

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

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

Description and purpose

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

On our Website:

www.schoolink.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

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www.schoollink.chw.edu.au



Welcome to the first edition for 2020,

Covid-19 has certainly changed our lives in many ways and we would like to say a sincere thank you to all the health, education and disability staff who have had to adapt to new ways of working. Please remember that School-Link is able to provide support and advice for school or disability staff on relevant mental health services for children and adolescents with intellectual and developmental disabilities. Please contact us by email schn-chw-schoollink@health.nsw.gov.au or call our School-Link mobile on 0409656899.

There have been some important developments in the mental health and disability sectors.

The Royal Commission

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability began earlier this year. In Sydney the public hearing in late February looked specifically at the provision of health care or services for people with cognitive disability, including people with intellectual disability, autism and acquired brain injuries, including barriers to accessing services, training and education of health professionals, delayed diagnoses and misdiagnoses, life expectancies and specific issues for First Nations people.

The Brisbane public hearing has been suspended due to Covid-19 and once it resumes will explore the barriers in the education system to students with disability in accessing and obtaining a quality education, and experiences of violence, abuse, neglect and exploitation, and the consequences which flow to students and their families when students have not been given proper access to equitable education.

If you would like more information, please visit the **Royal Commission homepage**

<https://disability.royalcommission.gov.au/>

The Henry Review

A key priority for the NSW Health system is the design and delivery of high quality, effective and safe health care services for children, young people and families, from conception until 24 years of age. A review of health

services for children, young people and families within the NSW Health system began in February 2019. The key findings of this review were released in late January 2020 and are based on a range of activities including over 250 stakeholder consultations, local health district site visits, and a range of submissions, previous reports and documentation. 77 recommendations have been identified around themes of improving system wide governance and accountability, SCHN governance, neonates, community paediatrics and child health (including developmental assessment and services), Attention-Deficit Hyperactivity Disorder (ADHD), young people, mental health, first 2000 days and measuring progress.

In regards to mental health, recommendations were made around: services providing assessment and ongoing case-management; building the knowledge and capacity of paediatricians; GP's, and nurses to manage complex behaviour and mental illness; and to increase the numbers of allied health staff working in mental health.

Read the Review of health services for children, young people and families within the NSW Health system.

School-Link Webinars

This FREE on demand webinar series is brought to you by a partnership between the Networked Specialist Facilitator -Strathfield, The Benevolent Society, and The Children's Hospital at Westmead School-Link. The webinars aim to assist school staff to support students with an intellectual disability and mental health needs in the classroom. Topics include, an overview of mental health and intellectual disability, understanding behaviour, self-regulation, reflective practice with other topics in development. Check out the on-demand webinars here: <http://www.schoollink.chw.edu.au/webinar-series/>

Happy reading

Jodie Caruana

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The 10 year celebration of the CHW School-Link and the Journal of the Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities.

Associate Professor David Dossetor

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

Introduction: The 10-year celebration of the CHW School-Link and the Journal of Mental Health (MH) for Children and Adolescents (C&A) with Intellectual and Developmental Disabilities (IDD) provides an opportunity for looking back and reflection. This article contains both a brief account of our history and achievements, and also some conjectures on the conceptual, scientific and service changes that have occurred over the last 10 years.

The people and first steps: In 2009 NSW Mental Health Drug and Alcohol Office funded CHW School-Link for mental health liaison with the schools that cater for children and adolescents with intellectual and developmental disabilities (IDD). Like the other Local Health District School-Link projects funded 10 years earlier, its aim was to support schools with the Prevention, Promotion and Early Intervention (PPEI) of mental health, training, and pathways to care. I want to first acknowledge the real leadership, energy and initiative provided by Jodie Caruana as School-Link Coordinator, and Hebah Saleh as Editor for the Journal and Project Officer who have stayed the course, despite 5 children between them! Alison Fettell, Helen Goltzoff, Terry Sarten and Kim Eisler also need acknowledgement who were the wonderful locums that maintained momentum during those maternity leaves.

The team started with a needs analysis entitled 'Leading the Way in Mental Health and Intellectual Disability' (2009) with a survey of the 58 school counsellors who provided services to the Schools for Special Purposes that cater for children with ID. This found staff felt an absence of training in the Intellectual Disa-

bility Mental Health (IDMH), the prevention programs that mainstream education used didn't work in this population, and there were no clear pathways to care for the mental health needs of these young people and paediatricians were likely to be the only accessible service. It was remarkable to find in 2009 what appeared to be 'a green field site' in the understanding of mental health of children and adolescents with intellectual and developmental disabilities in NSW! What we did have was a unique partnership between Health/Mental Health, NSW Department of Education and The Department of Aging Disability and Home Care (ADHC), and more specifically the Statewide Behaviour Intervention Service (SBIS), led by Lesley Whatson.

The establishment of Developmental Psychiatry Clinic and Partnership: This high-level partnership had grown on the back of the monthly joint consultation inter-agency tertiary Developmental Psychiatry Clinic (DPC) which had been running since 2000 when Lesley Whatson brought the SBIS in to partner the DPC. This clinic derived from a once a month clinic that I took over in 1991, that ADHC funded to provide psychiatric support to the developmental paediatricians employed by ADHC and run originally at Grosvenor Hospital and subsequently with the Inner West Disability Service. When the funding available through ADHC for these sessions ceased, I continued to provide the service to the paediatricians, which were now held at CHW, Lesley and her team joined, with the view that the cases in this clinic should be seen as priority cases to ADHC. This act was a game-changer that led to strong collaboration between Health and ADHC going forwards. The clinic sometimes had upward of 20 people bringing information and experience to the consultation. We would have the patient and their family, their disability service provider and respite staff and representation from the school which might include the principal, teacher(s) and school counsellor. Our interagency tertiary team had paediatrics, psychology, speech therapy, occupational therapy, family therapy, cross cultur-

“This article contains both
a brief account of our
history and achievements”

al, pharmacy, special education and psychiatry skills. The cultural issues became a regular aspect of the clinic's work, because of the number of cases from immigrant families, who have additional difficulty in accessing appropriate services. These clinics developed a reputation for problem solving difficult cases. Indeed, collaboration is necessary for complex cases as no one agency has access to all the professional disciplines. In 2014, this partnership between health, disability and education was subject to an independent review by The Centre of Disability Studies under Professor Patricia O'Brien (2014). The report found that the partnership provided best quality standards of patient-centred care, in keeping with the National Standards for Disability Services (2013) and it represented a world best practice for community-based care and support for the most complex cases, on minimal funding. It was seen as a beacon of hope, and several families reported that without this level of support they could not have gone on caring for their child or children with disability. The main recommendation was for expansion of the service and more funding support.

The development of specialised eclectic IDMH for children and adolescents.

Back in 1987, NSW disability services were transferred from health to welfare. Although the expertise of the medical assessment teams went with them, they were then handed back to health in 2013. In 1990 the Training Resource Unit (TRU), the tertiary disability resource for ADHC developed an applied behaviour analysis (ABA) service, based on the principle that all behaviour in those with intellectual disability could be explained by external antecedents and consequences, ie. 'the black box principle', and you didn't need to know anything about a state of mind. The then head of the TRU reported to a special interest group of psychiatrists that she saw no role for psychiatrists for people with intellectual disability. There is no doubt that in early development, behaviourism is important, but a narrow interpretation can exclude the relevance of consciousness and inter-subjectivity. This philosophical or prejudicial standpoint is mirrored by the mental health clinician who said "if he can't talk, he can't have a mental health problem!" There is no dispute that the strongest evidence-base for intervention in emotional behavioural disturbance in children with intellectual disability is behavioural. This is illustrated by the epidemiological intervention of Stepping Stones Parent Training, which is cost effective, and illustrates improved mental wellbeing in parent and child and improved attachment behaviours (Einfeld *et al*, 2018). I conceptualise behavioural intervention as a non-verbal communication. This is to say, improved behaviours also improves how you feel, the feedback you receive, and improves what you think of the people that matter. However, recent research also emphasises the

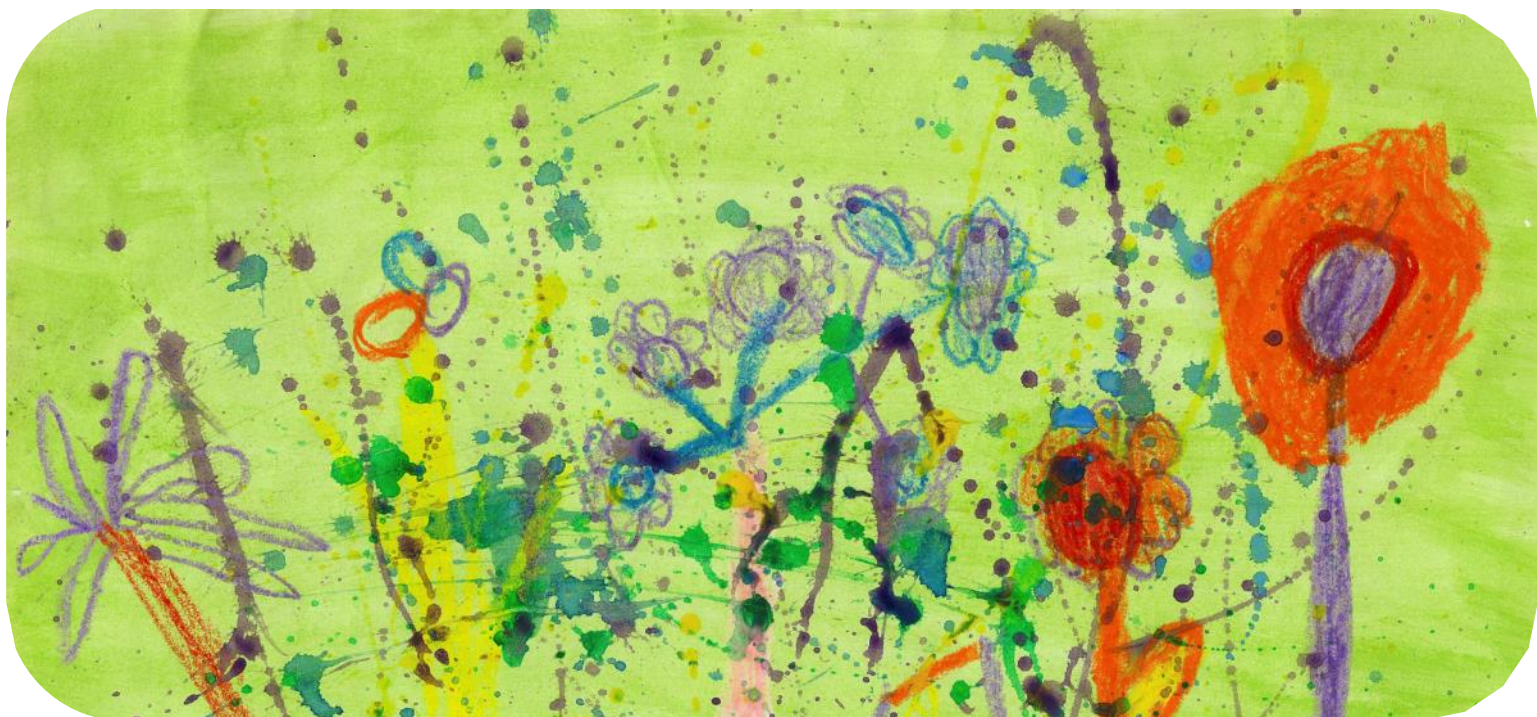


limitations of ABA and emphasises co-design with participation of the client in the process (Hastings *et al*, 2018).

I must acknowledge that subsequently ADHC and SBIS, the successor to the TRU, not only took a primary concern for the challenges of emotional and behavioural disturbance but spent a good 10 years building collaboration with mental health services, developing the MOU between Health and ADHC (2010).

I feel that in recognising the contribution of the individual with autism, we also need to take account of our understanding of the sequential development of the mind as propounded in the developmental psychology and psychiatry model that we have written about (Dossetor 2015).

I reflect on the developments of developmental psychiatry in the context of my career and on the rate of change in ideas and service models. When I arrived in Sydney in 1991, the Department of Psychological Medicine had been dominated by the psycho-analytic model of child psychiatry and the problems of the department led to an external review by '3 wise men' of Ad-



ler, Carmichael and Werry, reporting on the lack of empirical and research approaches, the poverty of training and the lack of service to the children's hospital and of those with severe psychiatric disorder. Under Ken Nunn's leadership, appointed as the new head of department, there was a renewal to a modern, empirically-orientated, multi-modal, bio-psycho-social model with an interest in child neuro-psychiatry. This included an assumption that children and adolescents with intellectual disability should have equity of access to the service, something that is still lacking in many CAMHS services. Under his leadership the Department of Psychological Medicine prospered, nested in the tertiary/quaternary paediatric hospital for NSW, developing tertiary services in consultation liaison and medically unexplained symptoms, eating disorders, developing the CAPTOS (Child and Adolescent Psychiatric Telemedicine Outreach Service) to all of regional NSW in 1999 and an inpatient service in 2004. I continued to keep my specialist interest in children with intellectual disability and autism, and in 2004 I received funding for the first clinical psychologist to work in the mental health of children and adolescents with ID in NSW.

Dr Michelle Wong, who as a clinical psychology intern did her PhD on 'Vicarious Hopefulness' (i.e. the hope you have for your child) and was very experienced in ABA, was appointed. I determined that as we were such a small resource that half her time be designated to research to have a wider impact. She developed Emotions-Based Social Skills Training (EBSST) for autism and, with numerous important partners including Belinda Ratcliffe, we now have published the manuals with on-line training with the Australia Council for Education Research. The Westmead Feelings Program 1 (formerly EBSST) is for primary school aged children

who are verbal but not literate and program 2 for those who are literate (www.acer.org/au/westmead-feelings-program).

Westmead Feelings Program for adolescents with mild intellectual disability will be next, courtesy of our research fellow Anita Gardner and funding from a private hospital donor. There is 15 years of research demonstrating improvements in emotional literacy with the large effect sizes and improved mental health, in partnership with the NSW Department of Education, Aspect and other community clinicians. This research is central to establishing the developmental nature of autism and of emotional skills, and emotional regulation which contributes to mental wellbeing.

The developmental psychiatry curriculum and framework: In 2004-5 in partnership with ADHC we provided 2-day workshops around the state in the assessment and treatment of emotional and behavioural disturbance in autism, but this service was subsequently provided nationally by Aspect with federal funding. In 2006-9 our partnership was funded by both NSW Mental Health and ADHC which funded Donna White to manage the 'Training Curriculum Project' to develop an evidence-based 2-day interdisciplinary curriculum for the mental health of children and adolescents with intellectual disability. This was based on a literature review, a stakeholder survey, a review of training requests, but also based on clinical multidisciplinary expertise of what works. The curriculum included:

1. The scientific foundations for the bio-developmental-psycho-socio-cultural multi-causal framework.
2. Family adaptation and the burden of care.
3. Multidisciplinary interventions that promote de-

velopment.

4. Interventions that promote MH including formulation, medication and safety planning.
5. Models of service and collaboration.

Over 600 clinicians were trained with subsequent evidence of impact on practice. This project led to the publication of the textbook: *Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A framework for professional practice* (Dossetor, White & Watson 2011). This in turn has led into this School-Link Journal for the Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities which has been led by Hebah Saleh with an interagency editorial board (which now includes Barbara Lewis from Carers NSW) for 10 years and 24 editions. The journal provides a continuation of the same philosophy of providing an up-to-date evidence-based interdisciplinary journal on what you need to know about the changing world of this area of professionalism. It is a free downloadable electronic journal available through www.schoolink.chw.edu.au and has a readership of 2000 across NSW and around the world.

One of the limitations of working with a minority population is the lack of academia and funding for research. The professionals who work in this area also feel their minority status but share a self-belief that we can help. In between the critical difference between ‘the evidence of absence’ of effect and ‘the absence of evidence’ (where there has been no research funding to test the hypothesis) is most of developmental psychiatry. There is a huge amount of important evidence, but much of it is based on cases studies, clinical cohorts, professional consensus and control studies. Further within these populations there is such diversity. Yet science is regularly working on a single mechanism model, looking for the single cause or a single cure, for example in autism.

Clinically, I feel the important work is describing and defining the developmental nature of autism and the co-existence of their multiple psychiatric disorders. Children follow the same developmental sequence seen in normal early childhood of skills in emotional literacy and theory of mind – this is paralleled in autism but delayed. This model explains why they have trouble understanding others but does enable us to have a framework for understanding the way they think and feel.

Child Psychiatry has tended to be anthropomorphic, and only slowly are we understanding the differences of childhood awareness from adults, and progressively demonstrating this sequence of social and emotional

“Only slowly are we understanding the differences of childhood awareness from adults”

development scientifically through our autism research.

The development of psychiatry and mental health is the art and science of progressively refining our knowing of others, and particularly how to understand those that fail to integrate socially, or in other words suffer a mental disorder. When everyone puts high priority on their own conscious world, why is mental wellbeing considered a low health and scientific priority? Pinker describes civilisation as the awareness of human consciousness of the world of 7 billion separate internal worlds (Pinker, 2017). At least quality of life is now an area of academic study and is found not purely related to affluence and gross national product (Cummins, 2012). Martin Seligman’s studies of flourishing in European countries, show that only between 7 and 33% of people feel they flourish, and are heavily influenced by the social reality and politics of equity (2011). Flourishment of course includes not just belonging but having something to contribute to others. It is fundamental to being human that we are connected and engaged with others. Robert Cummins described disorders of quality of life as the nearest thing to psychiatric disorders (2012).

Changing models of disability service provision: In the UK in 1980s a dominant view was the psychotherapeutic notion that having a child with a disability is a state of perpetual grief in the parent for the anticipated perfect child. Psychotherapy may be an interesting educational theory, but it is not helpful for many, especially with such real hardship. Evidence shows that caring for a child with intellectual disability involves care (predominantly by a mother) an average of 7 hours a day and 7 days a week. The level of emotional and behavioural disturbance has more effect on the wellbeing of parents and family than the level of disability. In the 1990s in the UK, the model of service provision was moving from psychiatric specialists in intellectual disability providing care ‘from cradle to grave’ to having child psychiatrists include young people with intellectual disability in their practice. I was amongst the first child psychiatrists to be trained in intellectual disability and so my MD research thesis aimed to bring child psychiatry methodology to the homes of 92 families who had a teenager with intellectual disability with

4-hour interviews.

In this 4-year study, I learned that these families truly love these disabled young people but also how isolated and little understood these families are. Many felt so indispensable to these young people that 20% said they would rather have their child die than to go into an institution! These were complex children and families, but my research, including a 7 year follow up study, gave me a special understanding of these teenagers/young adults and their families. It was at this time the Minister for health (in the UK) declared that no child should be raised in a hospital, and huge amounts of welfare funding was made available to re-house 25 severely disturbed young disabled people that I struggled to manage as they were moved from the intellectual disability hospital to community based residential units. Importantly, it must be realised that this was at approximately 3 times the cost! The lesson is that a humane standard of care does not come cheap. Mainstream child psychiatry really had no therapies that could help the level of emotional and behaviour disturbance of these challenging teenagers, and in tackling this disturbance and distress my mentor Dr

“Relying on symptom counting with questionnaires misses the most important information about relationships”

Agnes Hauck taught me that “any doctor worth his salt had to be prepared to prescribe”. Conversely, providing realistic hope is necessary to be therapeutic. However in the context of the severity and chronicity of disturbance, even small improvements made a big impact on the young people with intellectual disability and their families. Medication therefore had a potential for creating miracles in situations of chronic, irremediable adversity and disturbance.

Accordingly, my first dictum is that it is possible for any child and their family to have a ‘good enough’ quality of life (there is no such thing as perfection) and we should be aiming for that. The principles of what creates a quality of life for the general population also applies to those with intellectual and other disabilities.

Innovations in Skilled Practical Respite: One of my MD research findings was that family wellbeing and a positive relationship with the teenager with intellectual disability was correlated with practical help and support (rather than emotional support) from friends or rela-

tives (Dossetor & Nicol, 1990/91). Often this help was only once or twice a week and only for an hour or two. This importance of practical support from a friend or relative was explored in an ADHC funded NGO project that Leslie Watson and I were involved in. This project did enable and legitimise a family to register a relative or friend to receive funding for supplying respite. It also aimed to provide support to the family and respite carer by providing Stepping Stones Parent Training. Although I think the principals were good, the NGO were unable to fulfil the commitment to deliver the parent training, and not many friends or relatives came forward. It did however establish the legitimacy of funding a friend or relative to provide respite, thereby enhancing the natural supportive relationships.

We were also involved in another NGO project of residential respite care, on the basis that the family were prepared to learn specific behavioural skills learned from the respite unit, enhanced by Stepping Stones Parent Training. The clients found this project popular and effective, but funding was not continued. The burden of care is the main handicap for parents and families, and I find that too many parents with a child with IDD are highly stressed. The lack of support from others also contributes to them feeling indispensable and exclusively responsible. Inadequate support and help from our community leads to a heightened risk of parental murder suicide ideation. Is there any evidence that support funding from the NDIS has shifted this?

Scientific Methods and Relationships in Mental

Health: I impress on my medical trainees that the clinical process to psychiatric assessment has reliability and validity and relying on symptom counting with questionnaires misses the most important information about relationships. The methodology for evaluating the quality of relationships is derived from the Rutter Marriage Semi-structured Interview, which in turn led to the importance of high expressed emotion of the next of kin on the psychiatric wellbeing of the person with a psychiatric disorder (Leff & Vaughn, 1985). Humans, even 3-year-olds, have an absolute capacity to deceive their nearest and dearest. A fundamental question of every assessment is whether you have a reliable basis of knowing the child and family. When you provide them with the formulation, does it ring true to them in language that they understand, does it help them understand the predicament of their child and their family, and will they listen to and act on your advice? As a result, do you have a therapeutic engagement and a common understanding of the problem(s).

Study of the Psyche or soul, psychiatry, is therefore about the objectification of the state of mind of the presenting patient, or the description of phenomenolo-

gy. Despite the capacity of someone to deceive another and the issues of reliability of eliciting subjective phenomena, it is inherent to our social nature that we give objective validity to mental states. Not surprisingly there is greater difficulty reliably recognising the nature of the conscious world of children and people with intellectual disability. This does not mean they do not have a conscious world, but making a best judgement of what they experience is a special skill and a growth area of research enquiry. Professor Graeme Watts in his PhD (2010) described that the development of theory of mind skills at 2.5-3 years is historically described as when the spirit enters a child. They then appreciate that others have this skill of consciousness of others' and a recognition of social belonging as a human. The Westmead Feelings Program of emotional literacy education arose out of the question of what do you need to teach a child with autism, after they have had what ABA can contribute? In this framework, someone with autism has a social understanding of a 2 year-old or less, and for someone with Aspergers it is less than 4.5 years. It is also recognised that they progress in their emotional literacy over time, especially with specific education and support.

Elaborating the developmental model: I have long propounded the general laws of development and those of delayed development (Dossetor, 2011): 'Where there is life there is development in a systematic sequence' (Werner). 'Development involves orderliness, sequentiality, and apparent lawfulness of the transition taking place from the birth or conception of an organism to the attainment of maturity' (Zigler, 1963). It progresses from relative globality & lack of differentiation to increasing differentiation, articulation and hierarchic integration. Both individual and context differentiate, leading to a development-transactional approach. If development is delayed it still progresses in a predictable sequence, despite a diversity of identifiable causes of delay. If development is delayed, it is likely to be unevenly delayed across the different domains of development. If one area is delayed, then there is an increased likelihood of another area being delayed. Behaviour and emotional connection is best explained in the context of the level of development. Development is due to the increasing mathematical complexity of neuronal connectivity rather than neuroanatomical differences. Since I first made this observation, brains scans that picture connectivity of neuronal networks have developed, and atypical connectivity is described in autism (Ray et al, 2014). Importantly, parents and indeed the child themselves understand such developmental descriptions and this allows parents to modify their parenting to help a child with intellectual disability or autism. Developmental theory implies possible benefit from a whole range of development enhancing

interventions to help someone with developmental problems. This can be sensory/motor development, behavioural learning, speech or emotional literacy and indeed education as potential means to enhance skills and wellbeing. Such approaches are similar to positive psychology or 'the recovery model' of psychiatry which complements the illness model or the scientific model which aims to simplify disorder and identify single causal mechanisms. The recovery model or developmental model is individualised but assumes a multi-causal model of delay and disorder in context.

As Dr Ken Nunn recently articulated, all of human perception is through their body, and therefore the developing consciousness arises through awareness of the body in touch and pain and perceptual location, movement and rhythm, sound modulation and sight. These are also early sources of reciprocal engagement through touch and cuddles/massage, engagement in coordinated movement, which can be enhanced with music and dance, and gaze. Describing different domains of developmental stages is the best measure of ability before a child has a capacity to use their intellectual and conceptual skills which are then measured by psychometric tests. This developmental metric applies to all children, whether with or without developmental delay. Indeed, one can argue that this developmental progress is a measure of the influence of reciprocity which includes the nature of the emotional

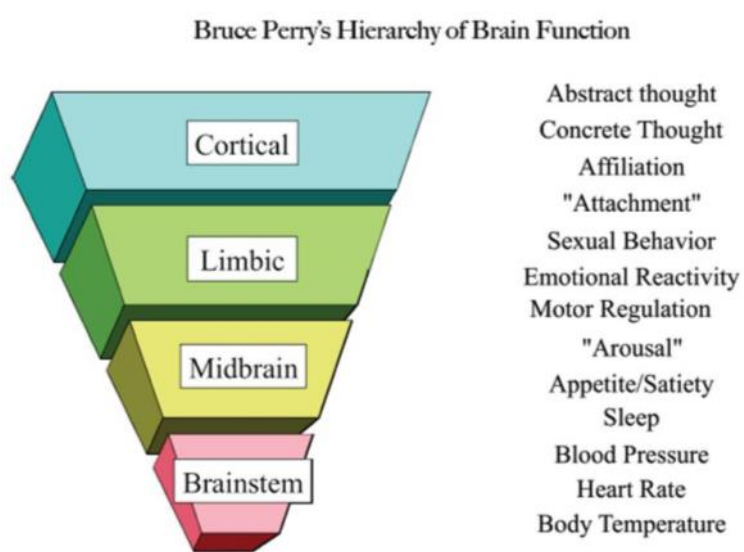


and stimulating environment on the developing child. Similarly, we need to ensure that therapy is developmentally appropriate for children with IDD.

Nicolette Soler, our team Occupational Therapist, is demonstrating in her PhD how sensory therapeutic input, in terms of a modified Alert Program, has dramatic benefit to Tourette Disorder (Soler et al, 2019). What she has also found is that an abnormal sensory perceptual profile is not specifically related to Tourette but is associated to the number of co-occurring neurodevelopmental disorders (Soler et al, 2019). She is now working on improving the measurement of sensory profiling. Does the alert program work through increased sensory/motor awareness or self-control, or greater sensory/motor reciprocity?

Daniel Siegel working with traumatised children has described a similar neurodevelopmental sequence of the brain and mind, equating developmental awareness of: 1. arousal, 2. sensation/movement, 3. emotions and then 4. higher skills or executive functions to 1. brain stem (reptilian brain), 2. midbrain/cerebellum (rodent brain), 3. limbic system (mammalian brain) and 4. frontal lobes (human brain) respectively (Siegal & Szalavitz, 2017). Each level has to integrate with the lower level, and trauma at an early age can lead to 'stuckness' in an earlier component of reciprocal functioning. He too therefore advocates for the therapeutic benefits of touch and massage, movement, rhythm and music, all to enable engagement in emotional awareness and attachment because of the consequent impact on affect and higher human functioning.

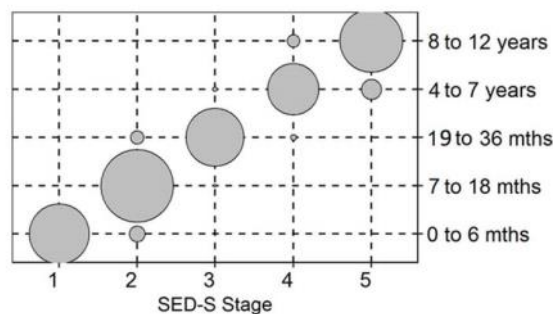
Figure 1 Neurosequential Model



Understanding these early types of reciprocal engagement are important for developing attachment in normally developing infants, but provides potential innovative therapies for developmental disorders which

Agreement of the SED-S overall score and the respective age groups

- SEAD-overall classification: 80.6% exact agreement, Quadric weighted Kappa 95.1
- Interrater reliability: N= 25 Cohen's kappa 1.0



Sappock T, Bohm J, Brilner J, Roth G, Henrich M (2019) How is your mind-set? Proof of concept for the measurement of the level of emotional development. PLOS ONE: 14(4): e0215474. <https://doi.org/10.1371/journal.pone.0215474>

need empirical study.

Anton Dosen and colleagues from Belgium have demonstrated a similar emotional development model now available in the English literature as illustrated in figure 2 which uses a similar neuro-anatomical functional sequence. Using the Scale of emotional development (Vandeveldt et al, 2014), they have demonstrated this sequence of emotional development correlates highly with age in normally developing children and with the level of intellectual disability in adults. This scale assesses 10 dimensions of skill: dealing with his/her own body; interaction with a caregiver; experience of self; object permanency; anxiety; interaction with peers; handling of material objects; verbal communication; affect differentiation; and aggression regulation and grades them on 5 levels. Further, Sappock and colleagues (2013) have demonstrated that adults of average age of 36 years with Autism and ID have a lower average emotional age of 1.5-3 years, than those with just intellectual disability whose average emotional age was 3-7 years. The emotional age was also predictive of emotional and behavioural disturbance.

Discrepancies between the level of ID and ED

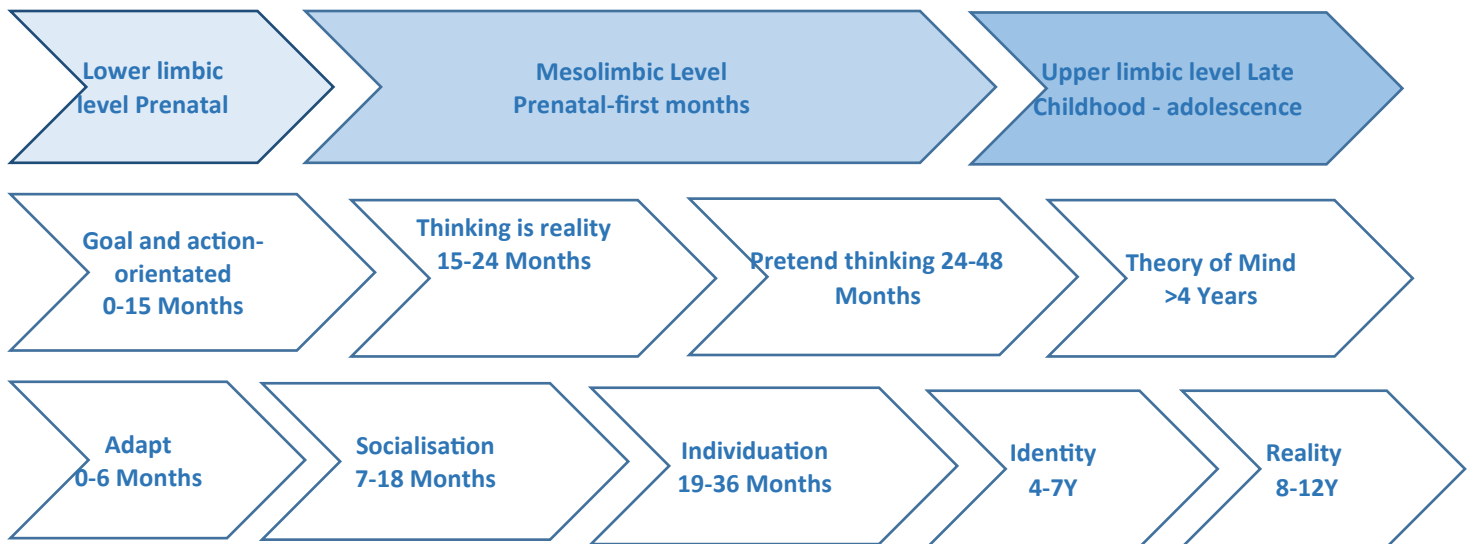
As expected, the level of ID and ED are highly correlated: $r = -0.6$, $p < 0.01$
BUT: the level of ID and ED differed in every second person!

		Level of ED n (%)				
		SED-1	SED-2	SED-3	SED-4	SED-5
Severity of ID	Mild	1 (3)	2 (5)	1 (3)	20 (52)	14 (37)
	Moderate	1 (1)	5 (5)	21 (20)	61 (58)	17 (16)
	Severe	3 (3)	24 (25)	44 (45)	23 (24)	3 (3)
	Profound	4 (18)	4 (18)	13 (59)	1 (5)	0 (0)

N = 262, mean age 38 years, 54% male

Bohm, Dziobek and Sappock. (2018). Emotional development, aggression regulation and challenging behaviour in individuals with intellectual disability. Fortschritte Neurologie/Psychiatrie.

Development of Brain Networks, Cognitive and Emotional Functioning



The establishment of this emotional developmental model of understanding is certainly helpful clinically and therapeutically. Our autism research is also progressively establishing evidence on emotional and social sequence. It may also inform our future autism intervention research for those with moderate intellectual disability examining these earlier processes and skills of reciprocity in the future.

Insell and others have criticised the limitations of the scientific validity of DSM-5 and proposed the novel Research Domain of Criteria model of psychiatry (Insell, 2013). Although individual scientific discoveries can make stepwise contributions to our understanding of the brain and mental health, I do not see it replacing the phenomenological approaches to understanding others. Further, I feel that any empirical epidemiological mental health study for neurodevelopmental disorders and children will need to include a methodology for multidimensional developmental staging as well (Wing, 1981). In effect, in biology we cannot understand the mechanisms of the brain without also conceptualising the mind. In the same way the mathematics of flight is necessary to understand how the wings of birds fly.

10 milestones of the last 10 years of CHW School-Link:

1. School Clinics: We trialled interagency complex case discussions with Schools for Specific Purposes (SSPs) of Western Sydney LHD but this could not be sustained. However, we have continued to support school clinics at SSPs as an initiative and we support Dr Gillian Brooks' school clinic at Kurrambee SSP. We also ran a one-year research school clinic at Aspect

Vern Barnett School for autism, which identified how specialist school-based multidisciplinary clinics identify and treat needs not identified by community treatment-as-usual (Singhal et al, 2018).

2. In partnership with ADHC we supported the development of the first specialist parenting skills in SSPs using the Stepping Stones Parenting Program, which demonstrated dramatic effectiveness (Ray et al, 2019). We have subsequently been a partner to the MySay study to make an epidemiological and cost-effective difference to emotion and behavioural disturbance in children with intellectual disability and autism (Einfeld et al, 2018).

3. Workshops on understanding, preventing and intervening in the mental health problems of children and adolescents with intellectual disability and autism have continued and been well attended, although the demand has declined from a peak of 20 workshops a year. Since the introduction of the NDIS, there appears to be a decline in interest in interdisciplinary education on the mental health needs of young people with intellectual disability and autism.

4. We have supported mental health prevention, promotion and early intervention in intellectual disability, partly through watching and promoting those interventions that have an evidence-based literature, which you can find a list of in our promotional leaflet, available on the School-Link website. The collaboration with NSW Department of Education to provide emotion-based social skills training (Westmead Feelings Program) in a controlled study to 350 children across the state through the training of 64 school-counsellors, was a huge achievement and success (Ratcliffe et al, 2014 & 5). This study demonstrated large effect sizes



and improved mental health of high functioning primary school aged children with mild ID and Autism. We have since had a successful implementation study to all 8 NSW Aspect Schools for Autism. Westmead Feelings Program I was published with the Australian Council of Educational Research, with associated 'online' training in 2017, and WFP II in 2018, making these available to the English-speaking world (www.acer.org/au/westmead-feelings-program).

5. There have been numerous Conference presentations both national and international. I recall IASSID in Rome in 2011 and Melbourne in 2015 where in partnership with SBIS we presented and subsequently reviewed the validity of our curriculum framework and explored whether there were new or better educational curricula for the mental health of C&A with ID.

6. "Meet Jessica" an animation and mental health awareness training workshop was developed in 2016 in partnership with NSW Department of Education and SBIS and which reached over 1000 clinicians and teachers across NSW with a train-the-trainer workshop and promoted approaches to reasonable adjustment to support the special needs of C&A with IDD (<http://www.schoollink.chw.edu.au/workshop-resources/>).

7. Webinars in IDMH have been developed in partnership with The Benevolent Society and educations Network Specialist Facilitator and hosted on the School-Link website, with more to follow. Current titles include:

- Curiosity, collaboration and action: Understanding & Responding to Behaviour in the Classroom;
- Cool, Calm, Collected & Connected in the Class-

room: Supporting Students with Self-Regulation;

- The Mental Health of Young People with Intellectual Disability: What you need to know and what you can do.

8. WellSEQ is a project to translate a mental wellbeing specialised questionnaire in easy to read English with a sound track and illustrations on an iPad for young people with mild and moderate intellectual disability from Swedish to English, and re-validate for free to air usage. This has the potential to become the Strengths and Difficulties Questionnaire (SDQ) equivalent for those with ID.

9. Several awards have been received by School-Link and the Westmead Feelings Program including: The Mental Health Matters Award for Cross Sector Collaboration in 2012; in 2014, Emotions-based Social Skills Training in Schools Project won the Cross-Sector Collaboration Award; and in 2014, CAPTOS won the same award. In 2016, 'Jessica' our mental health awareness animation and training received the quality and innovation award from the Sydney Children's Hospital Network in 2016 and was the highly commended Mental Health Matters award for collaboration. In 2016, I was awarded the SCHN Collaborative Leader of the Year. In 2019, Westmead Feelings Program received the Aspect "Professional Advancement Award".

10. Over the 10 years we have moved from a newsletter to a journal, the only one that focuses on mental health for C&A with ID. Over time I suspect we will gradually move from an interagency edited educational, best practice and informative journal towards more peer reviewed research. We try to encourage external

submissions. Kids art from SCHN makes it so attractive. There have been some key contributions to the Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities including:

- Innovative treatments and advances, including Positive Behaviour Support, safety planning, trauma informed care
- Allied health therapies, play therapy, music therapy, pet therapy
- Reviews of prevention promotion and early intervention, including Mind Matters, Westmead Feelings Program, Stepping Stones Parenting in SSPs
- Behavioural phenotypes, psychiatric disorders, Autism, diagnosis, formulation, and prescribing guidelines
- Service Development, School Clinics and understanding families
- The Medicine Cabinet: a different medication each edition
- Planning, policy, funding and the politics of IDMH
- Conference Reviews
- Interviews with experts
- Book reviews

Future Opportunities and Threats:

Enhancement: Our service has received some additional funding to be recognised and provide a statewide second opinion and problem-solving service. Until now it has been an initiative of the Children's Hospital at Westmead, built on recognised need and the opportunities that arose, providing and sharing tertiary expertise, teaching and clinical research. This enhancement will also build on the telepsychiatry outreach service of the CAPTOS service. It should ensure the future of Specialist Developmental Psychiatry in NSW.

The shifting sands of collaboration and the NDIS: The arrival of the NDIS has clearly been an important reform helping many. Some patients have benefitted from additional care support and the greater availability of funding for therapy. However, there have been problems in accessing reliable and good quality assessments for support and therapy. Many young people are accessing multiple therapies without a system to show evidence of benefit. Others are failing to find clinicians or support workers with the abilities to help, partly because they don't live in a large urban centre and partly because their problems are challenging and complex. The funding to enable collaboration and joint meetings is hard to get in complex cases. Perhaps the establishment of NDIS research funding will help evaluate therapy but also test out newer attractive therapies, such as a range of pet therapies. There are other significant problems. Health/Mental

Health NDIS representatives or champions are concerned about other problems such as access to dysphagia or oxygen support, or residential care for those with chronically disabling psychosis or personality disorder. Currently it seems there are problems accessing services for complex emotional and behavioural problems for which there needs to be access to the 'complex support needs pathway'. There may be a focus on recording restrictive practice which may be a proxy for recording major incidents, but little access to quality multidisciplinary positive behaviour support, or reactive management plans for severe aggression or recurrent self-injurious behaviour. There is a need for a mechanism for urgent disability response, and a decline of the availability of emergency residential respite.

It saddens me that The Benevolent Society who took over the staff and tertiary service provision of SBIS of ADHC have disbanded this service. Although they are contributing to some training webinars, we have lost their interagency leadership role and academic leadership with the journal and research, and also the clinical collaboration for the Developmental Psychiatry Clinic. Funding problems are the explanation given. Evidently as a federal insurance system, the NDIS does not have any mechanisms to collaborate with state-based Mental Health Services as was negotiated and established over a 10-year period of relationship building to create the MOU between ADHC and Health/Mental Health. There is increasing pressure for health therefore to provide accommodation of last resort when troubled young people with intellectual disability arrive in emergency departments with a breakdown of disability funded care with acute and chronic disturbance or mental disorder, and there is a lack of a mechanism to bring higher level skills to residential services. A warning is provided by the recent British Children's Commissioner report on the number of children spending excessive time in psychiatric wards (Longfield, 2019).

There is a lack of agreement on what is restrictive practice and what are the implications between NDIS and Mental Health. When a guardianship tribunal declared that any psychotropic medication is a restrictive practice, this representative for disability services evidently didn't consider the need or human rights of someone with disability to receive mental health treatment.

Over the years of collaboration with ADHC, the main role of restrictive practice guidelines in the cases I see is to enable restrictive limit setting to be therapeutic, in the best interests of the child and in the context of best practice and effective treatments. It is critical that different agencies work together to support parents

and other carers to have reactive management approaches, and systems of ensuring safety (Whatson et al, 2011). Establishing parental authority is often the key to improving complex challenging behaviour (Dossetor, 2016).

Some in the NDIS, with experience of the best that the state-run disability services did particularly for complex emotional and behavioural disturbance, remain hopeful that some of these problems can be improved. The new Director of Planning of the new Complex Support Needs Branch, of Service Delivery and Performance of the NDIS remains optimistic that skilled professionals in different agencies can work together for those of greatest need. My message of hope that I give patients is don't give up as the NDIS is legally obliged to provide sufficient and reasonable support, which includes provision to enable safety.

Over the last 10 years there is increasing awareness of the significance of emotional, behavioural and mental disorders in people with intellectual disability. They certainly need access to specialist health and mental health services. Sometimes they need brief diagnostic admissions (including medical assessment made possible under anaesthetic), but I think long term care and support should be managed in the community. While major/psychotic mental illnesses need access to assessment and early treatment in a mental health setting, it is not appropriate and is contrary to the Mental Health Act to be admitted to a psychiatric service in the absence of such mental illness. This area of work needs priority access to disability services and expertise. Much of the reputation and influence of the Developmental Psychiatry Team and CHW School-Link has come from the power of collaborative approaches and the associated richness of ideas. We shall continue to work toward re-establishing similar rich and productive relationships of interagency collaboration, tertiary expertise and academic excellence in the context of the NDIS for these complex cases.

Research Partners and Promise: Clinical research has been central to advancing the mental health and well-being of young people with ID on limited amounts of funding. CHW School-Link has had a range of external academic partners for example with Julian Trollor, the first established chair of IDMH, and the University of NSW Department of Developmental Disability Neuropsychiatry, Susan Hayes and the University of Sydney, Belinda Ratcliffe and the University of Western Sydney, and the Agency of Clinical Innovation Disability Network. The appointment of Adam Guastella as the Michael Crouch Chair in Child and Youth Mental Health at the Children's Hospital at Westmead and Brain and

Mind Institute, opens new avenues of 'large data' approaches to exploring neurodevelopmental disorders with a consortium proposal to centralise information on 2000 new neurodevelopmental cases a year. This consortium proposes a national research enquiry, looking at genetics, immunology, drug studies, parenting, and community integration. My hope is that some of the strengths of the models that we use will be incorporated, and that government funding will support such a world leading innovation.

The next 10 years: CHW School-Link has established important roles in advocacy, leadership, education, training, research and clinical services, with contributions in awareness raising, prevention promotion and early intervention and tertiary collaborative clinical services for young people with IDD. The CHW School-Link 10-year anniversary has been a chance to celebrate its contribution to building collaborative interdisciplinary, interagency developmental psychiatry that did create that beacon of hope for the most troubled families. If people appreciate what can be done with such collaboration of expertise, I hope it will again. School-Link for children and adolescents with intellectual and developmental disabilities is an organisation of significant influence in NSW but has a presence nationally and internationally and I wish them and all their partners to have a continued growth, success and influence in the next 10 years.

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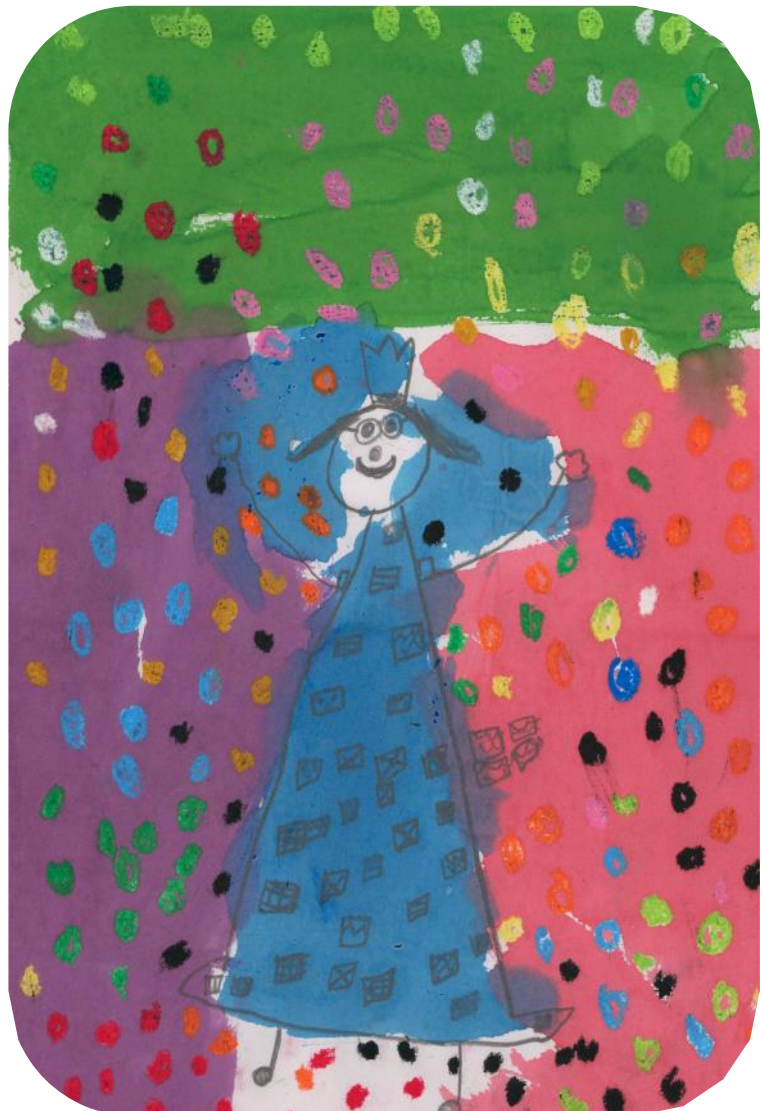
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The Medicine Cabinet: Oral Health

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Oral health is important for all children and adolescents and especially important for those who take medications which can affect both teeth and the oral cavity. Poor oral health – mainly tooth decay, gum disease and tooth loss – affects many Australian children and adults contributing to 4.4% of disease burden in 2011 (AIHW). Dental cavity rates vary within populations due to many factors. Oral disease and the maintenance of oral health can present challenges to children with chronic diseases and other special healthcare needs (AIHW, 2019)

There are many causes for enamel loss and dentin loss in teeth; some genetic and some environmental. With enamel and dentin loss, there is a surface for infection to enter the body and this can have very adverse effects. Australian Dental Association recommends teeth cleaning from 6 months of age and to continue for life. Factsheets and further information about dental services are available <https://www.schn.health.nsw.gov.au/find-a-service/health-medical-services/oral-health-dental>

Social disadvantage is also linked to poor oral health and patients with disabilities also require specialist services which are not freely available. Medicare Australia does cover the dental needs of all children under the age of 18. Sugary drinks not only add to the obesity rates but also figures indicate that 70.3% children (9-13 years) in Australia consume too much sugar (ADA, 2019).

Teeth grinding

Bruxism is often listed in lists of adverse effects of medication but it also can occur naturally. Bruxism or teeth grinding occurs more in childhood and can be characterised by association with sleep apnoea and micro-arousals from sleep and activation of the autonomic nervous system (Gerster, 2019). Fluoxetine (Lovan®, Prozac®) has been associated with bruxism treatment. There have been reports of the use of gabapentin (Neurotonin®) or dose reduction. Amitriptyline and clonidine has been used in adult patients for teeth grinding with some effect.

Dry mouth (xerostomia)

Medications that affect the cholinergic/muscarinic sys-



tem such as amitriptyline and clomipramine can cause dry mouth or xerostomia as one the adverse effects and thus lead to further tooth decay risk. Alternative antidepressants may also cause dry mouth but to a lesser degree with fluvoxamine having the greater potential of the SSRIs. Other medications that also cause dry mouth are olanzapine, risperidone and quetiapine but also to a lesser degree aripiprazole and paliperidone. In clinical trials there were reports of dry mouth with amphetamine salts so dexamfetamine and lisdex-amfetamine could be implicated. Sucking on ice helps alleviate the dry mouth and increases saliva.

Carbamazepine which is a mood stabiliser and also used in aggression management, also has reports of

“Social disadvantage is also linked to poor oral health ”

causing dry mouth. In some clinical trials, there has been reported adverse effects. Clonidine is often used to help decrease arousal and help with impulsivity associated with attention deficit hyperactivity disorder or even due to its sedative effect given at night to help with sleep.

Some of the preventer asthma preparations such as those containing beclomethasone or fluticasone can cause dry mouth, so patients are encouraged to rinse their mouths after using to prevent the dry mouth and increased steroid systemic absorption. Reports of dry mouth are also noted even when using non-sedating antihistamines such as cetirizine. When omeprazole and esomeprazole as well as famotidine are used to treat gastrointestinal reflux they have been reported as causing dry mouth.

So with all medications there is the potential to cause dry mouth and the effect can be additive so this common adverse effect needs to be monitored and addressed by keeping hydrated and increasing the saliva in the mouth by sucking on ice chips or unsweetened hard lollies.

Impact of dosage form on oral health

Consumption of free sugars – monosaccharides and disaccharides are the main contributor to dental caries in children, young people and adults. Free sugars are available in honey, syrups, fruit juices and fruit juice concentrates as well as in liquid medications. Reducing the amount of free sugars consumed is an effective strategy for improving dental health as well as metabolic health.

Most common available dosage form used in children is the solid dosage form either tablet or capsule but when a child can not or will not swallow tablets or capsules then a liquid preparation is needed. Liquid preparations are often sweetened with either sucrose or artificial sweeteners to mask the often bitter taste of the original medication. Also to make a product soluble, often the medication has to be in an acidic or alkaline environment, and both these can have detrimental effects on teeth and the oral cavity. One of the product Ferro-liquid® (A liquid iron preparation used to treat iron deficiency anaemia and often used to correct poor nutrition) has a pH range of 1.4-5.3 which is

very acidic thus leading to increased dental decay. For reference a popular cola drink has a pH of 2.5 and a sugar content of 106 mg/ml but Ferro-liquid® has 600mg/ml. If using sweetened or any oral liquids always rinse the mouth after dosing or suck on some ice.

Some medications can be prescribed as tablets and then crushed and dispersed in water immediately before giving the dose. As not all medications can be given this way it is always best to check with the dispensing pharmacist as they have resources to confirm the suitability of this method. The same with some capsules where the contents can be mixed with apple puree or yoghurt and given; this method might be problematic for patients with oral sensory issues as it leads a grainy texture.

A good resource to help teach children to swallow tablets or capsules is <https://www.rch.org.au/pharmacy/medicines-information/Teach-children-how-to-swallow-tablets-and-capsules/>

Another method to avoid use of sweetened liquids is use of a medication lubricant which is an aid to help swallow tablets/capsules, these can be flavoured and vary in thicknesses and are primarily used in the geriatric population.

Conclusion

It is important for the general health of all that the oral health of a patient is monitored and cared for. Reducing the need for sugary drinks both in general consumption and via the use of medications will also help maintain good oral health as well as drinking water.

If the patient has oral sensitivities and thus needs oral liquids speaking with your occupational therapist about some desensitising strategies would also be helpful.

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Inappropriate Sexualised Behaviour in the Classroom: A short case study

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The following article is an excerpt from the JHFMHN Newsletter from Summer 2020 (AMHDAP [Adolescent Mental Health and Drug and Alcohol Programs] gives you access to a team of clinicians and psychiatrists who specialise in forensic mental health. Send through any questions you have regarding the needs of Young People involved in the criminal justice system to JHFMHN-Schoollink@health.nsw.gov.au

I have a 12 year old boy Kingston (not his real name) with a mild intellectual disability in my class. About two weeks ago, I noticed that he was often putting his hand down his pants in class, and just the other day, he began masturbating in the classroom, and was also masturbating on the school bus. Other students who saw this behaviour reacted by either laughing at him or becoming aggressive towards him, and some of the girls seemed frightened by his behaviour.

These reactions made Kingston feel upset. I had initially redirected Kingston to keep his hand out of his pants, and have since spoken to Kingston's parents about the masturbation incident. They seemed shocked and embarrassed and said they would have a talk to him and would be grounding him. Can you please give me some advice on how to support Kingston with this incident, as well as the other students? Thanks!

Hi,
It's really great you reached out to ask us this question as it is not uncommon for people with an intellectual disability to engage in inappropriate sexual behaviour such as masturbating in public. **Masturbation itself however, is actually a healthy and natural way for people to express their sexuality although when it is done in a private place.** We therefore want to refrain from responding to Kingston in a way that makes him think that masturbating is not acceptable, as it is appropriate for a boy his age (e.g. by Kingston's parents grounding him, it may evoke feelings of shame and thoughts that masturbating is wrong).

Have conversations with Kingston using simple, concrete words, about boundaries, such as when and where it is acceptable to masturbate, what he is thinking and feeling, and to try and understand why he is masturbating in class and on the bus (i.e. what is the function of the behaviour). It would also be helpful to

see what his level of understanding is of sexual health, and you could collaborate with learning support staff, the school counsellor, local youth health services, NSW Family Planning or The Children's Hospital at Westmead School-Link to deliver information suited to his developmental level, and in a way that he understands e.g. by using visuals, social stories (see example in our own newsletter here).



In using the ‘traffic light tool,’ I would say that Kingston’s masturbating in class and on the bus is ‘concerning’ (orange) as although it was in public and has caused others to feel frightened or uncomfortable, the behaviour is age appropriate, has happened twice, and seemed spontaneous. Providing intervention and support at this early stage will hopefully prevent or reduce the likelihood of it happening again.

Individuals with intellectual disability generally have more limited social networks, and therefore less opportunities to learn about socially appropriate behaviours and the effect of behaviour on others.

Asking Kingston about the impact of his behaviour (for example, “What did your classmates do when they saw you masturbate in class? Did they look comfortable or uncomfortable?”) or providing information around this can allow him to develop empathy for others and positively affect his ability to manage his behaviour.

Try and **be aware of when Kingston is about to masturbate** (e.g. has his hand down his pants) **in order to remind and redirect him back to task.** If the public masturbation continues, it is best to respond in a calm, matter-of-fact manner as you would with any other inappropriate behaviour. This will also help Kingston to stay calm as children and young people take their cues from us and may feel upset if there is a strong negative reaction. Ask Kingston to stop the behaviour and remind him of the difference between private and public behaviours. These reminders may need to happen multiple times before he learns more appropriate behaviour. For example, you might say to Kingston: *“I saw that you were masturbating in class before lunch. Masturbating is what you do in a private place, like in your room at home. School is a public place so you need to keep your hands outside your clothes. Masturbating makes other students feel uncomfortable and upset. I can see it makes you upset too when they feel this way. If you feel like masturbating again, you need to do it in private at home and not at school.”*

A **behaviour support plan** can be created with Kingston, his parents and support staff to assist him in developing more appropriate behaviours and for him to be praised and positively reinforced when he does. Doing so ensures that information and boundaries provided to Kingston are clear and consistent. Both school and parents can monitor his behaviour and help him to self-regulate his behaviour.

Conversations with students who have witnessed the behaviour could also be about sexual health, sexuality,

“Information and boundaries provided are clear and consistent”

and all the changes (that may seem strange and scary!) that happen to their bodies, and to their thoughts, feelings and behaviour when they go through puberty – and that it is OK to be curious about these things! It should be reiterated that aggressive or bullying behaviour is unacceptable and students can explore how they can be kind and supportive of one another.

Keep in mind that due to his intellectual disability, Kingston is more at risk than others of being exploited. Students should be encouraged to let you know if Kingston or any other student engages in inappropriate behaviour so that it can be managed. Where necessary, referrals for counselling support can be made for Kingston and other students. You can also speak with your Head Teacher or Welfare Team regarding support for yourself.

Download a copy of the JHFMHN newsletter on the CHW School-Link website
www.schoolink.chw.edu.au

Family Planning Resources:

About Masturbation for Males/ About Masturbation for Females (Booklet NSW family Planning 2007/2011)

Two separate booklets that teach about positive masturbation messages. The booklets use black and white line drawings and easy English in a story to teach about masturbation, privacy and hygiene. Includes additional notes for parents, carers and workers.

Hand Made Love: A guide for teaching about male masturbation through understanding and video (Hingsburger 1995)

A book and DVD set that discusses privacy, pleasure and the realities of sharing living spaces with others. The DVD includes a demonstration of male masturbation with simple voice over descriptions. Also available: *Finger Tips: A guide for teaching about female masturbation through understanding and video.*

These DVDs contain explicit material and is available for loan from NSW Family Planning

<https://www.fpnsw.org.au/who-we-help/disability/disability-resources>

16th International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Conference

Jodie Caruana

School-Link Coordinator

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

Scotland is renowned for many things...tartan, kilts, bagpipes, whisky, a certain loch ness monster and now for me the 16th International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Conference. IASSID promotes worldwide research and exchange of information on intellectual disabilities, and is co-sponsor of the Journal of Intellectual Disability Research (JIDR). This international conference was held in Glasgow from 5th to 9th August 2019 where we were welcomed daily by friendly volunteers, many of whom had an intellectual disability, to usher the crowds to our destinations. I have reviewed a couple presentations of interest and found a trip to Scotland was important to learn more about research from abroad and in our own back yard here in Australia.

Adapted DBT for ASD Clients

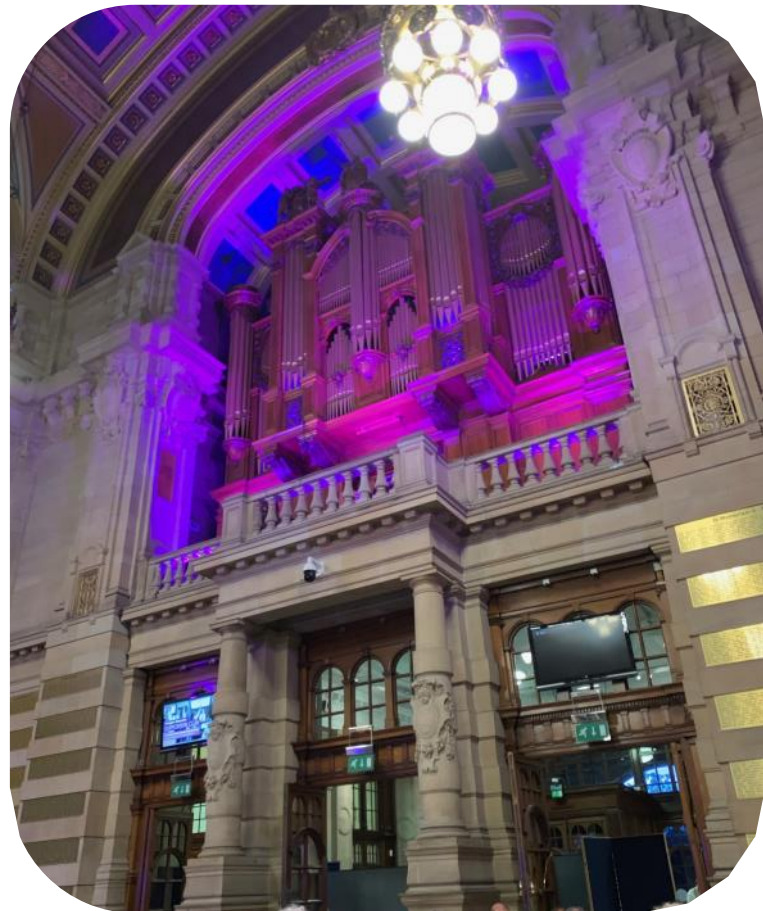
I attended a pre-conference workshop at the University of Glasgow called “*Adapted Dialectical Behaviour Therapy (DBT) Coping Skills Training for Clients with Autism Spectrum Disorder (ASD) presenting with Challenging or Offending Behaviours*”. The presenters were Joseph Sakdalan, Yvonne Maxwell, and Sabine Visser from Australia and New Zealand.

They presented that there is currently a limited evidence base for the use of DBT with clients who have ASD. The existing evidence is primarily for people with Borderline Personality Disorder (BPD). The presenters suggest that many features of BPD and ASD overlap, including; issues around emotion dysregulation; impulse control problems/emotional reactivity; cognitive rigidity; poor interpersonal skills and poor problem solving skills; poor coping skills; poor distress tolerance and self-harm behaviours and some problems with empathy. They also suggest that both groups have had extensive traumatic histories and had longstanding exposure to invalidating environments (i.e. being bullied, abused, or rejected for example) and may have biological predispositions to emotional dysregulation and impulsivity.

Core strategies in DBT include a balance between problem solving and validation. Their adapted DBT Coping Skills Training for ASD clients is largely based on Linehan's DBT Groups Skills Training Program.



Glasgow University on a beautiful summer day



Kelvingrove Art Gallery and Museum with 22 galleries , Glasgow



Their adaption uses simpler terms, more visual aids, repetition, and focuses more on the use of coping skills to manage emotional dysregulation and distress tolerance, as the authors suggest these are major contributors to their challenging/offending behaviours. Their program uses mindfulness training as adapted for clients with ASD to move into their 'wise mind' to modulate sensory input and to reduce mental overload.

This was an interesting presentation that illustrated the practicalities of adapting a more mainstream mental health intervention to the ASD client group. Obviously a greater amount of evidence is required however the authors should be commended for their innovative practice. If you would like to read more: Sakdalan, J. (2010). Pilot study on the use of DBT groups skills training with forensic clients with ID. *Journal of Applied Research in Intellectual Disabilities*, 23(5).

Inclusive Special Education

Professor Garry Hornby from the University of Plymouth in his controversial keynote on inclusive special education suggested that total inclusion without a specialised setting was not, in his view, favourable. He suggested that choice is paramount- but preferred a more balanced approach to inclusion somewhere in between full inclusion and segregated special education. I agreed with Hornby that a student's sense of belonging, whether in special or mainstream environment's is important. Hornby highlighted that schools

“Their adaption uses simpler terms, more visual aids, repetition, and focuses more on the use of coping skills to manage emotional dysregulation”

should be using strong evidence based practices, strategies and interventions (such as direct instruction, parental involvement, building teacher/student rapport, functional behaviour analysis, metacognitive strategies, cooperative learning and peer tutoring), and to avoid those that don't. Similar to what I hear in NSW, Hornby explained that having staff who are well trained and experienced in inclusive special education share their expertise in mainstream and special schools is critical. He shared a personal experience from a few decades ago where he taught in a special school in New Zealand to highlight that inclusive special education should develop independence, employment skills and successful inclusion in society after school.

Anxiety and ASD & ID

Caitlin Murray from the University of Warwick presented on anxiety in children with intellectual disability with and without autism. In their UK data research Murray et al reviewed 648 children with ID, 50% of whom al-

“Poverty and parental mental health may play a more important role in child anxiety”

so had ASD from the Cerebra longitudinal study. Initial findings indicated that children with ID and ASD have greater anxiety symptoms compared to children with ID only, which is in line with other research in this area. What was most interesting however is their suggestion that poverty and parental mental health may play a more important role in child anxiety than either autism diagnosis or ID severity. Her study measured parental mental distress using Kessler 6, and 23.5 % of parents scored above clinical rates of distress. Murray concluded that this had significance for targeting interventions at children of parents with poor parental mental health. This presentation made me reflect on the importance of parenting programs such as Triple P Stepping Stones which in our own research here at CHW reduced stress in parents by up to 50% and how this could potentially have a flow on affect to childhood anxiety.

Adam et al from Griffith University reported on a longitudinal study using the Anxiety Scale for Children with

Autism Spectrum Disorders (ASC-ASD). They reported on data from Years 2–4 of a community sample of 92 children aged 9–12 years on the autism spectrum. Parents completed the ASC-ASD at each time point. High rates of anxiety were found, with 60–63% of parents rating their children within the clinical range over time. 77 participants had complete data sets over the 3 time points. At time 1 the mean age was 11 years with 11.6% of the sample meeting criteria for an anxiety diagnosis, and by time 3 when participants had a mean age of 13 years this had increased to 57.1%. This highlights the need for early intervention in the primary school years.

Self-Report Measures

I was impressed with the quantity of presentations on self-report measures for people with an intellectual disability- including our own research from the Children’s Hospital at Westmead on the translation of the Swedish Wellbeing in Special Education Questionnaire that I presented on. McElroy from The University of Newcastle, UK, presented on the development of a self-report scale for adults with ASD and ID called The Anxiety Scale for Autism – Adults with Intellectual Disabilities (ASA-AID).

Adams et al from Griffith University presented their research on a qualitative anxiety self-report survey for children (6-13 years) with ASD across home, school, and community settings (N=78). Nearly all children (98.7%) reported experiencing anxiety in at least one



Opening welcome was held at the Glasgow Science Centre



Scottish Bagpipe band at the conference centre

setting, with 41.9% of children reporting they experienced anxiety across the three contexts. There was wide variability in children's descriptions of their signs of anxiety (39 categories) which were classified under eight broad areas. The proportion of children who reported having someone to seek out to help reduce their anxiety differed across home (87%), school (74%), and community (48%) settings.

School Attendance in Children with ASD & ID

In two separate presentations the school attendance of children in Australia with ASD (Gray et al) and those with ID (Hastings et al) were presented and I have compared the findings here. Both were presented from data collected from Victoria Australia, with data from parents of children with ASD coming from the MySay community survey (n= 308) and from parents of children with ID (N=636) and their teachers (N= 376). In the last 20 school days, students with ASD were reported as missing 1.84 days versus students with ID who were reported as missing on average 1.6 days. 40% of children with ASD and 28% of children with ID missed more than 2 days of school in the 4 week sample.

For children with ASD the four most common types of nonattendance reported by their parents and were sickness (60%), refusal (21%), being kept home (16%), and medical appointments (16%). A greater number of

“A greater number of days away from school were associated with anxiety ”

days away from school were associated with anxiety and higher rates of parent mental health burden. The three most types of non-attendance for children with ID as reported by teachers and parents were illness, appointment and parent withdrawal of the child from school. These data provide a useful insight into reasons behind non-attendance in schools.

Free access to abstracts

A full list of the conference abstracts are available <https://onlinelibrary.wiley.com/toc/13652788/2019/63/7> . The abstracts are grouped into various topics including: Autism Spectrum Disorders; Challenging Behaviour and Mental Health; Communication; Down Syndrome; Ethics; Families; Inclusive Education; Profound Intellectual and Multiple Disabilities and several others.



Eating disorders and autism spectrum disorder link needs more research, experts say

By Larissa Romensky for the Sydney Morning Herald published on 13th of October 2019

Experts are calling for more research into the link between eating disorders and autism spectrum disorder to come up with better treatment and support services.

Key points:

- Nearly a million Australians have an eating disorder, according to the Butterfly Foundation
- One expert wants more research into what proportion of people with autism have an eating disorder
- He says it could be possible that autism may be a risk factor in developing an eating disorder

Nearly a million Australians are living with an eating disorder, according to the Butterfly Foundation, and anorexia nervosa has the highest death rate of all

mental illnesses.

Single mother of two Carrie, whose teenage daughter has been diagnosed with anorexia nervosa, said it was an all-consuming, isolating illness beyond most people's understanding.

"When you go out it's like having a toddler, you've got to pack everything, because you can't be guaranteed that anywhere you go there is something they will eat," she said.

"You could stand in a bakery for one hour and she would end up in hysterics, in tears because she couldn't decide what she wanted."

Carrie's 16-year-old daughter was diagnosed with anorexia by a psychiatrist two years ago after a lengthy



search for answers, but her mother said she probably had it for eight months prior to the diagnosis.

Living in Bendigo in central Victoria, Carrie had struggled to find the right support services.

It was only after reaching out online to a parents' support group that she was thrown a lifeline from a parent in Melbourne who helped her access the right services.

At times, Carrie's daughter's sheer force of resistance to eating was often matched by an angry determination.

"My daughter has tried to jump out of a car. We were going about 80 kilometres an hour at the time," she said.

Recently a new doctor asked Carrie if her daughter was on the spectrum.

"Maybe if she is on the spectrum, then maybe the eating disorder is a direct result of her anxiety," she said.

At a cost of close to \$2,000 for a full report from Autism Spectrum Australia, Carrie said she would "try anything" and has begun the process of diagnosis.



Photo: Carrie had to quit work and take her daughter out of school for two months to make sure she was eating. (ABC Central Victoria: Larissa Romensky)

“More children are being diagnosed with both anorexia and autism spectrum disorder”

More girls being diagnosed with both anorexia and ASD

More children are being diagnosed with both anorexia and autism spectrum disorder (ASD).

According to a senior social worker at The Children's Hospital at Westmead Eating Disorders Service, Colleen Alford, the prevalence is well known worldwide with more than 20 per cent of adults diagnosed with anorexia also having ASD.

"Now the research is about how do we adapt treatment to help these young people who have both conditions," she said.

Most of the research has come out of the United States and the United Kingdom, and Ms Alford said more research was needed in Australia, especially around treatment.

Westmead Hospital in Sydney has just started a small focus group and pilot project looking at adjunct treatment for children with ASD and anorexia.

"Families that have a child with this comorbidity feel even more isolated than families that have a child with anorexia without autism," Ms Alford said. She said having both disorders tended to amplify each other.

"They feel really stuck around how to support their child," Ms Alford said.

Is autism a risk factor for other eating disorders?

If you need help with an eating disorder, contact:

[Eating Disorders Victoria](#) 1300 550 236

[The Butterfly Foundation](#) 1800 33 4673

[National Eating Disorders Collaboration](#) 1800 33 4673

[Lifeline](#) on 13 11 14

[Kids Helpline](#) on 1800 551 800

Associate Professor in clinical psychology at University College London Will Mandy said the link between women with serious eating disorders and undiagnosed ASD was first written about in a Swedish study in the 1990s.

"Between 20 and 30 per cent of these people with anorexia nervosa were also autistic," Dr Mandy said.

Despite there being some initial concerns with the results, in terms of effective autism assessment and the psychological effects of starvation often mimicking the



characteristics of autism, subsequent research has found the same figures.

"When you do these studies properly with diverse methods you tend to come back to that figure," Dr Mandy said.

What was lacking was research looking into what proportion of people with autism also had an eating disorder.

"They've done it the other way round, they've said, 'What proportion of people with an eating disorder are autistic?'," he said.

He said it could be possible that autism was a risk factor for other eating disorders, such as bulimia nervosa.

“What was lacking was research looking into what proportion of people with autism also had an eating disorder”

'Maybe autistic women restrict eating to manage unbearable emotions'

Christine Naismith is the founding board member of Eating Disorders Families Australia (EDFA), a volunteer organisation made up of people with lived experience of being a carer of somebody with an eating disorder – and the parent who helped Carrie seek help.

Ms Naismith has two daughters, a 23-year-old who has recovered from anorexia and a 17-year-old-daughter diagnosed with Avoidant Restrictive Feeding Intake Disorder (ARFID).

"It's picky eating gone crazy," she said.

"She'll only eat certain brands of foods or it has to be cooked in a certain way or she won't touch foods that touch other foods on the plate.

"It doesn't have the body image side of things that anorexia or bulimia do."

But one of the common traits of people exhibiting both ASD and eating disorders is anxiety.

"We're investigating the idea that, in many cases, maybe autistic women develop very severe restrictive eat-

ing as an attempt to manage unbearable emotions that are associated with being autistic and not getting the support they need," Dr Mandy said.

"It's almost like the weight loss is a secondary consequence of that."

'Girls better at 'pretending to be normal'

Dr Mandy said the main barrier in diagnosing women with autism was the current conception that autism was based on a "male-typical presentation" that made up most of the studies.

"There's evidence to show that autistic girls and women are on average somewhat more socially motivated than autistic boys and men," he said.

Women were also more adept at masking or social camouflaging.

"They invest a lot of effort in learning how to pretend not to be autistic in social settings — many call it 'pretending to be normal'," Dr Mandy said.

He said there tended to be gender-specific patterns with ASD, with boys more likely to have difficulties with their behaviour, particularly at school, and girls more likely to experience anxiety and depression.

"So girls were less likely to come onto [the teacher's] radar and less likely to get the assessment they need," Dr Mandy said.

He said a timely diagnosis was crucial in providing the necessary support to girls, and he said more understanding around the precise nature of the eating difficulties of people with ASD was needed.

"We need to get a much better understanding of what mechanisms are causing and maintaining these really serious restrictive eating problems in autistic people," Dr Mandy said.

'Being around people who get it'

Ms Naismith said the biggest impact on families was exhaustion and a feeling of isolation and hopelessness.

"It's a long journey. The average time to recovery for anorexia is five years," she said.

For the first time in regional Australia, EDFA has started a new support group in Bendigo for parents and carers of teenagers and young adults with eating disorders run by facilitators with lived experience.

"It was amazing," Carrie said.

"It's being around people who get it, who understand

what you're going through, who know exactly how horrific it is and how restrictive it is and how terrible it is.

"It just makes you feel you're not alone."

Recently EDFA put in a submission to the Federal Health Minister for funding to allow them to roll out a pilot program of 15 support groups nationally.

Reference

<https://www.abc.net.au/news/2019-10-13/more-research-needed-into-eating-disorders-autism-link/11593828>

Further Reading

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School-Link Ten Year Anniversary Celebration

With a great sense of community and support, we celebrated the 10 year anniversary of the School-Link Initiative at the Children's Hospital at Westmead on Monday the 11th of November 2019 at the Lorimer Dodds lecture theatre, the Children's Hospital at Westmead. A multidisciplinary and multi-agency agenda was presented reviewing the successes and future challenges in our industry.

Session One: 10 years of CHW School-Link

Chairperson: Michael Bowden, Network Head, Department of Psychological Medicine

Presentation One:

10 Years of CHW School-Link Achievements by Dr David Dossetor

Child Psychiatrist with a special interest in Intellectual and Developmental Disability

The Children's Hospital at Westmead

Dr Dossetor gave us an history of the School-Link team and the Developmental Disability Team at the Children's Hospital at Westmead. To read an in-depth review, turn to page 4 of this edition and discover this journey and its accomplishments.

In this presentation David outlines the following:

- The people and acknowledgements
- First Steps: "Leading the way"
- Establishment of the DPC and partnerships, and CDS Review (2014)
- Development of specialised IDMH for C&A
- Developmental Psychiatry Curriculum and framework
- Changing models of disability service provision and innovations in practical respite services
- Elaborating the Developmental Model
- CHW School-Link: 10 milestones in 10 years
- Future opportunity and threats
- Enhancement
- Shifting sands of collaboration and NDIS
- Research partners and promise
- The next 10 years!

Presentation Two:

The Partnership between Disability Clinicians and Developmental Psychiatry

Lesley Whatson

Portfolio Manager Clinical Practice
SAL Consulting

Lesley provided us with an insightful view of what the future of collaboration could be if we all support each other in the ever changing world of disability.

Presentation Three:

Mental Health and Schools for Children with Intellectual Disability

Neale Waddy

Leader, Support and Development. Disability, Learning and Support and

Katrina Worrall

Principal Psychologist

NSW Department of Education

The NSW Department of Education delivered some mental health trends over time with an overall in-





crease in prevalence of psychological distress. Engagement and belonging were two topics of paramount importance.

Presentation Four:

20 years of School-link, looking forwards

Danielle Thomas

School-Link Program Manager

MH Children and Young People Mental Health Branch
Danielle gave the audience an overview of the last 20 years of School-Link with visual representation of major projects over the School-Link lifespan including Project AIR, School Refusal, Brain, Body Belonging project, pathways to care and other factsheets. We look forward to reading the new strategic plan in 2020.

Presentation Five:

10 years of Justice Health School-Link

Rene Jones

School-Link Coordinator

Justice Health and Forensic Mental Health Network
Rene presented about the complexities and challenges of youth in custody including mental health issues, access to education and Adverse childhood experiences. Details for future collaboration and considerations for the JH&FMHN were given.

Presentation Six:

The relationship between Developmental Paediatrics and Developmental Psychiatry

Dr Natalie Silove

Associate Professor

Department Head of the Child Development Unit at the Children's Hospital at Westmead

A beautifully depicted presentation that collated images and artworks from the Sculpture by the Sea exhibition with recent findings and rules of engagement within the MHID sector.

Presentation Seven: Westmead Feelings Program: Why teach Emotional Literacy?

Dr Michelle Wong

Clinical Psychologist

Department of Psychological Medicine

The Children's Hospital at Westmead

In this presentation Dr Michelle Wong will outline the following:

- What is emotional literacy?
- Models of skill development
- Engaging learners
- Controlled trials & translational research
- The impact of emotional literacy and the WFP

Presentation Eight:

A School Clinic for Children with Intellectual and Developmental Disabilities

Jodie Caruana

School-Link Coordinator

The Children's Hospital at Westmead

Jodie provides a snapshot into a school clinic that is run in Western Sydney. The presentation provides an overview and outlines the benefits of this outreach service that is run by health in conjunction with the host school.

Session Two: The advances in the mental health services for people with intellectual disability in NSW.

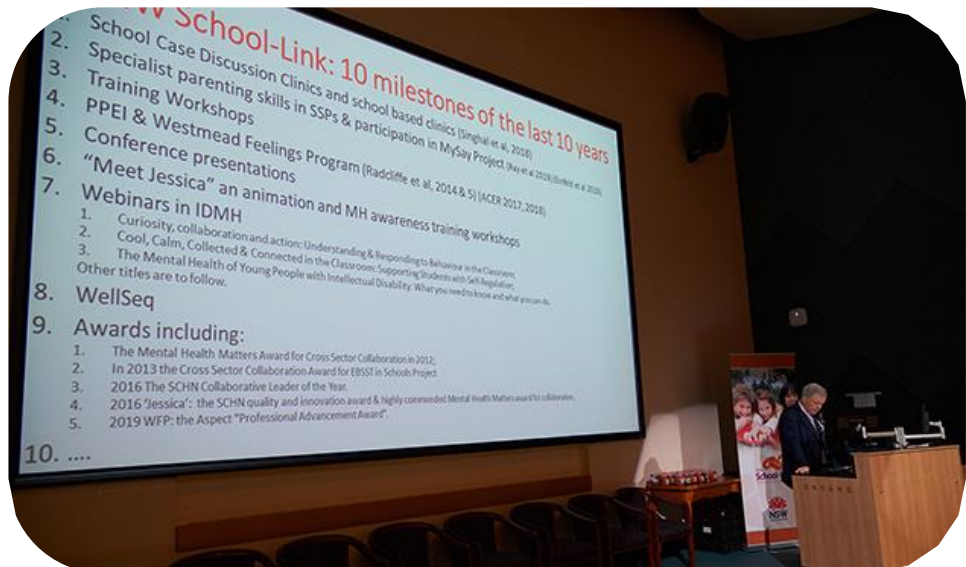
Chairperson: Adam Guastella

Professor, Michael Crouch Chair in Child and youth Mental Health. Brain and Mind Centre and Children's Hospital Westmead Clinical School

Presentation Nine: Intellectual Disability and Mental Health: a state-wide perspective

Vince Ponzio

Director, Intellectual Disability Mental Health. Mental Health Branch, NSW Ministry of Health.



In his presentation Vince outlines the following: challenges in accessing mental health care for people with ID; NSW state-wide strategic priorities; funding for Intellectual Disability and Mental Health; state-wide tertiary ID/MH hubs; cognitive impairment and forensic reforms; key lessons for future development of Intellectual Disability Mental Health

[Presentation Ten: The contributions from academic Developmental Disability Neuropsychiatry](#)

Julian Trollor

Chair

Intellectual Disability Mental Health
Head, Department of Developmental Disability Neuropsychiatry UNSW.

Julian discusses how people with an intellectual disability are core users for mental health services, and how research is being used to advance mental health services in NSW. Further details and resources are available at <https://3dn.unsw.edu.au>. Follow 3DN on twitter @3DN_UNSW.

[Presentation Eleven: Partnering for improvement- the work of the ACI Intellectual Disability Network](#)

Tracey Szanto

Manager, Intellectual Disability Health Network, Child and family stream.

Care across the lifestyle and Society, Agency for Clinical Innovation

Tracey shares important work from the ACI Intellectual Disability Network such as:

- Needs analysis from NSW LHD's
- The Service Framework to Improve the Health of people with Intellectual Disability
- 10 principles of good health care for people with ID
- Guidelines on pathways to care for children and adolescents with intellectual disability and mental health/challenging behaviours
- Say Less Show More resources
- Responding to the Needs of People with a Disability during Hospitalisation
- Building capability in NSW health services for people with intellectual disabilities: the Essentials

[Presentation Twelve: Have the needs of the carers been heard?](#)

Barbara Lewis

Manager

Carer Support Service

Northern Sydney Local Health District

Barbara gives an insightful presentation on the important role of carers for people with an intellectual disability and debates if their needs have been met. She then concludes her talk with where improvements

in the sector are most needed.

[Presentation Thirteen:](#) The role of NDIS in supporting people with disability with severe emotion and behavioural difficulty

Michelle Henwood

Director Planning

Complex Support Needs Branch

Service Delivery and Performance

National Disability Insurance Agency

There is a complex care pathway

[Presentation Fourteen: Do people with disability feel there is progress in caring in health/mental health?](#)

Jim Simpson

Lawyer and Senior Advocate

NSW Council for Intellectual Disability

Jim discusses how health and mental health has been a key advocacy issue for the Council of Intellectual Disability.

[Panel Discussion](#) with all speakers Chaired by Associate Professor *Patricia O'Brien*

Director

Centre for Disability Studies

Professor of Disability Studies, the University of Sydney
School of Medicine

Panel discussion topic : The mental health of young people with intellectual and developmental disabilities: current opportunities and threats

Please check the School-Link website for access to some of the presentations from the day. We look forward to working collaboratively with our partners into the future for the mental health needs of children and adolescents with an intellectual and developmental disability.

<http://www.schoolink.chw.edu.au/webinar-series/>



An accidental career

In the Psychiatry of people with an intellectual Disability by Bruce Chenoweth
(With apologies to Helen Beange for stealing her title)

Beginnings

Some as young as fourteen, they were marched out of their cells or the exercise yard, and into the bare office that served as my consulting room at the Worrimi Youth Detention Centre.

In my job with Adolescent Mental Health Services, I had always enjoyed my contact with 'goofy' mono-syllabic inarticulate adolescent boys. They would sit, cap on backwards, looking at their big, often-smelly feet, and grunting 'dunno' at every conversational overture. That is, until some quip would have them cracking up and we would be off and away.

These boys were different. Many of these offenders had obviously low or even of borderline intelligence, some illiterate, and obviously disadvantaged in so many ways.

Most of these kids were very likeable.

One young red headed boy, all of fourteen, and small of stature, was quite a legend around Waratah. He had stolen perhaps some tens of Holden Commodores over a two-year period.

He would 'case' a target, always an older model, easily 'hot-wired,' wait until the lights of the house had been extinguished. He would then break in, 'hot-wire' the car and would be off down the freeway to Sydney where he would part with the car for a few hundred dollars. This money would be subsequently blown on drugs, so two weeks later, he would do it all again.

He was too short to see over the car dashboard so always took a cushion with him to achieve adequate elevation.

He was none too bright, was funny, was illiterate and a reject from several schools. He touched my heart.

Then, I received an unexpected phone call from Mark Porter, Programme Director at the large Stockton Residential Facility.

Previously, this was a large asylum-type institution for

the mentally ill. It is now a group of buildings in a pleasant seaside setting noted for the century-old Norfolk pine trees and a very fine cricket pitch.

It then housed about 800 residents, all with moderate to severe intellectual disability, who could not, because of the complexity of their behaviours and physical co-morbidities, be placed in the community following the Richmond devolution of the 1980's.

Mark wanted a Psychiatrist to come regularly to review the state of the residents, many of whom were being given heroic doses of traditional anti-psychotic medications.

I was very underwhelmed by his request. I knew nothing of disability, nothing of the causations, and less of the syndromes or genetics underpinning many of the presenting behaviours.

However, I did agree to a visit. Walking through the units, I was not really prepared for the high degree of disability and dysmorphia that I encountered. Nor did I really want to take on what appeared to be this Herculean task with the promise of little in the way of a positive outcome for any of those 'poor souls.'

Around the perimeter road, we came upon a unit with about twenty wheelchairs lined up in the afternoon sun. 'What is that unit?' I asked Mark.

'Oh, sadly, that is the cerebral palsy unit' he said. 'We don't know just how much some of those guys understand what is going on, despite not being able to communicate'

'See that little guy on the end with the cap on?' he said.

“Walking through the units, I was not really prepared for the high degree of disability and dysmorphia that I encountered”



'I can understand him mostly and I make a point of coming by fairly often'

'He needed some dental work done. I knew that he would not cooperate so I did a deal.'

'If he got his teeth fixed, I would get him a ride in a police car!' (He had a fascination with police cars, Mark explained.)

His teeth were duly attended to and Mark found himself fronting the burley sergeant down at the Stockton police station...when there was one.

'Whadaya want,' the sergeant asked.
Mark explained his mission'
'Yeah, she'll be right!' said the sergeant.

On the appointed day, it was not a police car that turned up, but a paddy-wagon.

The little guy was hoisted up into the passenger seat, Mark needed to climb ignominiously into the back of the wagon and so they set off down Fullerton St. toward the Stockton village

The little guy was quite delighted....for a while. He soon becoming quite agitated and vocal.

'What's he want?' yelled the sergeant through the small trapdoor behind his head.

Mark had no idea. 'He wants to put your hat on' he yelled back.

'Right-o' and it was done.

This scene was repeated several times. First it was the flashing lights, then all bells and whistles, siren and all, to the absolute delight of the little guy.

At that stage, I was hooked! How could I not throw in my hat as well? I agreed to be part of that world and have remained so ever since.

That was in 1991.

The Task

I was a complete novice but I knew a few things.

Firstly, the high levels of traditional antipsychotics being used had to be reduced. Novel antipsychotics had recently arrived with fewer side effects and at lower doses.

However, the task of withdrawing the thioridazine and chlorpromazine had to be achieved very slowly to obviate discontinuation side-effects. These residents had been on these drugs for many decades and had semi-permanent neural receptor changes which would take months to years to reverse if at all.

Most of the residents had survived the dark days of harsh institutional living, had experienced loss of family, and sometimes been abused within the system. Some had been in an institution since being deposited at the Watt St Hospital as infants and had known no other life.

That old system had changed and continued to change over the decades. Gone were the old large wards, replaced by discrete residential units within those large buildings.

Residents began to participate in community day programmes. Psychology, OT, Speech Therapy, Activity Centres, Foster Grandparents, all contributed to a much-improved 'quality of life' for the residents. There was a 24-hr medical presence with CMOs who would accompany me on my rounds and discuss each referral in some depth.

Newer and much more stringent training of staff and procedural governance had been in place for a decade, a process that was progressing rapidly.

I had no interest in having residents brought down to the centre clinic preferring to see them in their own units, in their own milieu, getting to know the staff and wanting to experience for myself the quality of the prevailing relationships.

The gardens and grounds, the old pine trees, the cricket pitch, the soft light in autumn across Fern Bay, lent a sense of peace and 'contagious calm' that could at times, be all pervasive.

However, the old stigma of the institutional model still hung over the centre, more an ideological remnant than an actuality.

I am not sure whether it has been the opportunity to devolve all costs of a high-functioning disability service to the Commonwealth, or the ideological objection to 'institutionalisation' or both, but the imminent closure of the large residential facilities is inevitably resulting



in the profound loss of amenity and quality of life for those going out into the community. There can really be no justification for uprooting these residents to place them in group homes with limited resources, poorly trained staff, less specialist medical and allied health support and with uncertain funding models.

However, I digress!

I then heard about a small group of Psychiatrists proposing to meet in Sydney to discuss ID Mental Health.

With some trepidation, I drove down from Newcastle, expecting the meeting to be along the familiar lines of competing high profile egos; i.e. Those of big-shots from academia and Macquarie St.

Indeed, present were some very high-profile people including Profs Bruce Tonge from Monash, Stewart Einfeld, then from UNSW, David Dossetor from Westmead, Michael Fairley from Prince of Wales Hospital, and Peter Wurth who was establishing himself as the go-to person in Northern Sydney and regional NSW.

Feeling completely out of my depth, I was reassured by Bruce or Stewart, (I can't remember which), saying after a pause, 'Well, I guess that we are all here because none of us knows just what the hell we are doing!'

What a relief! Here was a group that I could belong to! We still meet regularly some 28 years later.

It happened by stealth

More and more referrals came to see me of those with Intellectual disability. I saw them in my private practice mostly. Sometimes, I saw the clients in their transport van in the street, or the hotel carpark next door if transfers into the office were too difficult.

For many years. I bulk-billed them all until it was clear that I was going backwards financially and that the Medicare rebates were not going to rise anytime soon.

I was propelled by sense of outrage that the mental health facilities actively denied access to those with an intellectual disability. Maybe, I had an inflated notion of myself as a 'caped crusader' offering an alternative mental health service to that population.

Since the devolution of disability services away from health services, we had as now, generations of Psychiatrists with no training in, nor experience in intellectual disability, nor in autism.



Fly-in, Fly-out

I began to offer a regional consultation service to regional and rural centres, beginning with Coffs Harbour, Port Macquarie, and then to Armidale, and Inverell.

Peter Wurth was already doing this extension work mainly in southern NSW. I inherited Inverell from him after he had overseen the closure of Ireby Lodge, a large residential complex in the centre of town.

Every couple of months, my long-suffering Office Manager and I would board a fairly decrepit Beech Aerostar at the Rutherford Airfield and set off for Port Macquarie.

The clinics were always interesting and appreciated. However, I could not discount the fact that it was the journey itself rather than the arriving, that held much challenge.

On one occasion, the landing gear refused to retract, and on another, the pilot had forgotten to turn on his transponder, which located us in relation to other traffic. In zero visibility, we had a narrow miss with an approaching QantasLink Dash 8 on a reciprocal course before he realised and switched on the offending instrument!

Clinics in other centres were accessed on regular passenger services with hire car added when necessary.

An Accidental career Part II

Sydney 2004

It was mentioned in mid 2004 at a Psychiatrists meet-

“We also had a strong commitment to capacity-building in these communities ”

ing in Sydney, that a position might be available at the Developmental Assessment Service (DAS) at St George Hospital. The previous incumbent, Helen Moloney was on leave and my memory is that Michael Fairley was covering for her. From the earliest days of that service, there had been a Psychiatrist at that clinic offering management of the many mental health comorbidities associated with Intellectual Disability. Helen Moloney was that pioneer, building a Psychiatric service from ‘cradle to the grave’.

Not only did DAS do initial assessments on children but over the years had expanded to provide a full range of specialist services to children, adolescents and finally to adults with ID.

Robert Leitner was the director there, a man of great vision and tireless energy who was able, in my time there, to expand the service to include several regional clinics as well as other outreach clinics to schools and to other ADHC-run facilities (the NSW Department of Aging, Disability and Home Care).

My appointment there firstly as a part-time, and then as full-time permanent Senior Staff Developmental Psychiatrist was the first such appointment in NSW.

He was responsible for generating the ‘Metro-Regional Intellectual Disability (MRID) service with clinics in Goulburn, Shell Harbour, Wollongong and even included outreach to my old clinics at the Stockton, and Kangra large residential facilities, and which also allowed me to continue clinics in Armidale and Inverell.

Whilst the clinical emphasis was on children and adolescents with ID, adults became a large proportion of our patient load. We also had a strong commitment to capacity- building in these communities and took the opportunity to provide educational talks and presentations to the local GPs and allied health as well as to the local disability support workers.

At one stage in 2014, we had five Psychiatrists working there, all part-time permanent staff including myself as a full-timer

“Training younger Psychiatrists from the Neuropsychiatric stream has been a consistent privilege ”

Our Disability clinic in Kogarah was staffed by many other specialist disciplines including Paediatrics, Neurology, Gastroenterology, Endocrinology, Geneticists, Sleep Physicians and others. There were Psychologists, OTs and Speech Pathologists at hand.

It was indeed a very comprehensive service to children, adolescents and adults and a great privilege to be part of that.

During my time at DAS, I was able to contribute in a small way to the generation of policy and planning through the ACI, (and hence the Ministry of Health,) sat on Complex Case Review panels for ADHC, was coopted on to the NSW Ombudsman’s expert panel on Abuse in Care, was able to present at conferences, publish, participate in research projects, and lecture to colleagues and other stake holders in the disability field.

Training younger Psychiatrists from the Neuropsychiatric stream has been a consistent privilege throughout the last 10 years.

I have also valued greatly my association with the UNSW Dept of Developmental Disability and Neuropsychiatry.

Why bother?

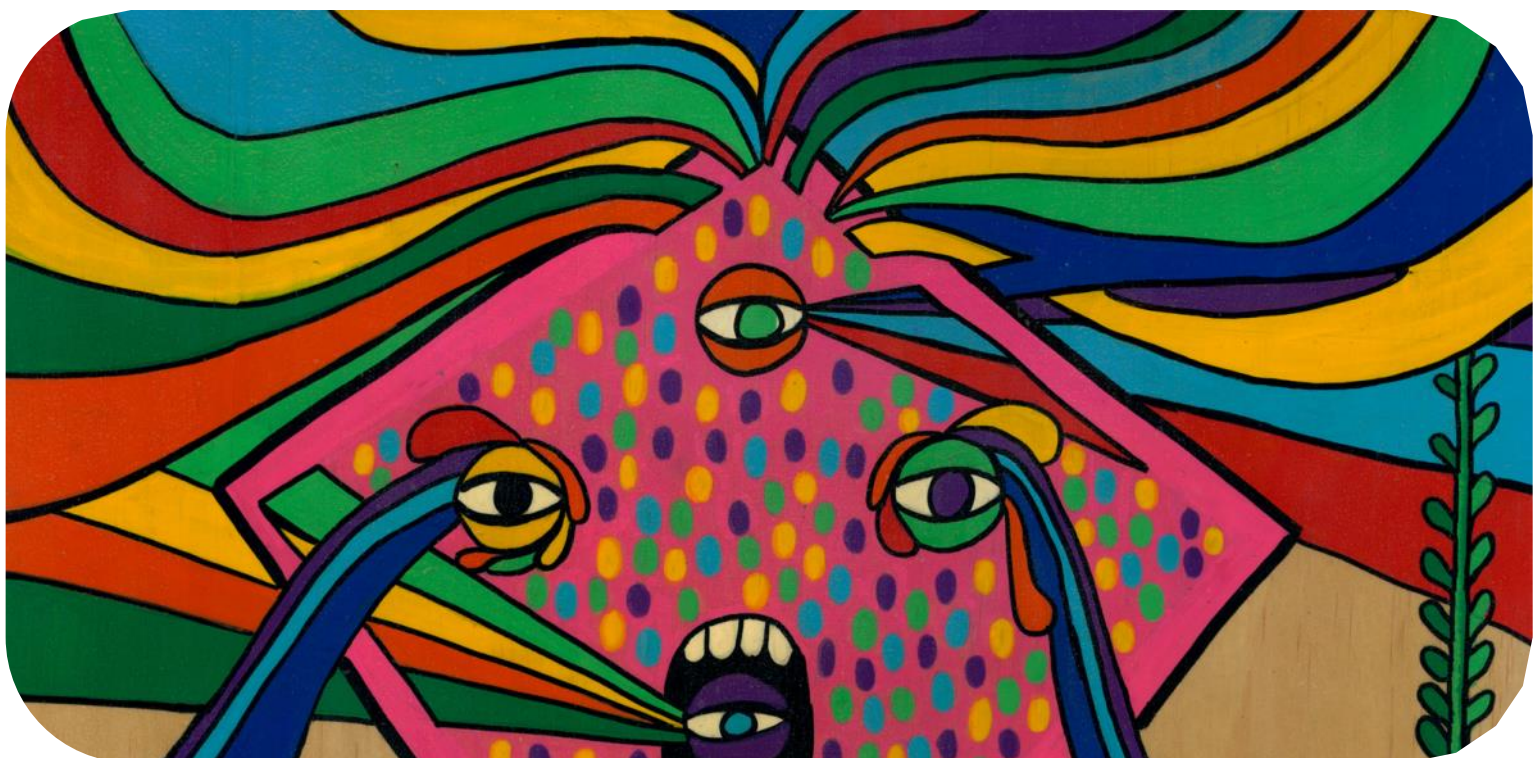
The field has an intellectual fascination encompassing every aspect of what I had learned and then some.

The rapidly expanding hard scientific domains of Neuropsychiatry, Genetics, Neuropsychopharmacology, and others, were grafted on to my previous experience as a Psychotherapist; i.e. in Attachment Theory, Family Therapy, and Developmental trajectories. All could be potentially brought together in one complex presentation of one complex patient.

Next, the human factor.

It has been such a privilege to meet people who, to quote Michael Fairley, are the most ‘noble’ of people. The parents and carers selflessly give of their lives to love and to care for those incapable of the usual or expected reciprocity and who demand so much of them.

Finally, unlike some other areas of Psychiatry, there is authenticity and a relative absence of subterfuge or duplicity. What you see is what you get!



A note from Dr David Dossetor

Bruce Chenoweth wrote this article at the time of his retirement from his career as a psychiatrist. He is a much loved and respected doctor and colleague, who had an interesting and eminent career. He qualified in medicine at Monash University, trained in psychiatry in UK, was in charge of Psychiatry Services at Royal Brisbane Hospital for a few years, before moving to Newcastle in 1985 working with adolescents and adults, where this account starts. He has a rich training background from psychotherapy, attachment theory, family therapy, drug and alcohol and neuropsychiatry. He has contributed widely in training and education and published broadly. He has been a key figure in the development of psychiatry of intellectual disability in NSW, collaborating across agencies, and contributing to expert panels for example the NSW Ombudsman Panel on abuse in care.

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Supporting students with ASD transition to High School

Kim Eisler

School-Link Coordinator

Individuals with an Autism Spectrum Disorder (ASD) have impairments in the areas of social interaction and communication combined with a tendency for inflexible patterns of thinking and behaviour (Volkmar & Klin, 2005). As a result, students with an ASD have unique learning styles and may struggle to cope with various aspects of school. Evidence suggests that some of these students are significantly more likely than their typically developing peers to be suspended or excluded (Barnard et al., 2000), to be the targets of bullying (Myles & Adreon, 2001; van Roekel, E. et al, 2010), to suffer depression and anxiety (Kim, et al, 2000) and to under-perform academically relative to their level of intelligence. Families of children with an ASD in mainstream schools report being concerned by the lack of understanding among school staff, particularly in children at the higher functioning end of the autism spectrum (Whitaker 2007). While these articles show there is work to be done, there is also a considerable body of evidence about what schools are doing to successfully support students with ASD and their families. Some of these are discussed in this article.

Children with ASD often have difficulties in reading social cues and situations meaning they may not know how to respond or behave in many common social environments and fail to predict what might happen in a new setting. This can generate significant anxiety for children with ASD and result in a preference for situations that are familiar and recognisable. Additionally, rigid thinking may hinder their adjustment to the expectations and social rules of a new environment or social situation and are likely to take longer to understand it. Individuals with ASD find changes in their situation or transitions to a new setting especially difficult and challenging.

Moving from primary to high school is daunting for most students. Students with ASD will face additional challenges as a result of their diagnosis and need extra supports. Strategies to prepare students are best

begun in primary school and may involve a gradual reduction of supports, an expectation of more independent functioning, the development of self-monitoring and practice in seeking help (Roberts, Keane & Clark, 2008). This article seeks to describe some of the strategies that have been found to be helpful for children and young people in schools, including during the transition from primary to high school. However it should be noted that all students with ASD are not the same and that sometimes what looks like the same behaviour in two different children will actually serve two different functions for them. An analysis of an individual student's needs is always advisable. Teachers and parents could consider asking for assistance through school learning and support teams, from school counselling and other specialist education staff, or from specialist staff in other agencies. That said, the following are evidence-based principles for working with students with ASD that many schools have found useful.

Wherever possible, schools enrolling students with ASD should seek specific training in order to understand the impacts of ASD so they have realistic and appropriate expectations of students. This will also facilitate a consistent approach from staff across the entire school environment. Additionally, it is advisable to include regular, designated time in staff meetings for updates, ensure professional development is maintained and regularly review school policies.

Generally, individuals with autism like order and detail, so keeping workspaces and classrooms clear of clutter and tidy will help them feel more secure and in control. As they like to know what to expect, schedules which help anticipate what is coming next- ; such as picture schedules and visual timetables are especially helpful. These can be broad or detailed and include a sequence of events if appropriate (Smith-Myles et al., 2001). Students will also learn faster and find it easier if visuals are included to support their learning, as verbal instructions may require too much concentration and result in them 'tuning out'. These visuals can also be incorporated into stories to create a story board or cartoon illustration which clearly sets out the steps to be taken. Incorporate visuals into as many activities as possible indicating each step involved. For further information you can go to the following website: <https://www.autismspeaks.org/sites/default/files/2018-08/Visual%20Supports%20Tool%20Kit.pdf>

“Strategies to prepare students are best begun in primary school”



Depending on the child it may be necessary to simplify the language used and check in that you have been understood. Progress logically, one idea at a time, using concrete examples to follow a sequence that is understood. Avoid open ended questions or suggestions, rather provide choices. Keep language simple, specific and real. Ambiguities, abstract ideas, 'turns of phrase', metaphors and sarcasm are all likely to be misunderstood or misinterpreted (Smith-Myles et al 2001; Costley et al, 2012).

Many students with ASD tend to focus very intensely on tasks and struggle to change to a new activity. They may need time to move on and help plan longer term projects as following and understanding complex and multiple instructions is difficult, breaking them into smaller steps to avoid anxiety over unfinished assignments (Smith-Myles et al., 2001). Working with others could be especially draining and their processing time may be slower than that of their peers. These skills can further be hampered by physical problems such as fine motor issues if it is a writing task for example.

Sensory processing difficulties are also common and contribute to the challenges associated with transition periods as the student may quickly become overwhelmed with sensory stimulus in a new environment. An ASD student's ability to regulate their emotions is frequently affected by sensory processing difficulties. It can lead to over-stimulation, anxiety and outbursts. Their capacity to calm down, manage stress, or cope with frustration is impeded on multiple levels as they

struggle with social cues, physical limitations, rigid thinking patterns and limited language competence.

In the classroom, teachers need to keep in mind that all behaviour is a form of communication and seek to work out what the student is trying to say. Students with autism generally want to do the right thing and challenging behaviour is usually due to a lack of understanding about something (Smith-Myles et al., 2001). Interpreting the message behind their behaviour will assist both student and teacher.

For teachers maintaining a calm environment so as to reduce anxiety and aid concentration will be a key factor in helping students with ASD. Consideration should be paid to lighting, volume, space, and background noise when arranging work spaces. For instance, it may be helpful to seat these children away from windows and doors and to define teaching areas by using clear physical boundaries and colour coding (Costley et al, 2012).

Incorporating appropriate IT supports to assist students' executive functioning such as iPads, tablets, or smart phones is advised, with reference to the school's policies on devices. Individualised timetables that are colour coded and cross referenced to curriculum materials will be a great help (Costley et al, 2012; Keane et al, 2011).

Uniform visual resources ought to be implemented across the school, prominently displayed, it should be



positively expressed, clear and simple. Creating calm spaces in classrooms and other easily accessible/monitored areas to accommodate sensory/overload needs. The opportunity for students to participate in targeted playground programs which encourage peer to peer interactions will facilitate social skills. Autism-specific clubs, study groups and homework clubs provide opportunities to engage with the school community increasing the students' connectedness while providing a place to develop life skills.

Creating a Transition Planning Team (TPT) as early as possible in preparation for the move to High School is the most valuable means of ensuring a positive transition. It is advisable to start transition planning for ASD students as early as possible in the senior years of primary school, years 5/6. An effective Transition Team will involve key school staff from both primary and secondary schools, learning and support team members, parents, school counselling staff and any other significant health providers who are part of the students' life.

Gather and exchange as much relevant information as possible including individual profiles, NDIS plans, Behaviour Support Plans (BSPs), Individual Education Plans (IEPs), specialist reports, past assessments and information outlining support strategies. Clearly define the role of the Transition Team and the individuals involved; include meeting dates, a timetable of events or activities and a 'transition pack' for the young person.

The TPT should be prepared to have numerous meetings that will occur over several months and include a range of activities. Remember, it is unpredictability that causes the most anxiety in ASD students, espe-

cially if they have issues with problem solving and communicating their needs. The more preparation that is undergone the better.

Begin in primary school by exploring the differences they will encounter at high school and the expectations that come with being a secondary student. Introduce the concept of different subjects being held in different locations, how timetables and scheduling will work. Help them become familiar with using a diary or planner, checklists for specific days or subjects can be useful as can the use of visual cues such as colours or pictures.

ASD students will value the opportunity to get to know their new school through visits and orientation days. A map with visuals of the school which clearly indicates important locations like the school office, library, staff room toilets and lunch area will be of benefit, as will practice time for using the map to navigate during quieter times of the day. The opportunity for students to sit in on lessons or be introduced to key staff such as the librarian and school counsellor/school psychologist can assist students. However, be cautious about overloading the student with too much information as this can become counter productive if it creates stress and confusion. Consistently checking in with the student will be important.

Overall, although transition might be difficult for some students, a varied and detailed plan for transition across schools and agencies is a comprehensive way to remain positive and ensure preparedness for the school, student and their family.

Teacher Tips

- Keep instructions brief and concise and check for understanding.
- Give warnings of any changes to routine, even when changing activities
- Present information in small chunks or by highlighting key points – limit written work.
- Allow opportunities for breaks
- Write down any communication that may be difficult to understand, use visuals if possible
- Provide visual organisers for class and school routines – mini-schedules, user friendly timetables
- Teach diary use and insist on diaries for all reminders.
- Be specific when giving praise and instruction.
- Use the student's interests to encourage motivation either in the lesson or as reward
- Limit time spent on tasks and allow for work to be completed at home
- Provide structure and details for homework and assignments so the student knows exactly what is expected.
- If you see signs of distress, intervene as soon as possible – offer a Break opportunity.
- Keep in touch with parents and provide frequent feedback.

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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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