for SPD503study group A randomized, double blind, placebo-controlled study of guanfacine extended release in children and adolescents with attention deficit/hyperactivity disorder Pediatrics 2008; 121(1) e73-e84
3. Stahl SM ed Stahl's Essential psychopharmacology prescriber's Guide 5th ed 2014 Cambridge Univ Press New York
4. Wynn G, Oesterheld JR, Cozza KL, Armstrong SC. Clinical Manual of Drug interaction principles for Medical Practice. American psychiatric Press Inc 2009 Arlington VA.
5. Hervas A, Huss M, Johnson M, McNicholas F, van Stralen J, Sreckovic S, Lyne A, Bloomfield R, Sikirica, Robertson B. Efficacy and safety of extended release guanfacine hydrochloride in children and adolescents with attention deficit/hyperactivity disorder: A randomized controlled, phase III trial. European Neuropsychopharmacology 2014; 24: 1861-72
6. Wilens TE, Bukstein O, Brams M, et al, "A Randomized Placebo-Controlled trial of Guanfacine Extended -Release in adolescents with Attention-Deficit/ Hyperactivity Disorder," J Am Acad Child Adolesc Psychiatry, 2015; 54(11) 916-25
7. Scahill L, Aman MG, McDougle CJ, McCracken JT, Tierney E, Dziura J, Arnold E, Posey D, et al. A prospective open trial if guanfacine in children with pervasive developmental disorders. J ouranl of C&A psychopharmacology 2006; 16 (5) 589-98
8. Scahill L, McCracken JT, King BH, Rockhill C, Shah B, Politte L, Sanders R, Minjarez M, Cowen J et al Extended release guanfacine for hyperactivity in children with autism spectrum disorder Am J Psych 2015; 172: 1197-1206

Further information:
Consumer medicine information https://www.nps.org.au/medical-info/medicine-finder/intuniv-modified-release-tablets



New Resources....

Council for Intellectual Disability is thrilled to announce two new resources: the My Health Matters folder and me360 cards.

me360 cards

me360 cards help young people with disability to have conversations about the important things in their lives. Each me360 card asks a question that will help them think about their strengths and goals, and what they need to live a good life. The cards are useful during times of change and when planning for NDIS meetings. If you are a school or an organisation that works with young people and would like to know more about this resource visit www.nswcid.org.au/my-health-matters.html

My Health Matters folder

My Health Matters helps explain to doctors and other health people what is important. My Health Matters is an Easy Read folder, made by people with intellectual disability for people with disability.

To get a my health matters folder, visit the CID order form www.nswcid.org.au/my-health-matters.html

GP Flowchart

We have created a flowchart to assist GPs and health professionals determine the eligibility of their patient for the NDIS. Included on the rear of the flowchart is further information on the National Disability Insurance Agency and the NDIS application process. Download the flowchart at www.nswcid.org.au/gp

European Association for Mental Health in I ntellectual Disability, 2017. Luxembourg 21-23 Sept, Conference report.

Associate Professor David Dossetor
Department of Psychological Medicine,
The Children's Hospital at Westmead

The European Association for Mental Health in Intellectual Disability (EAMHID) must be one of the largest international, multidisciplinary, organisations that focuses on mental health in people with intellectual disability (ID). In 2017, it's conference was held at the European Convention Center, in the modern Kirchberg Plateau development of Luxembourg. Luxembourgish is the official local language, but most debate is had in French and the papers are published in German. Primary school is taught in German and High School in French. These are the presentations that stood out for me from the conference.

Mental Health and Intellectual Disability

Nick Bouras a founding member from King's College and the Institute of Psychiatry, London, spoke on EAMHID, its history and developments in evidenced-based practice. EAMHID was only founded in 1990, at a time of de-institutionalisation and uncritical acceptance of the social model. Across Europe there is wide disparity in service provision, which is generally worse in low and middle-income countries. This includes marginalisation from mainstream employment, limited access to mental health services and a lack of professional training. There has been a growth of research and epidemiology but it is seldom published in mainstream psychiatry journals and relies on the Association's 3 journals.

Bouras commented that data shows MH problems in ID are common, are associated with negative outcomes, that interventions need strengthening and that services are fragmented. He continued that we need large multicenter studies and outlined the barriers including who will fund MHID research? In USA 67% and Europe 74% of people with MHID don't receive services, compared with physical health where for example only 8% with diabetes don't receive services! Yet there is now a global MH movement, not necessarily including ID. We need to set priorities, define intervention packages, and identify countries that need to do more. We need to define the role of specialists, and increase training and supervision.

In September 2015, the UN 2030 Agenda for Sustainable Development included for the first time the promotion of mental health, not just physical health and the prevention and treatment of neurodevelopmental disorders. There is a right to quality MH care for every person with ID which includes assessment, comprehensive diagnosis and individualised treatment in the right place, time and appropriate social setting.

Why do children with ID have such high rates of behaviour disturbance?

Vaso Totsika from the University of Warwick presented data from a huge cohort study on the effect early adversity has on parenting and its relationship to behavioural disturbances in children with learning difficulties (LD). Testing used the Family Stress Model of Conger and Donnellan, which views families as systems in which children grow, and that negative behaviour comes from negative processes, which are associated with poverty, parental stress and child behaviour problems. But how do these risk factors work together? This has been studied in typically developing (TD) kids, but not in those with LD. They studied 555 families of children with LD (identified by a British Assessment Scale at 7 years) compared with 19,000 families of TD children from the Millennium Cohort, assessing parental adversity at 9 months and outcomes at age of 7 and 9 years. Parental adversity at 9 months was a poverty measure derived from below income poverty threshold, mean durable assets, family struggling financially and unavailability of grandparent support. This early parental adversity was related to emotional problems, hyperactivity, conduct problems and total behaviour problems at age of 7 and 9 years. However, positive parenting significantly reduced the association with behaviour problems, hyperactivity and emotional problems. The parenting was measured age 3 and 5 years. Adverse parenting was based on observations of: frequent discipline, conflict in the relationship and harsh parenting. Positive parenting was measured by observations of closeness and parental positivity. Accordingly, in children with LD, behaviour problems are mediated through adverse parenting and not by positive parenting. They conclude that to prevent behav-

Above: The Golden Girl of Luxembourg commemorating those lost in the first World War.

iour problems in LD, we need to reduce poverty, have universal screening of post-natal depression and provide universal parenting programs and specialist parenting intervention for children with LD (ID).

The importance of early intervention through parent training

Kylie Gray, Director of Monash University Developmental Psychiatry, presented initial data on the MySay project following the widespread implementation of Stepping Stones Parent Training (SSPT) across east coast Australia, with an aim to make a difference at a public health level to behaviour problems in children with ID. SSPT was provided to parents of children aged 2-10 years with developmental delay or ID. 251 professionals were trained in SSPT in Victoria and Queensland. 365 families received intervention with 3 and 12 months follow up. Both children with ID and ASD showed and maintained improvement in behaviour. Parenting with higher levels of coercion and inconsistency was associated with greater behaviour disturbance, and those with higher levels of coercion had smaller improvement, however where there was a change in coercive parenting style there was greater change in childhood behaviour. Both these studies reenforce the need to tackle adverse parenting.

MH problems in children with ID: a mainstream policy issue

Richard Hastings Cerebra Chair of Family Research at the University of Warwick presented on MH problems in children with ID: a mainstream policy issue. The UK Office of National Statistics surveyed 18,000 children aged 5-16 years and identified 3.5% (or 641) as 'likely to have ID'. Emerson and Hatton (2007) found those with ID had 36% psychiatric disorder (vs TD controls 8%), with emotional disorder 12% (3.5%), Hyperkinesis 8% (1%), and conduct disorder 22% (6%). Conversely 1 in 7 children with a mental disorder have ID. The Millennium Cohort Study identified 479 (3%) 5-year olds on British Disability Scales with ID. At 5 years of age, 48% were hyperactive (vs 15% TD controls), 40% had conduct disorder (22%) and 28% had emotional disorder (10%). The risk factors associated with MH are: single parent 30% (23%), poverty 47% (30%), 2 or more negative events 27% (18%), and a carer with no educational qualification. Three or more risk factors were found in 46% of children with ID vs 24% of typically developing children. Other factors identified as important: genetic and biological factors, difficulty recognising/labelling emotions, limited communication skills, poorer quality close relations, lack of diagnostic recognition, lack of access to services (only 29% accessed MH services in last 6 months). NICE guidelines identified an inequality in evidence, with fewer studies of parenting programs in children with ID, and what studies there are, show positive but less effect than in TD.

Challenging Behaviour (CB): Individual Difference Matters

Chris Oliver, Chair of Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, gave an exciting presentation based on research of behavioural phenotypes 'Challenging Behaviour (CB): Individual Difference Matters'. Using seven different behavioural phenotypes they propose that aggression (Agg) and self-injurious behaviour (SIB) has different causal mechanisms. It is also important to recognise

> "Significant advances in evidence that children with ID develop higher rates of emotional and behavioural disturbance"

dimensional severity. For example, both Autistic Spectrum and Autism found present in Fragile X in 80% vs 45% and in Smith Magenis Syndrome (SMS) 70% vs 30%. He talked about five important and different etiological pathways to CB: 1. physical disorders and sleep; 2. social drive and cognition; 3. cognitive and executive function; 4. emotional variation of anger and anxiety; and 5. sensory sensitivity and perception. For physical disorders, they use a behavioural pain and discomfort questionnaire, Face, Legs Activity, Cry & Consolability (FLACC) (Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006), such as identifying gastro-esophageal reflux with SIB in Cornelia de Lange's Syndrome, or the Sleep problems of SMS using Actigraphy, which shows them awake at 2am. 2. Angelmans Syndrome have higher social approaches but also aggression. They found higher aggression in low attention settings. Wilder showed with the Ainsworth Stranger Situation Test that those with SMS have a strong attachment to their mother and low interest in a stranger when compared with Down Syndrome are more likely to be distressed with mother's departure. 3. Repetitive behaviour and impulsivity are two elements of executive dysfunction in addition to ID. Repetitive behaviour predicts aggression in Fragile X, whereas impulsivity predicts aggression in SMS and Angelmans. They used go-no-go tasks to assess executive function. Prader Willi Syndrome (PWS) have increased reaction time after a shift paradigm, and this result correlates with repetitive questioning and adherence to routine. 4. Both Fragile X and PWS have high emotional response to an aversive stimulus. Lowes Syndrome have high impulsivity and high emotional output, which is associated to low executive function on the BRIEF.

Oliver concluded that ID leads to compromised learning and behaviours. Behaviours are related to other underlying deficits. Accordingly, the term challenging behaviour may have outlived its usefulness, as individual neuropsychiatric qualities need consideration. For example, people with PWS shouldn't be considered as obstinate, but the reaction times show that change of attention is harder for them.

Over all I was struck by the significant advances in evidence that children with ID develop higher rates of emotional and behavioural disturbance. There is also evidence that a lot can be done, particularly while a child is still under 10 years of age, to prevent and improve this challenging behaviour. Is anyone listening?

Psychopharmacology workshop: a brief overview of the evidence, theory and prospects.

Marco Bertelli, psychiatrist from The Research and Clinical Center, San Sebastian Foundation, Florence, President of the Italian Society for Neurodevelopmental Disorders and Past President EAMH-ID presented an innovative workshop on pharmacology in adults with ID. However, this presentation although strictly evidenced-based, was quite specialised and somewhat theoretical. 20-45% of people with ID receive psychoactive medications. Two thirds are on antipsychotics, 20% of those in a residential facility and 45% of those hospitalised. 45% of adults with ASD are on medication. Paton and Flynn (2011) study of 39 centres and 2319 clients found 27% had a psychotic disorder, 27% an affective disorder, but 6% with borderline IQ and 21% with severe/profound ID were on antipsychotics without a psychiatric disorder. In people with ID, 50% are taking antipsychotics for problem behaviour. Documentation was good, but the monitoring of side effects was less careful.

At Salford Disability Service (Griffith et al, 2012) of 178 patients, 72% were on antipsychotics of which 11% were on 2. 67% had a psychiatric disorder, 33% were prescribed for 'off label' reasons. 64% were initiated by a GP, 28% an unknown prescriber, and 8% a GP or pharmacy alone. There are diagnostic problems in defining MH in ID: difficulty in defining the additional impairment and difficulty in determining the level of distress or suffering. There is an overlapping genetic vulnerability for ASD, ID, Schizophrenia, Bipolar and Depression, and epigenetics play a role. Additional diagnostic problems include: Intellectual distortion (ie affected by communication skills and IQ; developmental appropriateness; psychosocial masking (ie cultural, interpersonal and environmental distortion); ID diagnostic overshadowing; atypical presentations eg aggression, maladaptive behaviour; neuro-vegetative vulnerability eg somatic complaints, circadian rhythms, nonverbal dystonias; cognitive disintegration. Life problems are common, about 60% have at least 1 life problem, with aggression, irritability, self-injury, hyperactivity, impulsivity, sleep problems and repetitive behaviours. The 2-year remission rate for SIB is 38% and Aggression is 27%. Conversely the 11-year persistence rate is 79% for problem behaviours, 70% for aggression, 65% for stereotyped behaviour, 49% for SIB. Per-

sistence particularly occurs in ASD and adults. Some authors suggest some behaviours may be symptom equivalents, other suggest they are a sign of distress. Can this all be attributed to the lack of competence of the multidisciplinary team? Before prescribing one should consider a functional analysis, the influence of ID/developmental level and organic factors.

He summarised the vastly *different types of antidepressants*, many that are novel, and their mechanisms and attempts to provide a rationale for their different effects and when to use them: SSRIs: GPs use citalopram or fluoxetine. Fluvoxamine has less impulsivity as a side effect, and has greater effect in young adults, related to 5HT transporter polymorphisms, but literature suggests more side effects. He prefers Escitalopram. Escitalopram and citalopram improve anxiety, irritability and mood. Of the SNRIs (selective noradrenaline reuptake inhibitors), he prefers duloxetine over venlafaxine because of side effects of sexual dysfunction and obesity, although there is no literature in ID. He published a case report of complete remission of globus hystericus (difficulty swallowing) with duloxetine. NDRI (noradrenalin and dopamine reuptake inhibitors) (buproprione) and NRI (reboxetine and atomoxetine): one study of atomoxetine in Williams Syndrome was less effective than Ritalin with greater side effects such as stomach pain and irritability. NaSSA/SNRI-alpha2 agonists also activate Histamine1: include Mirtazapine, Mianserin, Quetiapine and Asenazepine. SARI (Serotonin agonist uptake inhibitor) such as Trazadone and Nefazolone, are an alternative to benzodiazepines, and good in the elderly with CB with anxiety, irritability and activation. Agomelatine affects the melatonin system and helps in neuro-vegetative states, dystonia and somatic anxiety; in animal models, it improves sociability in ASD, but the evidence is yet lacking in humans.

Recent research links the serotonergic system with the glutamate system. Glutamate receptor 5 affects synaptic plasticity and synapse formation and GlucR5 receptor down regulation can prevent intellectual disability eg in Tuberose Sclerosis. Bumetanide (a chloride importer antagonist) in one study improved ASD. Memantine (antagonist to NMDA receptors) in an open label study improved social withdrawal, inattention, hyperactivity, and memory in ASD. Acamprosate (a gaba A agonist and excitory glutamate antagonist in an open label study improved social withdrawal, hyperactivity and social responsiveness in ASD. Lorastatin and Acamposate helped in Fragile X, as did minocycline and sertraline particularly in the first 5 years. Vortioxetine is a new agent which blocks the serotonin transporter, is a 5HT agonist, removes Gaba and stimulates glutamate which has improved cognition in the elderly with depression. Ketamine is another glutamate antidepressant. He suggests that depression can be split into: 1. Noradrenaline and 5 HT (serotonin) deficits which are associated with negative affect with irritability, anxiety and sadness and responds to SSRIs, SNRI and SARI. 2. Deficits in dopamine and noradrenaline is associated with reduced positive affect along with somatic symptoms of reduced energy, sleeping, eating and stress and responds to NDRI SNRI, NRI, modafinil or a stimulant. 3. Is the combination of 1&2 and needs SNRI or SSRI plus NDRI.

He further breaks affective disorders into main groups: Prominence of physical symptoms: from low 5HT and

Below: The Battlements and Spires of Luxembourg

noradrenaline needing SNRI and pregabalin and gabapentin (alpha 2 stimulation);
Hypersomnia needing stimulant and histamine;
Prominence of emotional symptoms/anxiety needing 5HT and gaba with SSRI or SNRI;
Vasomotor symptoms from low 5HT and noradrenalin needing SNRI and possibly oestrogen; Sexual dysfunction from low dopamine, needing NDRI. There is a growing trend of using more than one antidepressant to enable different antidepressant effects through such multimodal treatment, rather than resorting to other augmenting medications.

Antipsychotics: There is better evidence of the benefit of new generation antipsychotics (NGAs) in improving problem behaviour than with traditional antipsychotics. They also have fewer side effects. Both Risperidone and olanzapine are shown to work. Risperidone, Aripiprazole have FDA approval for irritability in ASD in children and adolescents. Risperidone has greater effect with topiramate or memantine on irritability, hyperactivity and stereotypic behaviour. Main side effects of increased appetite and weight, sleepiness and high prolactin. Paliperidone is similar to risperidone except it is not metabolised in the liver.
Olanzapine is effective in case series for aggression, SIB and disruptive behaviour.
Aripiprazole helps aggression, SIB, tantrums and mood changes in ASD and shows effectiveness vs placebo across the lifespan. Recent open label study showed effectiveness on Fragile X.

Asenapine has a bigger effect on serotonin and therefore may need a higher dose to work on dopamine. Useful alone or with valproate or escitalopram. Ziprasidone has evidence of utility in problem behaviours but has the advantage of being weight neutral.
Clozapine has been used in problem behaviours. If you get neutropaenia you can restart after a one month break. Clozapine and NGAs cause early synaptogenesis through microglia and removal of redundant and maladaptive synapse. There is growing understanding of additional effects of NGAs including additional neurotransmitter effects eg blockade of NMDA agonists, increase in gaba neuro-steroid allopregnanolone, increased neurotrophic effects eg increase in neurotrophic factors eg BDNF, increased neurogenesis, preservation of acetyl choline neurones and cognitive function, and increased cell protective functions eg increased antipoptopic proteins, anti-oxidants, and mitochondrial respiration.

While there is growing demand for pharmacological knowledge and solutions, the evidence is slow to accumulate and depends mainly on case series. I think that critics have little idea of the harm and distress caused by extreme problem behaviours or CB. Conversely there are real concerns of the failure of general medical clinicians and GPs to provide follow up and ongoing monitoring, so when studies are done to try and withdraw a NGA, it is found that 50% do not need continuing medication (but 50% still do).

Mood stabilisers include valproate for irritability, aggression and stereotyped behaviour; lamotrigine (blocks the release of glutamate) for anxiety and depression and Levetiracitam which has one open label study improving mood stability and aggression. Melatonin has accumulated good evidence of benefit in sleep disorders over the last 5 years.

His presentation reminds us that psychiatrists have to keep up to date with the ever-expanding theory and research arising around new medications. One also needs to watch out for exploration into neuroceuticals such as theanine, an analogue of glutamine, found in tea and helps cognitive function, sleep, menstrual pain and stress; passion flower extract may have gaba effects and benzodiazepine like properties; and N-Acetyl Cysteine which may have effects on PTSD in war veterans.

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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