

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 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 NDIA and NSW Department of Education. We are extremely proud to present these ideas and invite you as authors to help develop this field and the knowledge base to help support children and adolescents.

On our Website:

www.schoollink.chw.edu.au

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

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

Editorial

School-Link Team
The Children's Hospital at Westmead

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Welcome to the 14th volume of the Journal of Mental Health of Children and Adolescents with an Intellectual or Developmental Disability.

I recently asked my AI (Artificial Intelligence) what she knew about mental health of children and adolescents with an intellectual disability, the response was interesting, using words like inclusivity, unique challenges and promotion of understanding and empathy. I tried this little exercise to see if I agreed with what has been collated about this topic and moreover whether it is accurate for the wider community that may be accessing this information. Although AI is contributing positively to many fields, just as the mainstream media, social media and commentary has done; it is always acceptable and encouraged to seek expert opinion and voices of lived experience which adds the most value, knowledge and experience that AI generated information just can't live up to. So we continue with our endeavour to share useful knowledge to empower communities that read this journal.

In this edition you will find an article from Dr David Dossetor, highlighting a case study of comorbid ADHD, intellectual disability and autism. A review of the developing brain clinical research colloquium by Arrielle Hope, and an article by Anita Gardner and Ellen Mcbrarty showcasing small changes and big impacts for young people learning about emotions. The medicine cabinet by Judy Longworth will focus on weight gain and antipsychotics and a final article presenting the behaviour tip sheets we co-developed with SAL consulting earlier in the year.

We are interested to know if you would like us to continue to produce the journal in this format. Send us your comments and feedback to the email below or fill in our end of year survey.

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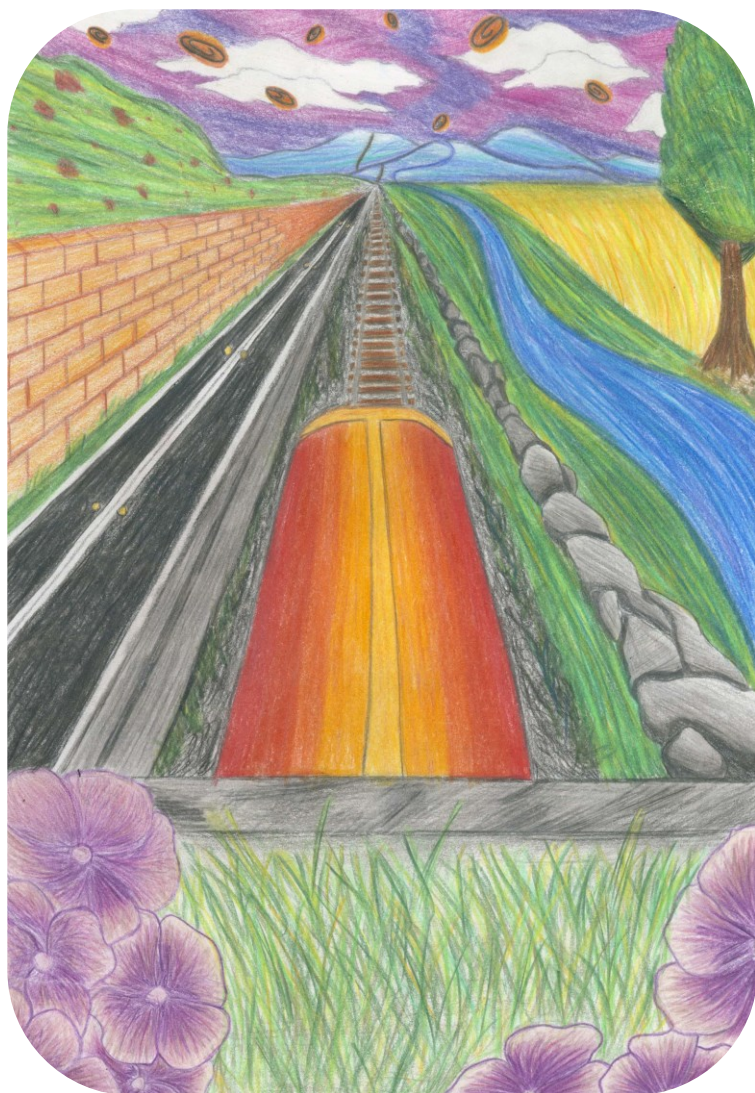
Enjoy reading this edition of the journal.

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Some important numbers to remember:

Lifeline: Call 131114 or
Lifeline Text: 0477 13 11 14
13YARN: 13 92 76
Kids Helpline: 1800 551 800
Headspace: 1300 737 616
Reachout: Reachout.com.au
Parent line: 1300 1300 52





Attention Deficit Hyperactivity Disorder (ADHD) in intellectual disability (ID) and autism.

A literature review and case example.

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The launch of the Australian Evidence-Based Clinical Practice Guideline for Attention Deficit Hyperactivity Disorder (ADHD) (2022) has had an impact on raising awareness, acceptance of this diagnosis and the need to access paediatric and psychiatry treatment. It is therefore a good time to review our knowledge base on ADHD in intellectual disability (ID) and autism. The guideline emphasises that those with neurodevelopmental disability, ID, autism, language delay, or motor development problems have much higher rates of ADHD. However, the guidelines have a paucity of literature on ADHD in these populations. In retrospect it is hard to understand how the presence of autism in DSM-IV excluded a comorbid diagnosis of ADHD. This was revised in DSM-V in 2013, even though researchers were reporting how commonly they co-occurred prior to that date.

Prevalence of ADHD

While the recognition that ADHD in those with mild ID and the diagnostic instruments used are reliable, and has many features of those in the mainstream population, there are recognised differences: For example, a literature review by Antshel and colleagues (2006) found that an ADHD diagnosis could be made reliably in patients with borderline to mild ID. The predictive validity showed a similar trajectory but identified differences. ADHD was found in a third of cases and the rate increased with lower IQ (0.3 correlation) and in the presence of autism (67%). There was an equal prevalence between males and females, a stronger association with factors of (poorer) family functioning and a greater association with aggression, non-compliance and disruptive behaviour disorders, anxiety and depression, and poor social skills. There were also differences in treatment, as stimulant drug treatment was somewhat less often effective, clonidine was equally effective, and risperidone was more effective. Patients were more prone to side effects on stimulants such as social withdrawal. The biggest challenge was that clinicians had to be open to the recog-

nition of ADHD in this population and avoid the trap of diagnostic overshadowing, attributing all the emotional and behavioural problems to their disability. Puusepp-Benazzouz (2019) emphasised differences in medication effects in a review that showed that in ID and autism only 25% responded at first treatment with stimulants, with a greater frequency of side effects, and similarly in the use of SSRIs, 50% suffered the side effect of behavioural activation.

Einfeld and Tonge (1996) found of those with an ID, 40% had a severe emotional or behavioural disorder. Dekker and colleagues (2002) found in children with borderline to moderate ID, 21.9% met criteria for an anxiety disorder, 4.4% for a mood disorder and 25.1% for a disruptive disorder. In addition, 14.8% were diagnosed with ADHD, and these rates were similar regardless of whether they screened positive for pervasive developmental disorder. Thirty-seven percent had more than one disorder. Similarly, Ahuja and colleagues (2013) found that children with ADHD and mild ID had higher rates of oppositional defiant disorder (ODD) and conduct problems (CD). Some psychiatric disorders are much more prevalent in young people with ID: Anxiety Disorder, ADHD, ODD, Disruptive Behaviour Disorder, Pervasive Developmental Disorders and Autistic Spectrum Disorder (Einfeld *et al*, 1996; Borthwick-Duffy, 1994). Substance abuse is less frequent. Depression, eating disorders and psychosis are not significantly more frequent than controls without ID. However, the rates of depression and psychosis are variable because of the difficulties of reliable identification (Emerson, 2003). Rates of emotional and behavioural disturbance are higher in young people with moderate and severe ID, and lower in those with profound ID.

Simonoff and colleagues (2008) found in an epidemiological sample, that of children with autism, 70-80% had a psychiatric disorder and 40% had more than one, including 20-50% with ADHD. Regrettably, alt-

“Those with neurodevelopmental disability, ID, autism, language delay, or motor development problems have much higher rates of ADHD...”

Although this study reports a wide variation of severity of autistic disability, it doesn't describe the levels of intellectual disability of the sample. However, Simonoff's group describes the complexity of comorbidity: at 5-9 years of age, 59% had ADHD, of which 49% also had any emotional disorder and 24% had ODD or CD. By 12 years of age, 31% had ADHD, of which 24% had any emotional disorder and 30% now also had ODD or CD. So, although this suggests a decline between the age of 7 to 12 in those with any psychiatric disorder from 85% to 60%, there was also a reduction in ADHD but an increase in emotional disorder (26% to 39%) and ODD and CD (24.5% to 50%). Could this in part be explained by a failure of treatment of ADHD early, leading to later increase in emotional and disruptive behaviour disorders?

Franke and colleagues' lifelong review (2012) emphasises the persistence of ADHD throughout life, its association with a range of co-morbidities, but also illus-



trates how treatment can improve outcomes in terms of employment, social outcomes, morbidity and mortality. In addition, treating ADHD can reduce accidents and the impact of co-morbidities including substance abuse and conduct problems. Joshi and colleagues (2010, 2012) describe in clinic populations of youth and adults with autism that 95% had 3 or more conditions and 75% had 5 or more conditions with the incidences increasing with age. Joshi's group describe the increased rates of anxiety (42-56%) including phobias, physical anxiety, separation, social and generalised anxiety, PTSD and OCD, and these different anxiety disorders often co-occur.

Other studies of autism with or without ID suggest that as well as elevated rates of ADHD (50%), ODD (7-24%), CD, and tics (22%) there are also an elevated rate of enuresis, encopresis, motor coordination disorder, language disorder, depression/mood disorder (12-70%), bipolar disorder, schizophrenia, catatonia, pica, self-injurious behaviour (up to 50%), somatisation disorder, stereotypic behaviours, eating disorders, sensory processing disorders, sleep disorders (50-80%), and more recently reports of gender dysphoria. Aggression occurs in 68% often towards caregivers, and contributed to by problems of empathy, anxiety, sensory overload, disruption of routines and difficulties of communication. The ASPECT study of people with autism reported 70% reported experiences of being bullied, having no friends and not fitting in. Further, 60-75% needed access to services, though mental health services tend to exclude ID and ASD and 68% of parents stated educators were not well informed about mental health. Finally, the study estimated that 100,000 individuals have ASD and co-occurring MH problems in Australia (Baldwin *et al*, 2013).

Further, one in eight young people with ADHD also has autism (Zablotsky *et al*, 2020), and it still holds true that approximately 50% of those with ID have autism (Postorino *et al*, 2016). Although idiopathic (unknown cause) autism is considered to be highly genetic (explaining 40 to 80% of the variance), up to 25% of those with autism has a specific genetic syndrome.

It is important also to recall that although ID occurs in 2-3% of the population, the psychiatric co-morbidity accounts for 14% of the mental health burden of care. Adding rates of autism with this figure, it is thought to go up to 25% of the burden of mental health care in children and adolescents (Emerson & Hatton, 2007). In Australia, health service evidence suggests that those with ID account for 6% of cases seen by mental health services, and there are no records on the presence of autism, but plenty of hearsay of them being excluded.

“It is often difficult to know whether this is anxiety or ADHD or a failure to learn mood regulation...”

Impairment of psychiatric disorders on children with intellectual disability and autism

There is a paucity of psychiatric research on mental disorders in moderate, severe and profound ID, even if it is recognised that their rates of severe emotional and behavioural disturbance are even greater and highly persistent. On the one hand there are greater challenges of reliably recognising subjective mental states, and there is less funding for research for a smaller minority population. Yet there is a valued workforce of specialist clinicians who recognise these disorders, and growing reports on how much difference psychiatric expertise can contribute. One case notes study (Dossetor, 2014) of a tertiary mental health service for young people with ID found that the average number of diagnoses of 3.5 psychiatric diagnoses (not includ-

ing the ID), in whom the level of impairment from these disorders were on average as severely impairing as their intellectual disability or autism, each contributing 20-30 points on a Child Global Assessment Scale or CGAS (See note on page 17 for CGAS description).

These young people present as very impaired in the 20-55 points range on the CGAS, many equivalent to having the dependency of an inpatient and high rates of risk but being managed by their family in the community. Despite having been seen by several services and clinicians prior to referral to a specialist tertiary service, intervention on average produced a gain of 20 points. They had tried an average of 3.4 different medications prior to being seen in the specialist service and were managed on an average of 2.2 (0-6) medications at discharge. There are a number of additional lessons from this clinical study: firstly polypharmacy, where a number of medications each make a contribution to several co-morbid disorders, is the norm. Although all interventions are multimodal, with emotional and behavioural disturbance of such a severity, non-pharmacological approaches alone often have limited impact.

Acceptance of the role of psychotropic medication has to be seen as essential to making a difference to these children and their families and restoring their capacity



to aim for a quality of life. Indeed, the recognition and treatment of the psychiatric disorders are the reversible part of their disabilities. This compares with Joshi and colleagues in an adult autism clinic found a lifetime burden of psychiatric disorders of 6 ± 3.4 (2013).

My most common presentation is unmodulated over-arousal and in the absence of a subjective account, it is often difficult to know whether this is anxiety or ADHD or a failure to learn mood regulation. A careful history from parents, teachers, and one's own observation and engagement with the young person provide 'a best bet' for a primary diagnosis. Although behavioural intervention is always a first line intervention, my training has taught me that if you are going to help the most troubled disabled children, one needs to be prepared to prescribe. One needs to be aware that this population has an increased rate of side effects, and sometimes lower rates of efficacy than in a mainstream population, but most cases can be helped.

It is highly regrettable that in my opinion, the NDIS does not accept the critical role of specialist mental health intervention and of psychotropic medication. Their attitude that all mental health intervention, whether it be to support safety in the home and for the individual, or to provide medical treatment, is designated a restrictive practice, and only reinforces the attitude that mainstream mental health services should not be given to those with a disability, and both agencies work on an assumption that all behaviour is explained by disability, and they cannot have a mental health disorder. 'Diagnostic overshadowing' now has a long history and literature and constitutes a failure of human rights to deny the recognition of mental health disorders and treatment in those with ID. Until there is professional and institutional collaboration between disability services and mental health services for which I and my subspecialty colleagues, and indeed the families caring for these children, continue to advocate for, this population will continue to be stigmatised and harmed by the neglect of both services.

Comorbidities in IDD

It is important to consider the evidence on developmental comorbidities: Bradley (2006) showed that 15% of teens with ID alone had ADHD, but if they had ID and autism this went up to 50% with ADHD. ADHD and Developmental Coordination Disorder each occur in community studies at a rate of 7% but co-occur in 50%. Indeed, where you have a delay in development, you will find that delay is unequal across developmental domains. If you have a delay in one domain, there will be an increased risk of delayed development across another domain. For example, motor coordination disorders have an increased rate of ADHD, au-



tism, specific learning difficulties, language problems and a host of psychiatric disorders. The explanation is likely that polygenetic processes underlie the developmental processes of the brain and its delay across different dimensions of development.

It is curious that ADHD is particularly high in Behavioural Phenotypes as listed here: Smith Magenis Syndrome at 90%, Fragile X at 75%, Williams Syndrome at 65%, Charge Syndrome at 50%, Neurofibromatosis at 50%, 22q11.2(VCFs) at 43%, Cornelia de Lange's Syndrome at 40%, Soto's Syndrome at 38%, Tuberose Sclerosis at 35%, and Turners Syndrome at 24%. That environment is also important as illustrated in Fetal Alcohol Syndrome where ADHD is found in 49%, but is also associated with ID in 55%, learning disorders in 46%, ODD in 41% and anger, mood disorders and sleep disorders in 50%.

Taking these observations of the diversity of aetiological causality both of ASD and ADHD in ID indicates that ASD and ADHD are 'developmental psychiatric disorders', whereby developmental sequence and its delay has multiple causes. Accordingly, ADHD in ID

represents a common outcome of the impaired development of the coherence and efficiency of consciousness, rather than a specific disease process. This does not devalue the diagnostic reliability nor validity of this disorder. It is still important to identify co-morbid ADHD and the additional impairment to functioning that this diagnosis implies, particularly because of the potential impact of drug treatment in reducing impairment. Accordingly, Developmental Disorders have high risks of co-occurrence, are highly genetic and may all relate to problems of developing neural complexity.

Medication Management

Hazell (2007, 2010) helpfully introduced the notion of primary, secondary and tertiary medications for the treatment of ADHD. He recommended stimulants as primary, atomoxetine and clonidine as secondary, and mood stabilisers and major tranquillisers as tertiary level options. In those with autism and ID, my modification based on clinical experience of outcomes in a tertiary clinic is:

- Primary is clonidine,
- Secondary is stimulants, amitriptyline, guanfacine and atomoxetine, and
- Tertiary is major tranquillisers which can be second generation, dopamine stabilisers, or traditional major tranquillisers and mood stabilisers, such as valproate, carbamazepine and lamotrigine.

The rule of medication management is to make one change at a time, so improvements and side effects can be closely monitored and changes made as needed. Except in an emergency/crisis presentation or under undue time pressure of inpatient treatment, do not start two medications at once. A useful expert consensus on identification and treatment guidance on ADHD in autism (but without a focus on ID) is recently published from a UK group (Young et al, 2020). The guidelines for treating autism produced by Subramanyam and colleagues (2019) provides a similar algorithm to that which I have suggested. However, it is important to consider other medication types that have a limited literature such as moclobemide, bupropion, mirtazapine, propranolol, modafinil, lithium, CBD oil and other medications not necessarily available in Australia. The emphasis is on medications that influence the dopamine or noradrenergic systems. SSRIs are not recommended, except for cautious treatment of co-morbid anxiety. I have separately written about my prescribing guidelines for children and adolescents with ID and autism (Dossetor, 2019).

Case study :

An 11year old boy with autism was referred by his paediatrician during the covid lock down and seen by



videoconference. D had behaviour problems that were so severe that he had not been to his special school for disruptive young people for 12 months. He was violent towards his mother which included biting, kicking, throwing objects, and even pushing her onto the road, with a devilish look. This violence was occurring multiple times a week and he was getting stronger weighing in at 54kg. He attacked his brother and complained he was noisy. He was also aggressive at school, for example if a pencil was in 'the wrong place'; he had to have a classroom to himself and also 'had pulled up' trees. He was severely constipated, refusing laxatives, and hadn't had his bowels open properly for 3 months; he could not be made to sit on the toilet but wouldn't touch his soiled clothes. He had selective eating particularly for air-fried chips. He didn't sleep. He would complain of boredom and his mother would end up sleeping with him and cuddling him, or he would get physical. These problems had been getting worse for 2-3 years. His mother explained: 'If you take something off him, he hits me or puts holes in the wall. Punishments don't work because he says he 'doesn't care'. He was thought to be depressed by his psychologist, whom he saw regularly.

In his motor development: he could run but didn't want to; he could catch a ball, but wasn't active and

stayed in his room all the time with tv and computer games. In his self-care: he could dress himself, but if he soiled himself, he made his mother undress him. He picked his nails off. He would wipe his runny nose on his mother's clothes. In his communication skills, he didn't talk to anyone. It was difficult giving instructions. For example, he would growl if asked to sit on the toilet. He could write 3 letter words, or his name and he was spelling better with online education. In contrast he was doing year 5 maths. He used to do 50-piece jigsaw puzzles. In his social development and play skills: he would only play monopoly if he was winning, or he would destroy the game. He had no imaginative play but played video games with his brother. He did construct things on Minecraft. His mother described his autism as: he repeats things such as hissing noises, he hated change, likes routine, and expected his mother to do everything for him, even get him a drink. He had been trialed previously on Stimulants and Strattera with no benefit.

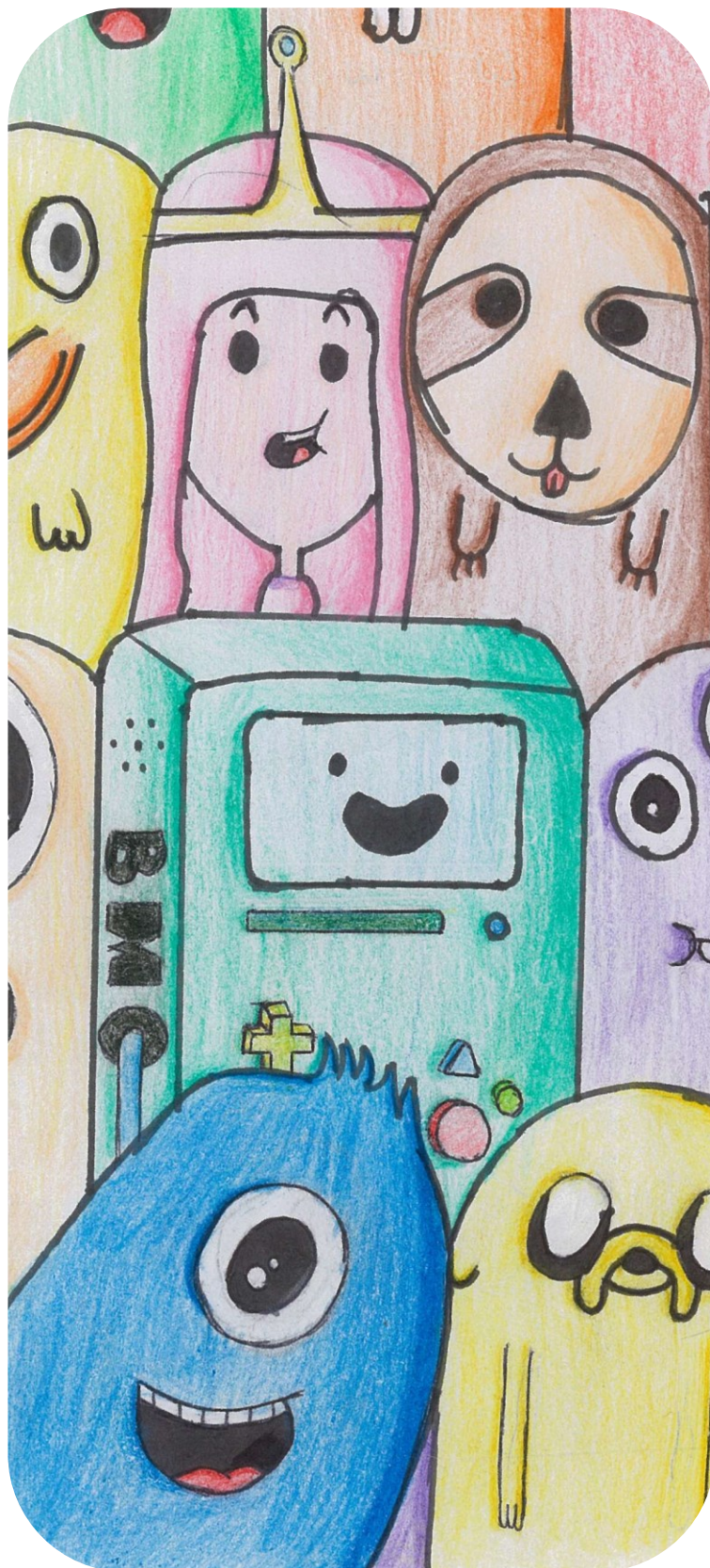
The family context: mother was 43, worked in accounts, but not since D was born. She had some health concerns: a bad knee which D targeted. She had polycystic ovary with pain and heavy bleeding and gastro oesophageal reflux. By nature, she was polite, listened to advice, and helped others. She felt her mental health was fine but got stressed and got hot flushes. She grew up on acreage with animals and had a good childhood. She was a good student and made friends at school. She had also made friends through the hospital. She was not irritable except when suffering poor sleep, often because she was affected by pain. She got upset and cried when D said 'I hate you'.

His father was 44, suffered glaucoma, was a truck driver working from 6am to 4pm, and liked working on his car where his sons would often join him. D's 16-year-old brother had long standing complex medical conditions: a gastrostomy and tracheostomy till recently. He also had mild ID, autism, sensory processing problems, ADHD, and anxiety. He was getting physiotherapy and did a social group through his psychologist.

The formulation and diagnosis included: Mild to Mod ID & autism, ADHD, violence, ODD or Disruptive Mood Dysregulation Disorder. His emotional and behavioural disturbance was associated with a significant loss of independence skills. The initial treatment plan was:

1. Stop sertraline due to concerns about behavioural activation, as he was more violent since he started 3-4 years previously

“The rule of medication management is to make one change at a time, so improvements and side effects can be closely monitored...”





2. Behaviour management of violence: with loss of stimulation/attention, a safe room to de-escalate and chill out

3. Change routines: expect him to play and do screen time in communal area to reduce his social isolation

4. Moderate his arousal problems with Clonidine 50mics 7am, 11 am, 3pm and 7pm and 50-100 pm. (instead of 200mics nocte)

5. Osmolax 68mg daily.

At his second visit 2 weeks later, he was '50% better'! He was calmer and more communicative; There had been no assaults on his mother. He accepted 'chill out' if angry and was settling quickly; he was spending much less time on his own; his screen time was down from 9hrs to 4hrs/day. He would go for a walk with mother. He was having his bowels open x2/week with pellet like faeces; mother had increased his osmolax and added lactulose as a softener. We agreed he was to be rewarded with some ice cream every time he sat on the toilet for 10-15 mins up to x3/day as this was his favourite reward. Mother was appealing his NDIS for 'change of circumstances'. He now started paliperidone 3mg at night for anxiety, ADHD, stereotypic rigidi-

ty and mood regulation.

At their 3rd visit 4 weeks later he was '75% better'. There had still been no violence, and mother was no longer fearful of assault. He was more communicative and playing games. He had had some 90 minutes zoom sessions with his teacher and was making arrangements to return to school with 2:1 support. He was playing uno and monopoly with brother and father, even coping with losing! He was soiling less and doing poos in the toilet regularly. He needed a gel capsule to help with swallowing paliperidone.

On his 4th visit 4 weeks later he was '95% improved'. He was like 'his old self', happier and better than for years. He would talk and answer questions at home and school. He was talking with all the family and he even went to a restaurant for his brother's birthday party. School was going well, he was back in his support class, and no longer needing his chill out room. He was now drinking 1-2 litres of water a day and his constipation was under control. He had increased his variety of food and didn't need ice cream rewards anymore. His mother felt back in charge- he was doing as he was asked! His mother was getting more exercise and getting less pain.

At the 5th visit, 3 months later he was now in a mainstream class, doing his work, helping younger kids, and received the principal's award. He now didn't like being on his own and preferred his mother's company, including walking 15 minutes to school daily. He was modifying his diet to help manage his weight. He was more interactive and wanted to see his maternal grandmother on her birthday.

Aftermath: A trial to switch from paliperidone to risperidone because of the cost led to him becoming excitable, anxious, 'hyper' and becoming oppositional again. However, the cost of off label (private script) of paliperidone is now \$50 dollars a month at large scale chemists.

There are several clinical lessons from this case: Firstly, the importance of the bio-developmental-psychosocial-cultural assessment framework (Dossetor *et al*, 2011), and within that the primary importance of assessing and understanding social development as the core element of autism and associated emotional and behaviour disturbance (Dossetor, 2022). Second, this case is typical of many, illustrating the level of impairment of 25-30 points on the CGAS from emotional and behavioural disturbance on top of their ID and autism, and the complexity of several disabilities and psychiatric disorders challenging the capacity and wellbeing of all family members. This boy improved by 25 CGAS points but still had major needs for both long term psychiatric and disability support to further progress in choice and independence. More than one medication may be needed, which does not follow an algorithm for treating ADHD in a mainstream population. Medications used may also have to take account of co-morbidities. So often the medication reduces impairment, rather than 'cures', and needs to be continued. However, if it also improves wellbeing, independence, attachment, relationships, participation and choice, we know that these components have a long-term impact on future wellbeing.

Similar cases have responded to a range of different medication such as clonidine, and amitriptyline. Some have responded to a combination of primary, secondary and tertiary level medications for ADHD. One similar case of a well-built teenage autistic boy with mild intellectual disability, virulent hyperactivity and prone to oppositionality, street wandering, and breaking in to houses to inspect their lawn mowers had required: Concerta, clonidine, amitriptyline, guanfacine, paliperidone and lamotrigine with occasional crisis doses of risperidone. This is a courageous number of medications but physical health, ECG and blood pressure were fine. However, his carer and his disability care team and I feel confident that this regime has

“Further research shows that disturbance in autism drives family functioning, rather than the other way round, as often seen in mainstream families...”

kept him out of police custody and juvenile justice and kept him in a caring family and community who love and help him.

Always keep in mind the developmental and family context. Those with autism and ADHD or anxiety also have a primary delay in emotional competence and theory of mind, and lack emotional and relationship awareness, which can complicate attachment. Often, they respond to any elevation of affect as rewarding or reinforcing, whether this is positive or negative which can be part of a negative 'cycle of coercion' with parents (Patterson, 2002). Their attachment qualities are like a much younger person. My teaching is that those with pure autism have the social understanding of a child of 2 years or less (Dossetor, 2020, 2022). Those



“Some parents still seem to benefit from an examination of the developmental context of attachment behaviour...”

who progress or who have Aspergers have a social understanding like that of a 3-4.5 year-old. Further research shows that disturbance in autism drives family functioning, rather than the other way round, as often seen in mainstream families. Nonetheless, treating the burn out, anxiety or depression in one or both parents can have a huge impact on re-energising and growing the positives in the parent child relationship.

Behavioural Management

Behavioural management is the primary intervention, and this is illustrated in other tertiary cases (all too commonly). In the of lack of parental awareness of the need and skills for limit setting, medications often have minimal or no influence. Sometimes parents learn late in the trajectory of parenting, the importance of what behaviour management communicates and also understand their need to model emotional self-regulation. Sometimes things change and improve only when the young person moves to alternative foster or group home care. Many times, a change of style of parenting, with authority, and calmness exposes the

young person to establishing skills of self-regulation. In some cases where there is improved limit setting and learning of self-regulation, a few months later, their nature or underlying personality calms down, whereby they are not so over-aroused and hyperactive, they concentrate better, and they need less medication.

Specialist behavioural parenting programs such as Stepping Stones Triple P are the best evidence-based intervention to prevent and treat child emotional and behavioural disorders and are highly cost effective. Some parents still seem to benefit from an examination of the developmental context of attachment behaviour and how to improve one's understanding of the behaviour and its impact on them as a parent (Tran, 2021). However, understanding of families functioning as a whole also draws attention to the mental and physical wellbeing of parents. In my practice 50% of parents at presentation have burnout, anxiety or depression which limits their capacity to provide the parenting they would like to provide. Treating their mental health and wellbeing becomes a necessity for them to be able to help their child.

The management of aggression also has 3 levels:

- *The first* is behaviour management and positive behaviour support, as is now readily available from NDIS behaviour support clinicians.
- *The second* is to consider the presence of co-morbid psychiatric disorder, and its treatment. Treatment of the psychiatric disorder can reduce or prevent a predisposition to aggression and



Framework for the development of wellbeing

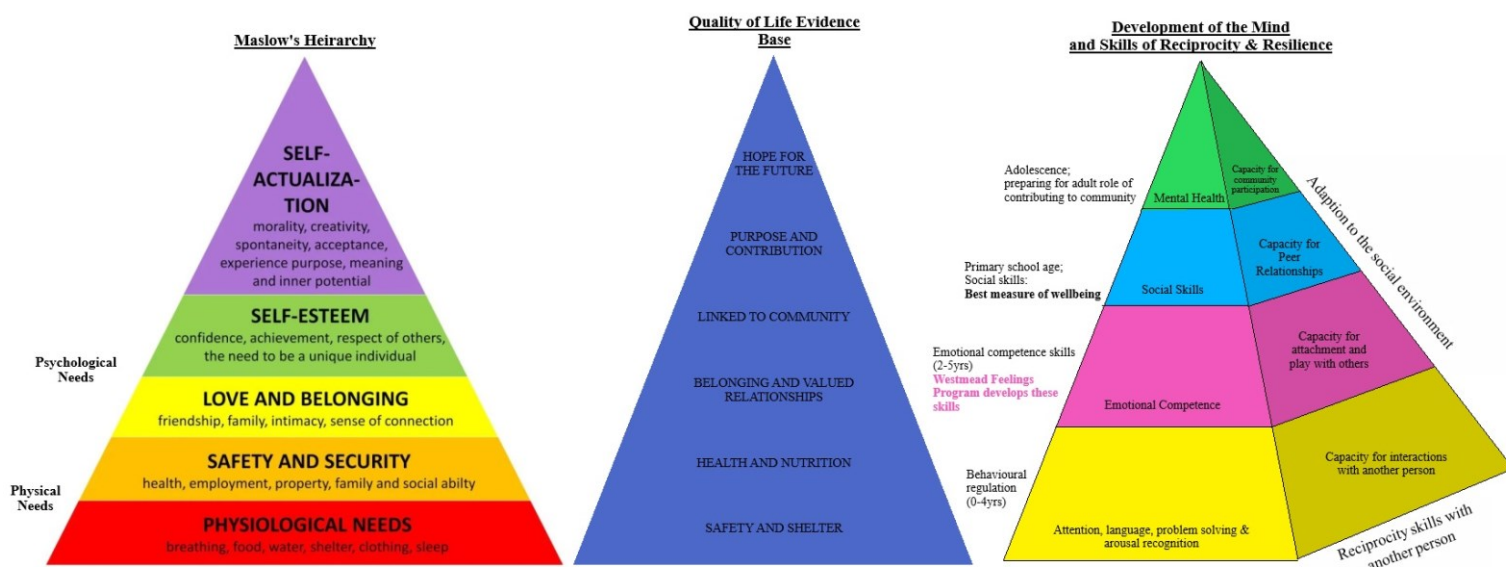


Figure 1: Framework for the development of wellbeing including Maslow's Hierarchy, Quality of Life evidence base and the Development of the mind and skills of Reciprocity and Resilience.

violence. However not all violence is related to psychiatric disorder.

- The *third level* of intervention is safety management: this on its own can be highly effective. A case example demonstrated a 95% improvement in a 100kgm non-verbal autistic boy who was a public danger at school, in the community and at home.

It is important to remember that restrictive practice guidelines are there to ensure a professional standard of restrictive practices. Parents have absolute responsibility, authority and control over their child below the age of 16 and if the child lacks capacity of informed consent and decision making. Serious challenging behaviour needs a multidisciplinary, multiagency approach and the range of skills that are needed (Watson *et al*, 2011, Dossetor, 2015, 2019). Because some will consider these statements controversial it is important to state that these articles were approved by senior clinicians in NSW Disability Services and NSW Department of Education. The evidence from a NDIS mental health liaison officer suggests that tertiary cases are often underfunded, and appropriate funding is an important key to improving their predicament (Shenoy, 2022).

However, medication is not a primary treatment for violence itself. I take the view that violence has to be treated with behaviour management. All too often aggression gets you what you think you want, and others'

acquiesce leading to further deterioration of the recurrent predicament. Sedation can be used by parents and professionals to prevent danger and assault. However, too often the outpouring of chemicals that occur in violence, whether it be maladaptively learned or malicious is difficult to manage with medication. If such medication were given routinely the patient would be asleep and is not therapeutic. Conversely, the arousal of extreme violence for example in autism can be so difficult to contain with psychotropic medications, that not infrequently the patient ends up anaesthetized, either until any acute medical condition is treated, or a safe place in which to contain them with sufficient staffing is established. Accordingly, any emergency transfer of a person with ID and or autism to emergency medical services, is a late stage of a failure of multidisciplinary, multiagency intervention and community care. It is important to avoid such medicalization of bad or distressed behaviour.

It is a basic truth that all kids need to learn a capacity for self-soothing, and emotional regulation is an important predictor of later mental problems going on into adulthood. In autism, the skills required may be more challenging to acquire, with an understanding of the pattern of developmental delay, the problems of sensory processing, the communication problems, the problems of stereotypic rigidity and yet the need to develop physical and emotional engagement and attachment.

This article has emphasised the need to be able to take a behavioural approach to understanding maladaptive behaviour, but also the full bio-developmental-psycho-social-cultural approach to understanding human behaviour and psychiatric disorder. This frequently involves a multidisciplinary approach, but also poly pharmacy to tackle the psychiatric co-morbidities that co-occur. While we need many of the mental health skills that mainstream mental health and disability services have, there are some complex cases that require specialist disability skills and specialist psychiatric and pharmacological contributions to be integrated.

To conclude: there is limited literature on ADHD and moderate to severe ID and in those with additional autism, which nonetheless builds a picture of differences in the assessment and treatment of these young people. This article is also substantially based on the 20 years' experience of the tertiary clinic in mental health in ID and autism in conjunction with our interagency and interdisciplinary partners.

Some cases of ADHD in ID and autism are really disabling and difficult to treat and requires multimodal, person orientated and family intervention from the collaboration of multidisciplinary, multiagency partners and their skills. Perhaps some of these cases would be easier to manage if their problems are picked up and treated earlier. Treating the problematic and impairing emotions and behaviours as exemplified in this article leads to gains that enable a young person with ID and or autism to engage with mainstream disability and carer services. We must always remember that the improvement of severe mental disorder enables all to refocus on a positive framework for health, wellbeing and optimal development as illustrated in the diagram on page 13. Marlow's Hierarchy, the domains of quality of life and the sequence of emotional and relationship development are helpful frameworks to guide all to bring out optimal wellbeing, participation, choice, contribution and inclusion for such young people with ID and or autism (Dossetor, 2022).

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Note:

CGAS: The Children's Global Assessment Scale (CGAS), adapted from the Global Assessment Scale for adults, is a rating of general functioning for children and young people aged 4-16 years old. The clinician assesses a range of aspects of psychological and social functioning and gives the child or young person a single score between 1 and 100, based on their lowest level of functioning. The score puts them in one of ten categories that range from "needs constant supervision" (1-10) to "superior functioning" (91-100). The measure can be used by clinicians as well as researchers to complement other scales measuring more specific symptoms. The CGAS was developed by Shaffer and colleagues at the Department of Psychiatry, Columbia University in 1983.

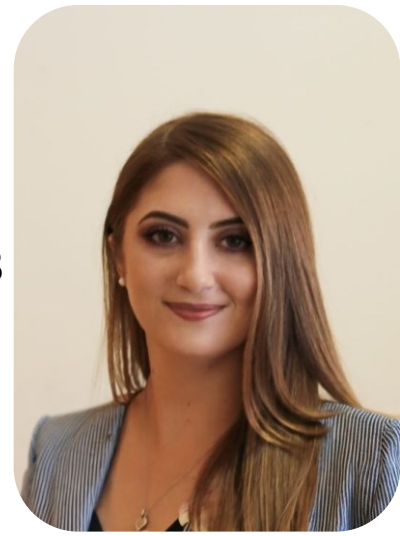


Developing Brain Clinical Research Colloquium

The Children's Hospital at Westmead, supported by the Sydney Children's Hospital Foundation. November 2023

Arrielle Hope

Kids Mental Health Research Manager



The Sydney Children's Hospital Network, The University of New South Wales and The University of Sydney, hosted the Developing Brain Clinical Research Colloquium at The Children's Hospital at Westmead in November 2023, supported by the Sydney Children's Hospital Foundation. The annual event was established by Dr Iain Perkes, Professor Russell Dale, and Professor Michelle Farrar, serving as a showcase of the clinical research collaboration across psychiatry, psychology, neurology, and neurosciences.

The colloquium featured two keynote addresses from internationally recognised leaders. Prof Michelle Farrar - Professor of Paediatric Neurology at UNSW Sydney and Sydney Children's Hospital presented 'The past, present and future of developmental neuroscience' and Prof Jennie Hudson, Director of Research at the Black Dog Institute, who discussed Child Mental Health research in Australia relative to her position of Chair of the Childhood Mental Health Research Plan Expert Advisory Panel.

We heard presentations from clinical researchers at the top of their fields;

Elizabeth Elliott, Professor in Paediatrics and Child Health at the University of Sydney and the Sydney Children's Hospitals Network explained the profound implications of alcohol consumption during pregnancy and noted the critical role of policy implementation in prevention, such as her contributions to advocating for

“A showcase of the clinical research collaboration across psychiatry, psychology, neurology, and neurosciences”

mandatory pregnancy warnings on alcoholic beverages. This initiative, aimed at raising awareness about the risks associated with alcohol intake during pregnancy, forms a crucial part of ongoing efforts to safeguard fetal health. You can explore the every moment matters website here:

<https://everymomentmatters.org.au/>

Sue Woolfenden, the Director of Community Paediatrics at the Sydney Local Health District and Professor





of Community Paediatrics for Central Clinical School, Sydney Medical School, at the University of Sydney, presented Epic CP, a project addressing the double jeopardy of disadvantage and disability in Cerebral Palsy. Her research found that 65% of families who took a screening form reported unmet social needs, with the majority noting issues with government entitlements, transportation and NDIS.

Dr Sarah McIntyre, Program Lead for Epidemiology at the Cerebral Palsy Alliance and Sophie Marmont, CP Quest Coordinator discussed CP Quest, a group launched to better integrate the lived experience of people with cerebral palsy into programs of research. Sophie delivered a compelling perspective on living with CP, highlighting the often-overlooked aspects of daily life that individuals managing CP grapple with, emphasising how certain challenges may elude researchers' attention.

Sarah-Grace Paguinto, SCHN Occupational Therapist presented her doctorate research 'Getting Wheels: Supporting transition to wheelchair use for paediatric neuromuscular conditions'. Sarah-Grace talked on the experiences faced by both caregivers and clinicians when transitioning a child to a wheelchair prescription. Her research identified the barriers encountered and highlighted the emotional complexities surrounding



1st place, Dr Natalie Fairbairn, Senior Occupational Therapist and Research Officer in the Grace Neonatal Intensive Care Unit

the recommendation of wheelchairs. Sarah-Grace developed a psycho-educational booklet aimed at aiding caregivers through the introduction of wheelchairs to their child's care. Sarah-Grace's success with the caregiver booklet will lead to the development of a child-centred booklet in the future.

This year's event received significant support from the Sydney Children's Hospital Foundation, facilitating the presentation of Research Publications Awards. The awards were presented by Adj. Associate Professor Paula Bray and The Hon Kristina Keneally, showcasing three researchers from the Sydney Children's Hospitals Network.

1st Place was awarded to Dr Natalie Fairbairn, a Senior Occupational Therapist and Research Officer in the Grace Neonatal Intensive Care Unit at the Children's Hospital at Westmead. Natalie's publication entitled **"Risk of Developmental Coordination Disorder in 8- and 9-Year-Olds Following Newborn Cardiac and Non-Cardiac Surgery"** is the first investigating the risk of developmental coordination disorder in the surgical population.

2nd Place was awarded to Dr Simon Paget, a Paediatric Rehabilitation Medicine Physician and Medical Director of Kids Rehab, the Children's Hospital at Westmead. Simon's publication **"Non-attendance at outpatient clinic appointments by children with cerebral palsy"** found a total of 12% of 50 121 scheduled outpatient days were not attended. Non-attendance increased over time and was more likely with older children, socioeconomic disadvantage, previous non-attendance and previous cancelled appointments.

And 3rd Place was awarded to Dr Eden Robertson, a psychosocial researcher, specialising in children with serious illnesses and their families. Eden's Publication **"Somewhere to turn to with my questions": A pre-post pilot of an information linker service for caregivers who have a child with a Developmental and Epileptic Encephalopathy"** found that Caregivers of a child with a Developmental and Epileptic Encephalopathy (DEE) often report challenges accessing relevant and understandable information regarding their child's condition. Eden and her team developed GenE Compass, an information linker service where caregivers are invited to submit questions and receive high-quality, personalised reports.

If you are interested in learning more about Kids Mental Health Research or the annual 'Developing Brain' Clinical Research Colloquium, please contact Arrielle Hope on arrielle.hope@health.nsw.gov.au.



2nd Place, Dr Simon Paget, Paediatric Rehabilitation Medicine Physician and Medical Director of Kids Rehab



3rd place Dr Eden Robertson, psychosocial researcher, specialising in children with serious illnesses and their families.

Reading List

Social anxiety and fragile X

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Smoking and vaping

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Cognitive behaviour formulation and therapy

Hronis, A. (2023). An AAIDD-informed framework for cognitive behavioral case formulation and cognitive behavior therapy for young people with mild intellectual disabilities or borderline intellectual functioning. *Clinical Psychology: Science and Practice*, 30(3) Pp. 312-313. <https://doi.org/10.1037/cps0000155>

Measures of sleep

O'Sullivan, R., Bissell, S., Hamilton, A., Bagshaw, A. & Richards, C. (2023). Concordance of objective and subjective measures of sleep in children with neurodevelopmental conditions: A systematic review and meta-analysis. *Sleep Medicine Reviews*, 71 Pp. 1-16. <https://doi.org/10.1016/j.smrv.2023.101814>

Parenting styles and self determination of children

Meral, B.F., Wehmeyer, Michael, L., Palmer, S.B., Ruh, A.B. & Yilmaz, E. (2023). Parenting styles and practices in enhancing self-determination of children with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 128(4) Pp. 282-301. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc22&NEWS=N&AN=2024-11110-002>.

Easy Read

Newman, B., Fisher, K.R. & Trollor, J. (2023). How do Australian mental health services use easy read to make information accessible for people with intellectual disability? *Journal of Applied Research in Intellectual Disabilities*, 36(6) Pp. 1354-1362. <https://doi.org/10.1111/jar.13156>

Irritability and Aggression

Ooi, A., Banno, B., McFee, K., Elbe, D. and Friedlander, R. (2023). Evaluating and managing irritability and aggression in children and adolescents with autism spectrum disorder: An algorithm. *British Columbia Medical Journal*. Volume 65, Issue 8, Pp. 291-301.

Stress in parents

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Mucopolysaccharidosis type 3

Tchan, M. and Sillence, D. (2009). Extrapyramidal symptoms and medication use in mucopolysaccharidosis type 3. *Journal of Intellectual and Developmental Disability*. Volume 34, Issue 3, Pp. 275-279.

Dysphagia

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Small Changes, Big Impact: Emotional Development of Autistic Adolescents with Co-occurring Moderate Intellectual Disability.

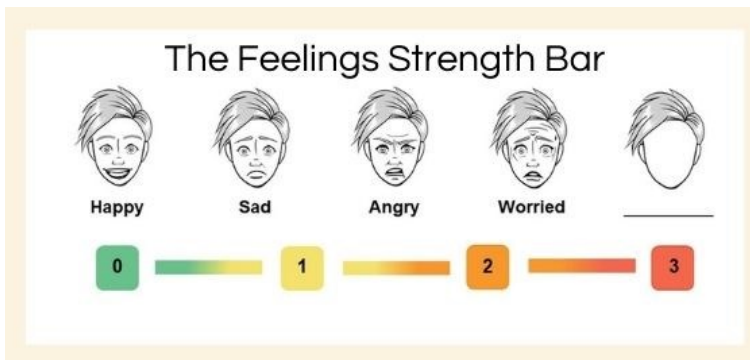
Anita Gardner & Ellen McBriarty

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

Introduction

Research into the importance of social-emotional learning for autistic children is emerging, however there is a dearth of evidence-based educational programs supporting autistic adolescents with co-occurring moderate intellectual disability. The Feelings Program for Adolescents (TFP-A) is adapted from the Australian evidence-based Westmead Feelings Program. It is a manualised wellbeing program which includes web-based lessons, age-appropriate videos and emotion-based visuals and worksheets designed specifically for autistic adolescents with mild intellectual disability.

The Feelings Strength Bar



Aim

Explore the emotional development of autistic adolescents with moderate ID in the context of participating in TFP-A as part of the PDHPE curriculum at school.

Methods

Autistic adolescents with moderate ID were recruited through a pilot of TFP-A (SCHN 2021/ETH00168), delivered by a teacher in an autism-specific secondary school class. Eligibility included assessment of cognitive ability (WISC-V), adaptive functioning (Vineland-3) and autism severity (via parent and teacher report on the SRS2). TFP-A was implemented 2-3 times a week across 2 terms, to a group of ten students in a life skills class. Each lesson ran for 10-15 minutes and

covered topics such as expressing and understanding feelings and emotion regulation strategies. Quantitative and qualitative data were collected from parents at baseline, after the program and at 6 months follow up, and from the class teacher at two time points.

Questionnaires included a measure of emotional competence (Emotions Development Questionnaire; EDQ), emotion dysregulation (EDI) and mental health scales of anxiety, depression and aggression (Child Behaviour Checklist; parent report CBCL; teacher report TRF). A Goal Attainment Scale (GAS) was developed by parents, and written feedback was provided by parents and teachers.

Participants

The four male participants (13:4 -14:10 years) had moderate ID (FSIQ<55; ABC 48-79), and autism (severe range in SRS2). All were reported as minimal verbal communicators (WISC-V VC below 0.1%) with some key word signing. Most (75%) had a diagnosed mental health condition (anxiety and/or ADHD). Similarly, three of the four had additional conditions (e.g., cerebral palsy, chromosomal duplication, dyspraxia etc).

“Explore the emotional development of autistic adolescents with moderate ID in the context of participating in TFP-A as part of the PDHPE curriculum at school.”

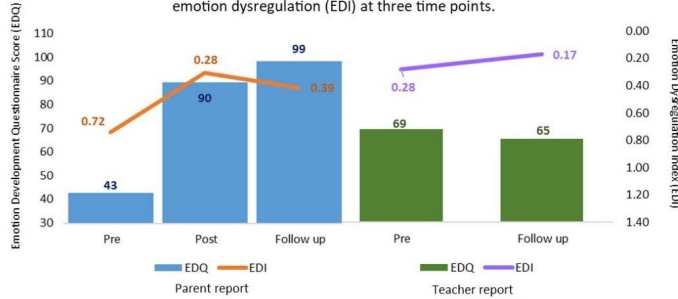
Results



"Ben is able to recognise his feelings and can sometimes deal with them independently".

Initially, Ben used self-harming behaviour and sounds to communicate his distress or anger. In addition to motor difficulties, Ben was also found to have clinical levels of anxiety (CBCL). By the end of TFP-A Ben was reported by his parent to have a clinical improvement in anxiety, with post and follow up scores in the average range. EDQ also improved at home, but there was minimal change reported by his teacher. EDI showed an improvement at home and school. On the GAS, his parents reported a mild improvement as Ben can now indicate how he is feeling using the Feelings Strength Bar, however this is having a significant impact on their life as his family can assist in validating his feelings and know more about what worries him.

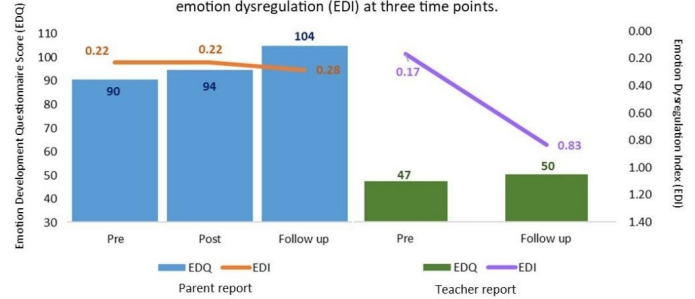
Ben's parent and teacher reports of emotional competence (EDQ) and emotion dysregulation (EDI) at three time points.



"Jack started to recognise and verbalise being worried and being able to say why at times."

Jack had no prior mental health or reported co-occurring conditions. Prior to the program, Jack could sometimes communicate he was feeling sad, but often relied on prompts from others. By the end of TFP-A, parent reported an improvement on the GAS, as Jack was able to verbalise "I am worried" and sometimes provide a reason for why. However, at follow up on the TRF and CBCL, there was a reported a decline on the EDI. His teacher also reported that anxious and aggressive behaviours were now in the clinically significant range (TRF). But Jack was reported to have a slight improvement in EDQ at home and school, including increased ability identify feelings in self and others and distracting himself when feeling an unpleasant feeling.

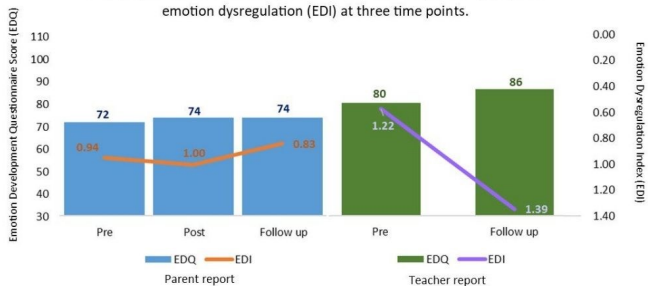
Jack's parent and teacher reports of emotional competence (EDQ) and emotion dysregulation (EDI) at three time points.



"Harry has begun to independently engage with more useful strategies to help regulate his emotions..."

At the beginning of the program, Harry's mental health and emotion dysregulation behaviours were all greater than his peers. Harry would express unpleasant feelings by acting silly, and needed adults to redirect him. After the program, his parent and teacher reported a slight improvement on the EDQ. His parent also reported an initial decline on the EDI, but improvement at follow up. His teacher observed a decline in emotion dysregulation behaviours at follow up. On the GAS, parents reported a mild improvement in emotions communication, and that Harry could now verbally identify a range of feelings and link feelings to a situation.

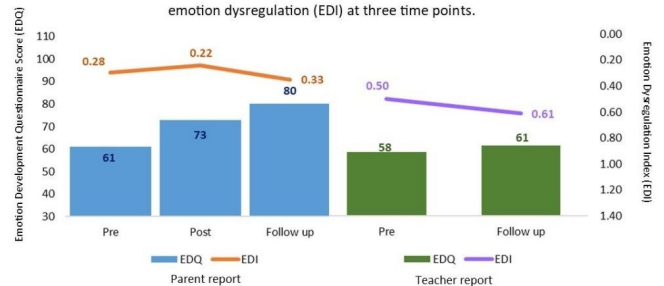
Harry's parent and teacher reports of emotional competence (EDQ) and emotion dysregulation (EDI) at three time points.



"Liam is able to communicate how he is feeling much easier [and] with just a little prompting can also tell me why."

Liam has a complex presentation with multiple co-occurring conditions. Initially, Liam verbally recognised feeling happy and sad, but only used behaviours to express feeling angry or worried. At the end of TFP-A, both parent and teacher reported an improvement on the EDQ, but an increase in emotion dysregulation behaviours (EDI). On the GAS his parent reported an improvement as Liam was now able to verbally express a range of both pleasant and unpleasant feelings in response to home and school situations, and was able to use the Feelings Strength Bar to identify two different levels of intensity.

Liam's parent and teacher reports of emotional competence (EDQ) and emotion dysregulation (EDI) at three time points.





Discussion and Recommendation

This case series study followed the emotional development of four autistic adolescents with co-occurring moderate ID, receptive and expressive language difficulties, mental health and other conditions. Results from the mixed method study suggests that engaging in an emotion-focused program improved teacher and parent confidence in developing emotional skills in students. While all students were reported to have improved in at least one area, the impact on each student varied. Relying solely on standardised questionnaires and quantitative data would have overlooked the impact of individualised goals and meaningful changes for autistic students with moderate ID and their families.

The class teacher reported that visuals and videos in TFP-A were appropriate for his class. However, a number of adaptations improved the program, these included more repetition and dividing lessons into smaller components. Parents desired more involvement from the school and support in adapting TFP-A for their family. Although this small study highlights the potential of TFP-A, there are a number of limitations. The study would have benefited from a larger sample size,

“A number of adaptations improved the program, these included more repetition and dividing lessons into smaller components.”

and data being collected during each lesson. Future research should address these limitations to further explore program feasibility and effectiveness.

Impact

This study demonstrates that when conducting research with students with complex learning and support needs, it is crucial to use individualised and meaningful goals that have been co-developed with parents.

Teaching emotional literacy in secondary school to autistic students with moderate ID is an essential life skill

that requires continuous focus. TFP-A provides teachers with an easy to use resource that students enjoy and teachers can easily tailor to their classroom. By involving both home and school, TFP-A can cater to each student's unique needs and aspirations, promoting holistic development and well-being.

Conclusion

This small study demonstrates that autistic students with moderate ID have the potential to improve their social emotional skills. The findings suggest that utilising materials from TFP-A, along with appropriate adaptations, can be beneficial in school and home. This study highlights the importance of further research and development to continue improving the quality of life for autistic students with moderate ID and their families.

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The Medicine Cabinet: Weight gain and antipsychotics

Judy Longworth

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The Children's Hospital at Westmead

Autism is associated with multiple medical, neurologic and psychiatric comorbidities. These comorbidities often exacerbate the disparities in quality of life and life expectancy and can be further exacerbated by some of the medications prescribed to control behaviours (Dhanasekara *et al*, 2023). Several recent meta-analyses have corroborated observational studies showing the risk of obesity is increased with individuals with autism (Dhanasekara *et al*, 2023).

Antipsychotics such as risperidone and olanzapine are known for their effectiveness in helping control challenging behaviours. But as a result, there is also the likelihood of adverse effects including weight gain leading to obesity which can lead to cardiometabolic syndrome which predicts an increased rate of arterial disease, health disease and diabetes which in turn leads to risk of premature mortality. Another consequence of weight gain includes sleep apnoea.

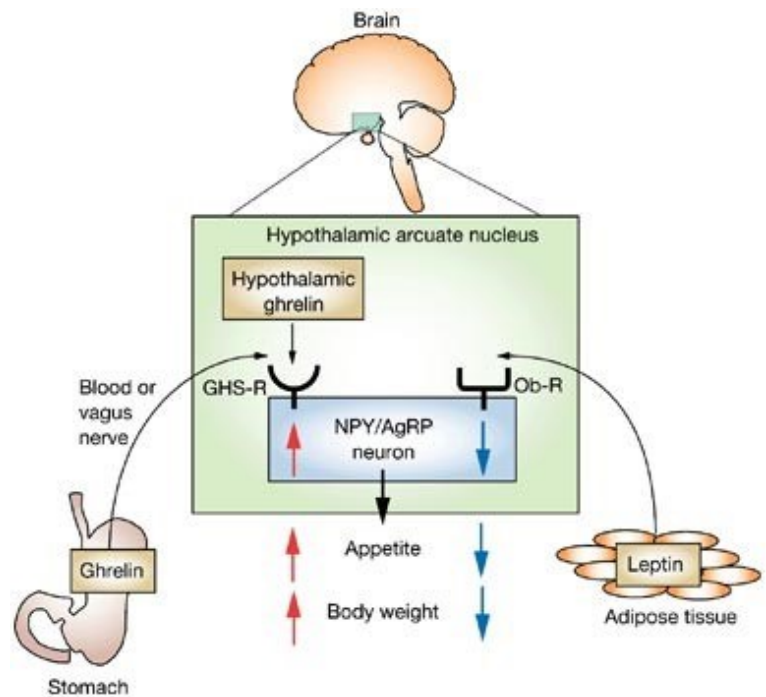
Ghrelin and leptin are both neuropeptides located in the brain. Ghrelin is appetite enhancing; leading to increase in feeding activity. Leptin is the opposite of ghrelin. There are preliminary findings that ghrelin and leptin levels may be altered in autism which are then linked to levels of androgens as well as growth hormone (GH) which can all in their own way contribute further to obesity. Ghrelin is known to influence the sleep-wake cycle as an orexigenic peptide and is known to suppress locomotor activity (Al-Zaid *et al*, 2014).

See Image from Kojima and Kanagawa 2005

The relationship between the actions of antipsychotics and these neuropeptides is not fully understood and continues to be an area of research.

Obesity

The World Health Organisation (WHO) defines overweight and obesity as abnormal or excessive fat accumulation that presents a risk to health. 1 in 4 Australi-



Kojima and Kanagawa, 2005

an children are living with overweight or obesity (Dhanasekara *et al*, 2023). The root cause of this is complex and embedded in how we live. Some aspects are controllable, and this article will highlight a few areas that might be manageable to control.

Besides the stigma associated with excessive weight gain there is also the direct and indirect costs involved on one's health and those that care for someone with obesity. Poor mental health can also be attributed to poor diet and exercise. This includes the impacts that weight-related stigma and discrimination can have on a person's self-esteem, mental wellbeing and feelings of inclusion. Impacts can be higher in populations who are already vulnerable to mental health issues through racism and other forms of discrimination (Dhanasekara *et al*, 2023).



People living in areas of most disadvantage are **1.16x** more likely than those living in areas of least disadvantage



People with severe or profound activity limitations are **1.22x** more likely than those without limitations



People living in regional & remote areas are **1.08x** more likely to be affected than those living in major cities



65–74 year olds are **1.7x** more likely to be affected than 18–24 year olds



Men are **1.25x** more likely than women



Aboriginal and Torres Strait Islander peoples are **1.16x** more likely than non-Indigenous people

Overweight and obesity contribute **7.2%** of the health gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians

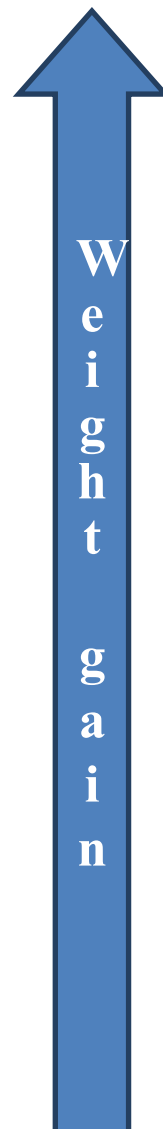
See Obesity Statics image above

One of the following graphics, the goals of the National Obesity Strategy 2022-2032 is to reduce overweight and obesity in children and adolescents aged 2-17 years by at least 5% by 2030². This will be achieved by increasing the consumption of vegetables and reducing the intake of discrepancy foods as well as other measures.

It is widely known that when certain medications are used for control of behaviours there is a consequence in driving the appetite to carbohydrate crave. This craving will lead to an excess intake of discrepancy foods and eventual weight gain. Some of this can be managed by rationalising the psychotropic medication but not all psychotropic medication is equal, and some are more effective than others, so each has to be individualised.

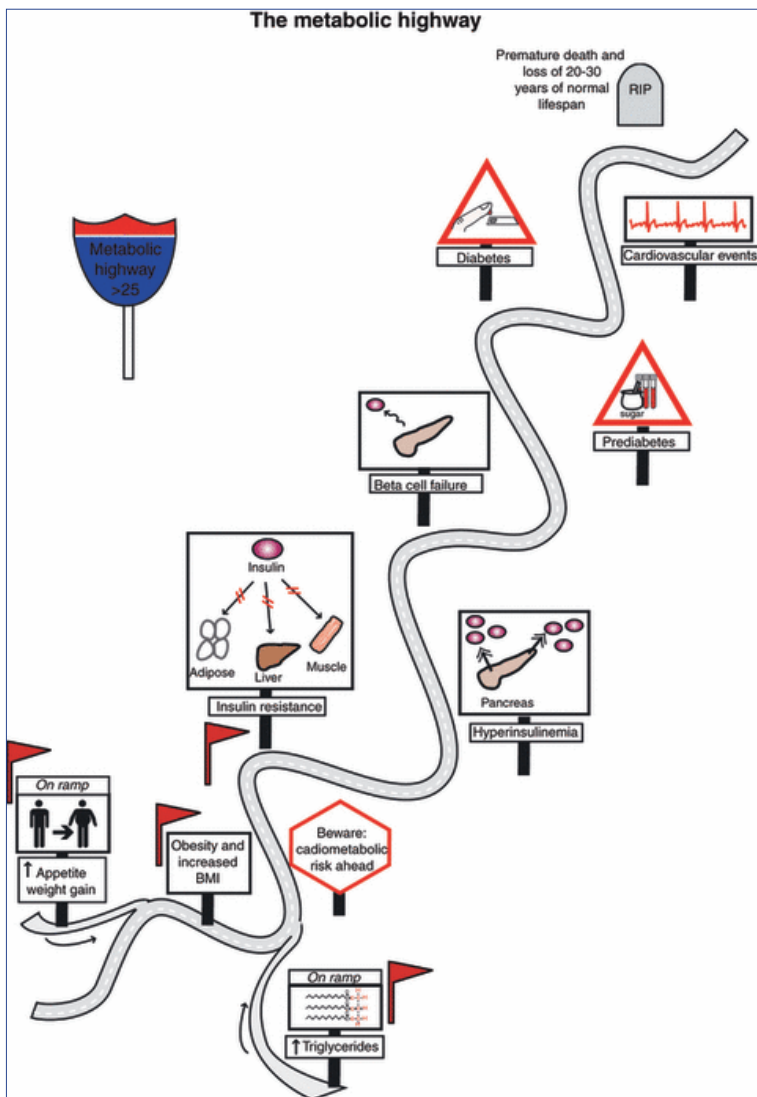
Weight gain amongst antipsychotics to induce weight gain of those available in Australia.

This graphic to the right is from Pillinger and colleagues paper looking at the effects of antipsychotic medications being taken for schizophrenia. Those with autistic spectrum disorder as well as children and adolescents have anecdotally shown to be sig-



- Olanzapine
- Clozapine
- Quetiapine
- Risperidone/paliperidone
- Asenapine
- Flupenthixol
- Brexpiprazole
- Amisulpride
- Fluphenazine
- Cariprazine
- Lurasidone
- Aripiprazole
- Ziprasidone
- Chlorpromazine
- Haloperidol

The metabolic highway



Role of Vitamin D and obesity

Vitamin D is associated with bone health as well as low levels linked to poor mental health. Vitamin D regulates the production of neurotransmitters including adrenaline, noradrenaline, dopamine and serotonin (Menon *et al*, 2020). Vitamin D can be converted in the body from cholesterol with sunlight. Cancer Council has recommendations on the amount of sunlight needed and time of year. <https://www.cancer.org.au/cancer-information/causes-and-prevention/sun-safety/vitamin-d>

New studies have also linked low vitamin D with obesity (Tobias *et al*, 2023) with both low blood levels and insufficiency. Although study in obesity and older adults and paediatrics needs to be done there is a compelling reason to supplement those who have low vitamin D levels as there is evidence to suggest a possible link between low vitamin D levels with cancer and cardiovascular disease.

Vitamin D levels have also been found to be low in several mental health conditions including depression and early psychosis. But there is evidence that supplementation of vitamin D does not help in the management of depression thus further studies into the relationship between vitamin and mood disorders is ongoing.

Overall ongoing research into the best antipsychotic for challenging behaviours in autistic children still needs further research so the right medication is prescribed for the right patient and their varying presenting symptoms (including but not limited to anxiety, aggression, mood swings, metabolism etc) which is achieved with minimal adverse effects. Recent guidelines include some advocating the early use of an old medication once primarily used in Type 2 diabetes but now shown to have some weight loss properties in those with prediabetes and even before this. There is also some preliminary data from the USA about the use of semaglutide in the treatment of obesity in children ¹⁰ these will be discussed in a further article in the future once evidence has grown.

References and further reading

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Commonwealth of Australia, (2022). The National Obesity Strategy 2022-2032. Health Ministers Meeting.

nificantly more affected and thus the significance of the associate weight gain might be different (Pillinger *et al*, 2020).

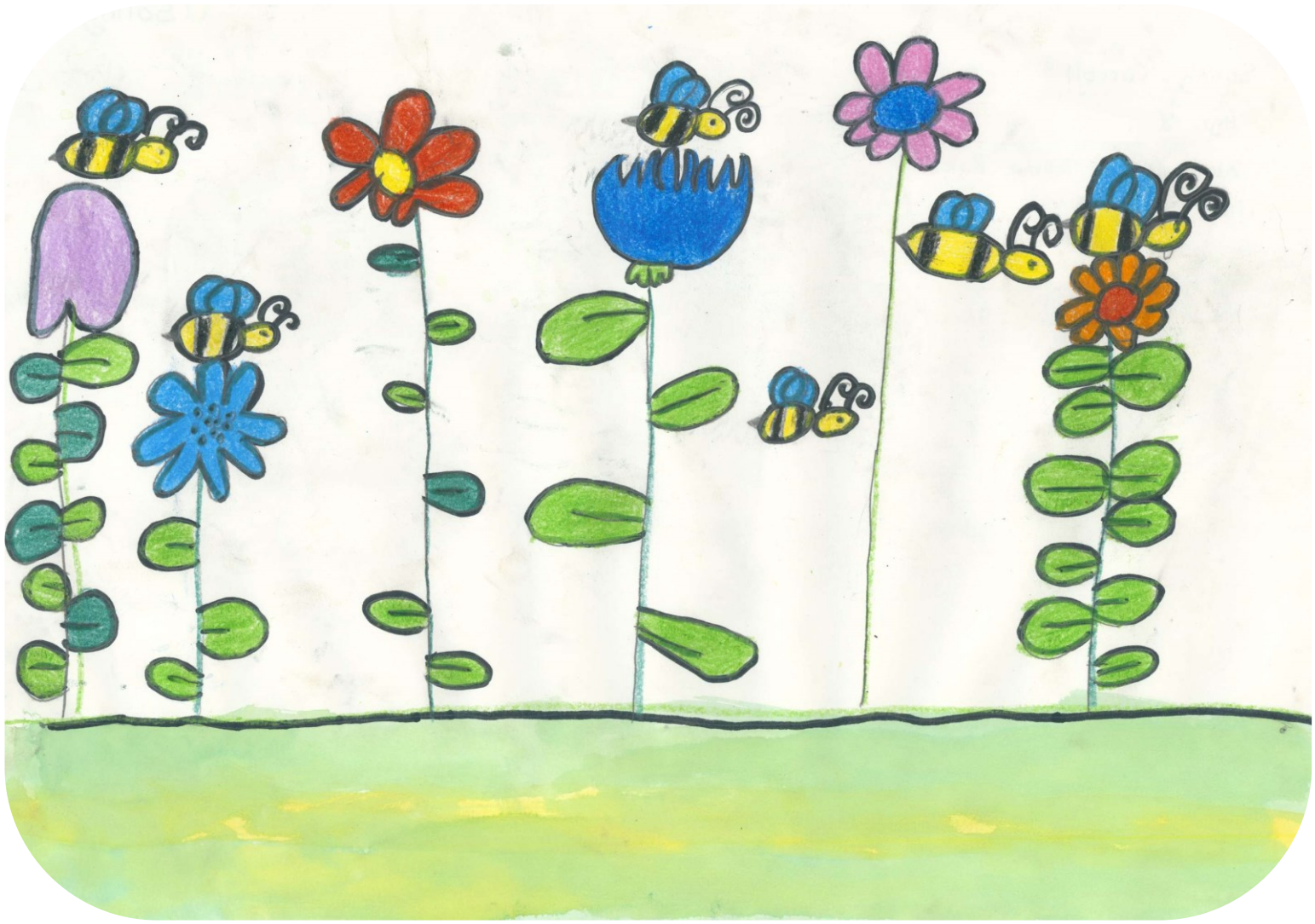
Stahl's (2009) illustration of the metabolic highway shows the link between obesity and cardiometabolic factors (Stahl *et al*, 2009).

Metabolic Highway image above

Obesity and Autism

From a recent systemic review individuals with autism have a 57.3% greater risk of developing diabetes compared to controls (Dhanasekara *et al*, 2023) and with children the risk is even greater [RR 2.84], although the impact of intellectual disability and use of psychotropic medication was not excluded as a confounder.

In conclusion of the review, it mentioned that children with autism seem to possess a higher risk of developing either diabetes (both types) and hypertension compared to children without autism (Dhanasekara *et al*, 2023). There is a need for further studies to identify which factors are contributing and then establish preventative strategies.



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NPHS - National Preventive Health Strategy

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dysregulation, and association with psychopathology: a systematic review and network meta-analysis. *Lancet Psychiatry*. Volume 7, Issue 1, Pp 64-77.

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Zuckerman, K.E., Hill, A.P., Guion, K., Voltolina, L., Fombonne, E. (2014). Overweight and Obesity: prevalence and correlates in a large clinical sample of children with autism spectrum disorder. *Journal of Autism Developmental Disorder*. (4) 44; Pp. 1708-19..

Changing Behaviours and Changing Capacity: Behaviour tip sheets for parents and carers of young people with intellectual and developmental disability.

H. Saleh, L. Whatson and J. Caruana.

Presented at SEPLA conference 2023.

Aim

To provide accessible and up to date tip sheets for parents and carers of children and adolescents with an intellectual or developmental disability and mental health concerns (IDDMH). These will be made accessible by providing the resources in English, accessible English and translated into a variety of community languages.

Objectives:

The objectives of the resources include:

- to co-design the tip sheets with parents and carers to ensure information is meaningful and useful
- to understand that children and young people with an intellectual or developmental disability (IDD) are more likely to have additional mental health needs and behaviours of concern
- to identify behaviours of concern and when children and young people with IDD need additional support
- to know where to seek help when additional assistance is required
- a collaborative tool between professionals and families that encourages help seeking behaviour

Introduction

There is an increasing amount of information about mental health in the typically developing population, and in some aspects about intellectual disability, but unfortunately, there is still a paucity of accessible and reliable information that professionals can use with confidence 'on the ground' when staff or families are in need and searching for more information about why children are changing and behaving in certain ways. We hope that this project will start an ongoing cycle of information gathering and translation to provide more and more professionals and families with an understanding of child behaviours and mental health needs,

in addition to professionals being more confident when presented with a complex case of dual diagnosis.

The planned tip sheets directly aligns with Strategic Objective 3 of the School-Link Action Plan 2020-25 whereby education staff and mental health professionals are more confident and knowledgeable, and better able to deliver coordinated care to children and young people with mental health concerns. In addition, the tip sheets will outline a general referral pathway for schools/services and families to follow and promote a partnership with schools as per deliverable under the Strategic Objective 2 of the School-Link Action Plan 2020-25.

TIP SHEET
Why is My Child Anxious?
Helping Children with an Intellectual Disability and Autism Manage their Anxiety

WHAT IS ANXIETY?
Anxiety is our body's natural response to stress. Anxiety can protect us from harm or threat (real or imagined) by preparing our body to respond to danger. Anxiety is feeling:

- Worried
- Stressed
- Scared
- Nervous
- Angry
- Hopeless

It is normal for a child to feel anxious sometimes. Autistic children and those with an intellectual disability tend to be more anxious. When someone is anxious, they often worry about what might happen. When there is a lot of worry or it lasts for a long time, it can be a problem. It is important for children to learn to manage their stress, fear and worries. Lots of worry can make it difficult for a child to be involved in daily tasks, enjoy themselves and try new things.

WHAT DOES ANXIETY LOOK LIKE?
Most children experience anxiety as changes in their body, the way they think and/or the way they feel. Children can find it difficult to recognise and tell others about what they are feeling. Anxiety can feel like:

- heart beating fast
- breathing more quickly
- feeling dizzy
- a sick stomach
- headaches
- sweating
- going to the toilet a lot
- having trouble getting to sleep and staying asleep
- sore or tight muscles
- not being able to sit still

Physical Indications of Fight, Flight or Freeze

Parents and teachers may also be able to see when a child is feeling anxious by looking at changes in their mood or behaviour. Anxiety can look like:

- needing a routine
- constantly looking for danger
- not joining in with family and friends
- being easily upset by small things
- tantrums in younger children
- being angry or aggressive
- not concentrating
- intense focus on one thing
- not going to school or not doing schoolwork
- hurting themselves, such as scratching their skin

Why is My Child Anxious? TIP SHEET | Developed by Sydney Children's Hospital Network, NSW School-Link & SAL Consulting | 1

The initial scoping and planning was presented to a multi-agency working group comprised from the following:

- NSW Department of Education state and local level
- Carer/Consumer representation
- Multicultural Health Communication Service and Transcultural Mental Health
- Sydney Children’s Hospital Network
- Developmental Psychiatry team at the Children’s Hospital at Westmead
- SCHN School-Link

In future, further consultation may be sought from but not limited to TAFENSW, 3DN and Developmental Paediatricians.

Stakeholders:

- School, and health staff working with children and young people with IDDMH.
- Parents/carers/families with children and young people with IDDMH.

Method

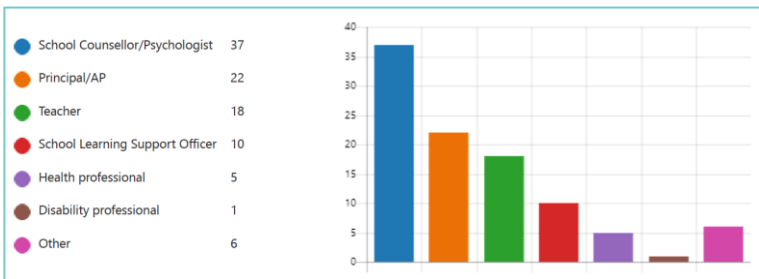
After submitting an application for a small implementation grant and successfully receiving the funding, the SCHN School-Link team was able to put together an initial plan and timeline of the process for creating the tip sheets package. See below.



Results

Survey Results

113 responses from professionals using an online 11 question survey designed in Microsoft forms. Responses from a range of professionals below helped us to prioritise content and develop tip sheets that will benefit young people with IDD and their families.



From the survey, the team was able to brief SAL consulting and support the development of a series of 5 information sheets (see images below) with long versions and short versions. The final topics include the following:

- Why is my child anxious?
- Why is my child hurting others?
- How can I help my child navigate adolescence?
- Why does my child hurt themselves?
- Sensory processing difficulties.

Each of these topics has a reference list and resource list that includes books, websites, packages and more. As per the initial survey, the tip sheets will be translated into Arabic, Vietnamese and Simplified Chinese. If we receive additional funding, we will be able to trans-

TIP SHEET

Why is My Child Hurting Others?

Helping Children with an Intellectual Disability and Autism Manage their Aggression

AGGRESSION IN CHILDREN AND YOUNG PEOPLE

It's common for children and young people with Autism and an Intellectual Disability to act aggressively sometimes when they are feeling angry, frustrated or anxious. Aggressive behaviours can include:

- Verbal aggression, such as verbal insults, arguments, name-calling and taunting
- Physical aggression, such as pushing, hitting, kicking, biting, hair pulling, scratching

Children and young people can be aggressive towards themselves (self-injury), property, or others.

There are two key types of aggression:

- Reactive aggression – sometimes a young person hits out and hurts someone or something without thinking. They act impulsively because they are frustrated or feel threatened. At these times, they are often distressed, angry or anxious
- Proactive aggression – is goal-directed and used to achieve something, other than hurting another person. It is often used to communicate something. If it's useful in achieving a goal (e.g. avoiding an activity, or taking an item from another person), it is likely the aggression will continue.

WHY DOES MY CHILD HURT OTHERS?

Children and young people with Autism and an Intellectual Disability often lack the skills needed to manage big emotions and the behaviours related to them. Some of these emotions include:

- Frustration – when they have difficulties making themselves understood
- Frustration – when a task is too hard, or goes for too long (wanting to escape the situation)
- Frustration or anger – when wanting to force access to an item or an activity
- Confusion – when having trouble understanding others, or a social situation
- Jealousy or competition – with peers, siblings
- Anxiety or stress – e.g. about changes, feeling overwhelmed by sensory input (e.g. lights), being surprised by unexpected touch or a sudden noise
- Curiosity – about what might happen if they hit out: sometimes the reactions of others are rewarding

HOW CAN I HELP?

You can help by remaining calm – stop, take a breath, and mirror the calm you want the child or young person to feel.

It's important that any response to aggression is matched to your understanding about why your child or young person is hitting out. If you understand why they use this behaviour to manage a situation or environment, you will be better able to:

- ✓ Prevent the behaviour
- ✓ Respond, rather than react, if the behaviour occurs
- ✓ Teach your child better ways to respond to emotions and manage behaviour

Find out as much as you can about the behaviour – what exactly does it look like? When does it happen? What is the child or young person doing when they become distressed or hit out? What triggers the behaviour? How do those around them respond?



late these topics into further languages and provide more topics as needed.

In June 2023, before the launch, downloads of the tip sheets include Sensory Processing (88), Anxiety (83), and Aggression (50).

Discussion

Overall, the tip sheet project idea was well-received by both the funding body and the professionals that we surveyed. Survey responses were positive and many topic ideas were suggested with overwhelming support for the topics of anxiety and self-injury. The literature review by SAL consulting was wide and varied inclusive of resources currently available to parents and professionals in this area. Collaborating was a smooth and enjoyable process that was precipitated by a good working relationship.

Unfortunately, we were unable to complete co-design measures as the application for funding initially had a very short timeframe. To have a complete co-design process we needed parent involvement from the outset. Feedback from parents has instead been sought alongside other professionals of the initial drafts. We hope that parent participation and feedback will help guide future topics and also the content of the 5 topics.

The iterative feedback process has taken longer than first thought. Many professionals were asked to participate in the review process, whereby we needed a matrix to summarise feedback received and record any gaps. Difficulties in the public mental health sector due to COVID-19 and ongoing staff illness and reduced working capacity, made the feedback processes considerably slower. Review was sought across professions and agencies.

There are many positives to this mini project. Parents, carers and professionals are be able to access and download the virtual resources online 24/7 for free. In addition to this;

- Once endorsed, it may be available as part of the School Counselling Service Induction Package in collaboration with NSW Department of Education in regards to IDMH.
- Additional topics and languages can be included as needs and funding arises
- With some amendments, could have links to the following agencies;
 - Raising Children’s Network
 - 3DN and
 - MH First Aid for ID

Evaluation Strategy:

- As part of our evaluation strategy we hope to track the number of tip sheets distributed and downloaded at 6 months and 12 months post launch.
- QR codes on tip sheets that link to both English and an in-language survey for broad feedback that will guide improvements over time.

TIP SHEET

How Can I Help my Child Navigate Adolescence?

Helping Young People with Intellectual Disability and Autism Navigate the Social, Emotional and Physical Changes of Adolescence

WHAT IS ADOLESCENCE?

Adolescence is the time between childhood and when a young person becomes an adult. It starts when a child is around 10 - 11 years old and ends when they are 19 - 21 years old. During this time, big changes happen to the young person’s body, their emotions (feelings) and how they interact with their friends and family.

Puberty is the physical and sexual development of a young person’s body and it happens during adolescence.

Children with an intellectual disability (ID) and autism usually have the same feelings and changes to their body as other young people, but often don’t have the skills to understand them.

CHANGES TO A YOUNG PERSON’S BODY DURING ADOLESCENCE?

Most young people will experience the following changes:

- **Body (physical) changes** in adolescence, such as:
 - Bones and muscles get bigger as they become an adult.
 - Changes in body shape
 - A deeper voice
 - Skin conditions (pimples and acne)
 - More sweat and body odour in different parts of the body
 - Hair growing in different parts of the body (on the genitals and under the arms)

THE PHYSICAL (BODY) CHANGES- HOW CAN I HELP MY CHILD?

It can be hard for young people with intellectual disability and autism to understand the changes they experience in puberty, and they may become anxious or worried.

Tips to help your child understand about puberty:

- **Talk to your child before their body starts to change-** so they know how their body will change and to reassure them that nothing is wrong.

BEHAVIOUR CHANGES IN ADOLESCENCE: In adolescence the brain grows and changes which can lead to behaviour changes such as:

- Feeling strong emotions that can change quickly.
- An increase in aggression
- Wanting to spend more time with friends.
- Wanting to do more things on their own, try new things, and testing rules and boundaries at home and at school.

For girls - menstruation (periods)
For boys - penis erections and semen ejaculations at night while they are sleeping (wet dreams).

Illustrations include a girl and boy, a person with a hammer, a person with a heart, and a person with a brain.

Navigation Adolescence TIP SHEET | Developed by Sydney Children’s Hospital Network, NSW School-Link & SAL Consulting | 1

- We will include evaluation questions in end of year SCHN School-Link Survey
- Use of CHARLI (project improvement within SCHN)
- A final report has been sent to the Perinatal, Children and Young People Mental Health Branch at the Ministry of Health.

For references or more information, contact us by email

SCHN-CHW-SchoolLink@health.nsw.gov.au

www.salconsulting.com.au

<http://www.schoolink.chw.edu.au/behaviour-information-sheets/>

Let us know what you think. We are collecting feedback about this project.

Tip Sheet Feedback QR code



TIP SHEET

Why Does My Child Hurt Themselves?

Helping Children with an Intellectual Disability and Autism manage their Self-Injurious Behaviour

WHAT IS SELF-INJURY?

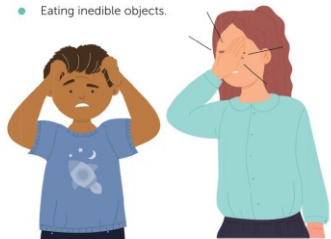
Self-injurious behaviour is when a person hurts themselves on purpose. Children may hurt themselves when they feel stressed or when they are trying to communicate a message or a need.

Sometimes, self-injury behaviours can start as repetitive behaviour used by the child to make themselves feel better (to soothe, calm down, or stay alert). The child can learn that these behaviours can get their needs met, because people respond to the behaviour.

WHAT DOES SELF-INJURY LOOK LIKE?

Self-injurious behaviours include:

- Biting themselves, e.g. biting hands or fore arms
- Hitting their own body with hands or fists, e.g. slapping their face, hitting their temple with a closed fist
- Hitting their own body with an object
- Hitting their own body against an object, e.g. banging their head on the floor or wall
- Scratching, skin picking or pinching
- Hair-pulling
- Eye poking and gouging
- Eating inedible objects.



WHY DOES MY CHILD HURT THEMSELVES?

Some reasons for self-injury include:

- **Physical health issues.** e.g. pain, ear infections, reaction to medication, constipation, poor sleep (being tired makes coping with challenges harder)
- **Genetic pre-disposition.** Some genetic syndromes can make a person more likely to hurt themselves.
- **Sensory sensitivities.** Self-injury can be used by a child to increase their level of arousal/alertness (e.g. touch, movement, sound) or when their sensory system is overloaded.
- **To get care from others.** Self-injury can make other people come to the child to help them, interact with them and to make them feel safe.
- **Communication difficulties.** A child might hurt themselves when they feel frustrated because they can't communicate what they want or need or when they have difficulty understanding others.
- **Escaping / avoiding activities.** Some children learn that self-injury can be used to avoid a task or activity, to leave a place, or to be left alone.
- **Emotional state.** A child might hurt themselves when they feel anxiety or stress to release the tension. Self-injury can release hormones (called endorphins) in the brain which make the young person feel good.

HOW CAN I HELP?

Self-injury can have a high impact on the child or young person, their family, paid carers and teaching staff. Watching them hurt themselves can be both distressing and exhausting. Concerns about wound care, and the risk of lasting damage to head, eyes, and other parts of the body, puts pressure on supports to understand and respond in a helpful way.

Seek help early. Timely assessment and intervention may prevent self-injury from becoming habitual.

TIP SHEET

Sensory Processing Difficulties

Understanding How Children with Autism or an Intellectual Disability Experience Sensory Input

WHAT IS SENSORY PROCESSING?

We all experience the world through our senses - sight, sound, touch, smell, taste, body awareness, movement and sensing our internal body state (e.g., feeling hungry, sick, tired). Sensory information (called 'sensory input') is what we see, sounds we hear, things we touch, how our body feels etc. Sensory processing is how our brains use sensory input to understand and interact with the world around us.



Everyone's brain processes sensory input differently. For example, some children don't like the feel of certain fabrics, some don't like being hugged, others seek out physical contact. Some children have strong food preferences, enjoy fast movement, or don't like loud noises.

SENSORY PROCESSING DIFFICULTIES

Children can become overwhelmed with too much sensory input (e.g., bright lights, cooking smells and noise at the playground) or not respond to sensory input in their bodies - this means they have sensory processing difficulties. Children with autism and intellectual disability can have sensory processing difficulties.

Children with sensory processing difficulties often have a sensory profile with one or more of the following characteristics:

Hyper-responsive - these children are more sensitive to sensory input than most children. They are often overwhelmed by sensory experiences, which can make them feel distressed and agitated.

Sensory Avoiding - these children actively avoid specific experiences because it creates unpleasant sensations for them.

Hypo-responsive - these children are less sensitive to sensory input than most children and can be unaware of or slow to respond to sensory input.

Sensory Seeking - these children seek out experiences where they will have specific sensory input that they enjoy.

WHAT DO SENSORY PROCESSING DIFFICULTIES LOOK LIKE?

Children who are **hyper-responsive** to sensory input may:

- Be easily overwhelmed by group activities and noisy or crowded places.
- Refuse to wear clothes they describe as 'itchy or scratchy'.
- Be easily distracted in class by noises or movement that others haven't noticed.
- Not like getting messy
- Spit out or refuse particular foods because of the taste and texture (how the food feels in their mouth).



Children who are **hypo-responsive** to sensory input may:

- Seem clumsy, bump into things a lot, and have poor hand-eye coordination.
- Want to touch and feel things all the time.
- Find it hard to sit still and want to jump around, jump on a trampoline etc.
- Enjoy crisp, crunchy foods.

Self-harm, Suicide and Safety Planning in Autism: Review of a one day seminar by Dr Belinda Ratcliffe, Phd/Clinical Psychologist and founder of The Emotions Clinic Australia.

Dr David Dossetor, Child Psychiatrist with an interest in intellectual and developmental disability, the Children's Hospital at Westmead.



SCHN funded a day's seminar provided by Belinda Ratcliffe for a wide range of front-line clinicians in SCHN and a representative from several CAMHS across NSW. This seminar is a by product of Belinda's time in lockdown, whereby she reviewed the literature and built a compelling clinical approach, which she has now shared with over 3000 clinicians in Victoria, ACT, NSW and Queensland. Single handedly she has drawn attention to the necessity and priority of this issue for every CAMHS service and, single handedly, she has shifted the attitudes to include those with autism and normal intelligence in many of these services.

Suicide accounts for 1.4% of deaths and is the leading cause of death in 15–49-year-olds. One in 8 consider suicide. 3000 Australians a year die from suicide and suicide costs \$551 billion annually and leads to 28,000 hospital admissions. Many more don't reach hospitals and are dealt with by GPs, school and community-based services. There are significant common risk factors: child abuse, alcohol use, domestic violence. Yet those with autism are 7 times more likely to think about suicide and have a 9 times risk of suicide in those of normal intellect compared to neurotypicals, whereas it is twice the risk in autism overall. Women with autism of normal intelligence have a thirteen times increased risk of suicide. While this enhanced risk is recognised in suicide guidelines in UK, it is yet to be included in the National Suicide Prevention Strategy in Australia.

Many suicidal young people have undiagnosed autism. Cassidy and colleagues (2022) reported 10% of those that suicided had autism at post mortem evaluation, of which 40% were undiagnosed. 40% of those with high functioning autism have attempted suicide! Even of those with autism and mild intellectual disability 20% have suicidal talk. Autism and giftedness has an extra risk with an increased odds ratio risk of 5.9 (Casten et al, 2023)! Their methods are generally violent: hanging, strangulation which is similar to neurotypical males; females complete as much as males. 72% of autistic adults have considered suicide and 10% have attempted or self-harmed. Kirby (2019) found those with autism were younger when they died compared with neurotypicals. Even non suicidal self-harm is increased three times, compared to neurotypicals.

Young people with autism have increased risks: increased rates of mental health problems, unemployment, isolation and loneliness. On top of this they lack social and communication skills and suffer social anxiety. They take things literally when abused eg: 'you



disgusting pig, you don't deserve to live'. Using eye contact can increase their cognitive load; they have problems of belonging, with an absence of reciprocal relationships with family, friends and society. Sensory sensitivities can cause anxiety, stress and physical pain. They may use repetitive behaviour such as stimming, rocking or finger tapping to self sooth and to cope. Repetitive and rigid thinking can increase the problem of catastrophic thinking and increase the risk of major depression.

In engaging with someone with autism, you should be aware of special interests as a means of self-soothing and competence. Camouflaging of symptoms is well recognised and a barrier to diagnosis and intervention. They may have alexithymia and difficulty at identifying emotions and benchmarking their feelings against others. They frequently have a longer processing time, which can lead to delay in seeking help and responding in interview even up to 2 minutes. They have increased rates of trauma, for example 40% have PTSD compared to 4-5% in neurotypicals. Every day events can be experienced as traumatic, but they also have marked increased rates of bullying, maltreatment, sexual abuse and 3 times risk of coercive control and domestic violence. Their social naivety can contribute to

being groomed and failing to pick up inuendo on social media. Parents need to check their access to social media and web-based content. They have a higher risk of gender diversity which is another associated risk factor to suicide and self-harm. Of trans young people 22.5% had autism. Employment protects from suicidality, as do supportive environments with special adjustments and social supports for example in schools.

The barriers to accessing services are concerning. Some report that CAMHS refuse access, even though this is unethical and illegal. Indeed Cassidy (2018) showed the lack of support from services is associated with suicidality and depression.

Belinda's seminar introduces approaches to exploring symptoms, such as drawing a triangle for 'Pen Therapy' which enables an autistic adapted exploration of the connections between thoughts, feelings and behaviours.

She introduces autism specific screening questionnaires such as the Suicide Behaviour Questionnaire (ABQ-ASD), modified by Sue Cassidy, who has been a leader in this field at Nottingham University. Darren Hedley from the Olga Tenison Autism Research Centre

(OTARC) in La Trobe University has modified the Suicidal Ideation Attributes Scale and added some visual scales.

She goes on to describe how to write a support plan and planning a safety intervention, which generally take 2-3 sessions to develop with the client. She then shares her Grounding for Autistic People (GAP grounding) (although it can also be useful for neurotypicals) which is 'a how to developing a kit' to keep the autistic client safe. It emphasises the 6 senses of taste, smell, touch, hearing, seeing and proprioception and how these are meaningful for the client to bring them back into contact with the present moment and provide a source of stimulation, what could be called a 'happy bag for high functioning autism' and others. It also focuses on from whom they can ask for help, how to communicate that need, how to make the home safe, what others can do to calm them down and then how they can plan to feel better and why they won't try to kill themselves.

While there are some autism specific skills, I think these skills are likely to enhance the management of all with suicidal ideation and intention. I couldn't help feeling that this was a potential modification or enhancement of DBT approaches, as used widely in Project Air widely across health/mental health and indeed schools across NSW. I felt her message was compelling and indeed every front-line clinician should be aware and trained in these skills, as Australia is now recognised to have the highest rates of autism in with world.

Belinda has made a significant personal contribution to this important service area, as there are no alternative training approaches available. The demand on her time and personal energy cannot be infinite, and I understand that her course will soon be available via e-learning. I feel that mental health, health and education managers need to review how they can enhance their service skills to meet this need. I was conscious that our SCHN MHID Hub is not the answer to this need, as most of our cases also have intellectual disability and we do not have capacity to take on the needs of this population, who by necessity must therefore be seen, understood and helped in mainstream services.

To register for Dr Ratcliffe's training, please visit her website at www.theemotionsclinic.com.au for on demand, self-paced and face-to-face training options. For direct access to the new Autism and Suicide online/self paced version of the course visit

[Suicide, Self-harm and Safety Planning for Autistic People \(theemotionsclinic.com.au\)](http://www.theemotionsclinic.com.au)

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://digital.artsunit.nsw.edu.au/visual-arts/operation-art/2021-exhibition>

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