

# 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 NSW Health, NSW Department of Education and Communities and disability agencies. 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](http://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

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Welcome to Volume 10, Issue 1 for 2019.

It was great to connect with many teachers and principals at the School-Link stall at the Special Education Principals and Leaders Conference at Rosehill Gardens on 22-23<sup>rd</sup> July. It was fantastic to see such an interest in professional development with around 1400 delegates on the teacher's day. We wanted to remind everyone about the free on-demand webinars that are hosted for teachers and other school staff on self-regulation, understanding behaviour and mental health. Over the next few months we will be posting webinars on anxiety, aggression and more. The webinars are available here:

<http://www.schoollink.chw.edu.au/webinar-series/>. To receive updates make sure that you are signed up to our e-list here: <http://www.schoollink.chw.edu.au/e-list/>

Peer support has been widely recognised as a valid way to share lived experience in both the disability and mental health areas. We are delighted to hear that Learning Links and MyTime are running a pilot project of scheduled online support groups. Delivered via a live video platform, the groups are for parents and carers in NSW of children aged 0-18 years old that have a disability, developmental delay or chronic medical condition. More details can be found on the last page of this journal.

In this edition, Prof David Dossetor, child psychiatrist shares with us his unique expertise about when to prescribe and what to prescribe for children with ASD/ID. He

highlights the difference between using medications as a restrictive practice vs a psychiatric treatment. Similar to David, but from her unique perspective Dr Helen Puusepp-Benazzouz, Pediatric Fellow outlines the complexity that arises from prescribing medications via a reflection of nine case studies within her paediatric training with the Developmental Psychiatry team at The Children's Hospital at Westmead. Author of the Medicine Cabinet, Judy Longworth, discusses the use of Pregabalin in children with ID/ASD.

The importance of behavioural interventions in mental health is highlighted by Dr Phil Ray, psychologist and his colleagues who have provided us with an original paper on the benefits of the parenting program Triple P Stepping Stones as delivered in a school setting. Other holistic interventions are discussed by Helen Ho and her team in their paper on a weight management group of children with ID.

Please enjoy reading this edition of the journal and send any feedback or your own contributions to [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au) or our editor, Hebah [hebah.saleh@health.nsw.gov.au](mailto:hebah.saleh@health.nsw.gov.au)

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## Westmead Feelings Scholarship Program



- The Westmead Feelings Program is a mental health promotion intervention that promotes emotional learning for children with autism and intellectual disability (aged 8-12 years), their parents and teachers.
- In September 2019, CHW will launch the WFP facilitator scholarship program in NSW. Awardees will receive:
  - WFP online learning and certification (valued at \$900)
  - WFP Therapy Kit (valued at \$900)
  - WFP child, parent and teacher manuals (valued at \$350)
- For more info on the scholarship program, go to [www.schoollink.chw.edu.au](http://www.schoollink.chw.edu.au)
- For information on WFP scholarship program, go to [www.westmeadfeelingsprogram.org.au](http://www.westmeadfeelingsprogram.org.au)



# Some personal guidelines for prescribing for the mental health needs of children and adolescents with intellectual disability and/or autism

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## Introduction

This article describes prescribing guidelines for the mental health of children and adolescent with intellectual disability (ID) and/or autism. It was seeded by my registrar Helen Puusepp-Benazzouz who wrote an article that highlighted increased problems when prescribing for this population of young people with ID/autism (ASD). Her article demonstrated that the evidence from the literature confirms that prescribing for young people with ID/ASD is significantly different from the mainstream population in the rates of therapeutic success and of side effects. It seemed therefore reasonable to describe more broadly some personal guidelines on prescribing based on my experience and reading in the population which may be helpful to parents or clinicians. This leads to differences in the choice of medications and how to manage them compared with a mainstream population. The amount of research specific to this population is limited. It seldom addresses severe intellectual disability, and research into autism is described as scarce (Accordino *et al*, 2016; Jobski *et al*, 2017) and usually fails to consider or describe that drug treatment is for a co-morbid psychiatric disorder. There is no known drug treatment for the primary treatment of autism (although some have come and gone e.g. diets, secretin, and oxytocin; others are unproven such as stem cells or poo transplants). Autism is considered by most as a neurodevelopmental disorder and therefore not expected to be treatable (like ID), and therefore it is the comorbid psychiatric disorder that needs assessment and treatment. Indeed, the feedback we get from patients, their families and paediatric trainees (many of whom are now highly regarded paediatricians) is that many of these severely troubled children are helped with medications. The challenge is that the success rate of many medications in this special population is less, sometimes much less, and the rate of side effects is much higher. This is observed in patients with problems of brain impairment of any type (Plantier *et al*, 2016). Yet access to psychotherapies is frequently limited by cognitive/communication ability and the severity of the disturbance. Accordingly, they are travelling between “the devil and the deep blue

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“Many of these severely troubled children are helped with medications”

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sea”, but with patience, we still expect to be able to help in most cases.

## Psychiatric Diagnosis and the importance of Context and Development

There is almost no literature on the reliability of diagnosis in severe ID and most young people with autism have an intellectual disability, and reliability studies are limited to those with mild intellectual disability (Antshel *et al*, 2006 and Larson *et al*, 2016). In the context of disabled children or young people, one must consider the nature of the interaction of the disturbance with the relationship/family environment. Every case needs to have an impartial assessment of family, parents and siblings and consideration of the impact on the quality of relationships. This includes the impact of the disturbance on the family and the impact of the family on the young person with ID.

In adults, it is sometimes assumed that the disturbance is more likely to be perpetuated in the individual, rather than related to environmental contributions (See Podcasts on Prescribing in children and adolescents with intellectual disability, 2017. Department of Developmental Disability Neuropsychiatry (3DN) <https://3dn.unsw.edu.au/>). In those with developmental delay, understanding the developmental context for shaping behaviour, is more important than chronological age. This is not to underplay the impact of adolescence. Adolescence often intensifies problems, partly from gaining size and strength which tests the trust and compliance in relationships, and partly from hormones which intensify your problems non-specifically for about 10 years, till the early twenties. Some behavioural genotypes

help predict the type of behaviour disturbance. However, it is by joining with the family to understand the nature of the child's disturbance in the context of knowing the family and appreciating the young person's developmental profile, that one obtains a pretty accurate view of the nature and function of a disturbance. Behaviours are likely to be reliably observed, but subjective emotional states of someone else with limited cognitive and communication skills are less reliable and benefits from using information from several informants in different settings, as well your own clinical perceptions (Dossetor, 2017; Dossetor et al, 2011). It is in this context that a trial of medication often illuminates the symptoms and provisional diagnosis from the expected effect from the medication.

It is recognised that toddlers are the angriest and most violent age group, with the least capacity for interpersonal connection and self-regulation. Skilled parenting is what humanises them, as they slowly develop awareness of self and others. Equally, this applies to young people with intellectual disability and autism, but they learn these skills more slowly. Nonetheless, skilled parenting is the first prerequisite as empirically shown from studies on special parent skills training (Stepping Stones Triple P, 2018).

**The Sequence of Social Development**

The process of the development of interpersonal connection is demonstrated in the 'Westmead Feelings Program: emotional learning for autism' (Radcliffe, Wong et al., 2017). This autism intervention researched and developed by our team is establishing that children with autism have the same sequence of emotional/social de-

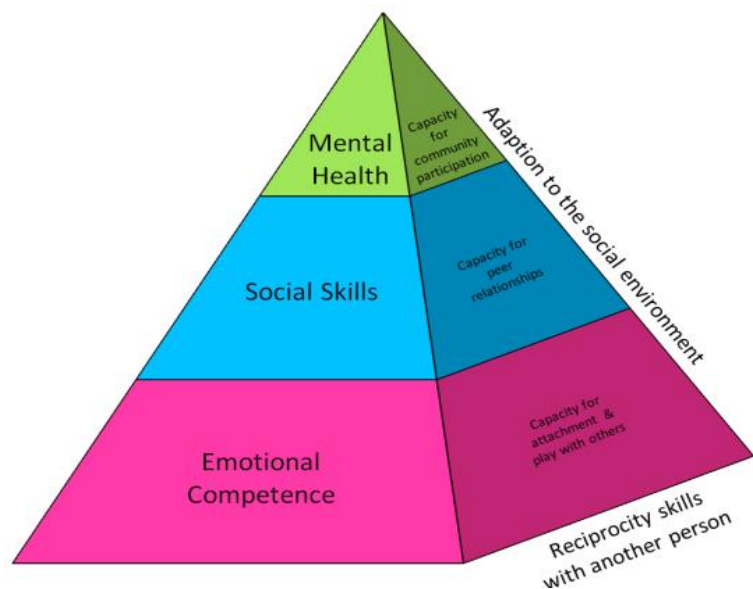


velopment as typically developing youngsters, but it is delayed and needs skilled, targeted and persistent training and support for these skills. This suggests that you have to develop emotional and theory of mind skills to develop attachments to parents and other significant adults.

Figure 1: the sequence of social development (Dossetor, 2004).

Stages of Social Development	
0-1 yr (Parent oriented)	Development of primary attachment and wariness of strangers. Develop preverbal babble, enjoy rough and tumble. <b>Affective reciprocity</b>
1-2 yrs (Adult oriented)	Develop capacity for short lived separations; widen range of adult attachments, develop sense of play and humour with adults, such as Peekaboo. Start to develop <b>joint attention</b> . Respond to gross non-verbal emotional communication.
2-2.5 yrs (Toddler Independence)	Copy adults, develop pretend and creative play, become aware of peers in parallel play. Sensitive to subtle NVC. Shame.
2.5-4yrs (Peer skill development)	Move progressively towards skills of reciprocity with single age related peer; develop skills of sharing and turn taking. Initially can turn take if in charge or organised. Becoming less ego-centric; popularity comes from organising positive initiatives. <b>Theory of Mind</b>
4-8 yrs (Peer Group Association)	Understand reciprocity to maintain friendship and the practical needs a friend fulfils e.g, a friend helps you feel happy. Learn to cope with group relations and social organisation by rules. <b>Second order Theory of Mind</b>
9-13 yrs (Pre-adolescent)	Learn to challenge and create group rules. Clear gender split, friendships based on similarity, emotional support, and how they might be viewed by others. Capacity for guilt/sense of object constancy.
13 yrs (Adolescence)	based on trust and self-disclosure and mutual or admired aspects of personality. Abstract cognitive capacity.

Emotional and social development starts with mirroring of affect to engage in learning early interpersonal attunement (affective reciprocity). This is the first stage of emo-



tional awareness and regulation. Our dictum is that you cannot learn social skills without emotional skills. The second stage/year involves the development of joint attention and of directional affect, such as frustration with the outside world and temper tantrums with limited understanding of theory of mind and of what is frustrating them. This is followed by developing skills of parallel play and turn taking before progressing on to reciprocal play/social interaction. Accordingly, learning emotional skills, perspective taking and then emotional relationship problem solving is a prerequisite to learn social and peer group skills. Managing peer group skills are then a prerequisite to developing emotional resilience and social adaptability skills (mental health) and capacity for community participation (as illustrated in figure 2 above).

All mental ill-health involves a failure of social adaptability and reciprocity. Those with ID/autism will have greater problems in emotional learning and social adaptability that needs additional support and scaffolding with skill building and prompting from a supportive home and school environment. We have found that in autism, social skills are a predictor of mental health (as it is in the mainstream population). However, in autism, the delay in emotional and social development contributes to the higher rates of emotional and behavioural disturbance (Ratcliffe *et al*, 2015). This is confirmed by Hedley and colleagues study which showed that loneliness, satisfaction with social support, and ASD traits predicted the increased rates of depression scores (2018).

### When to use medication?

Several drug audits in our department have shown that medications are more likely to be used in those cases (with and without ID) with the most significant impairment from their emotional and behaviour disorder as measured on a Child Global Assessment Scale (DSMV) or MOF (Measure of Function) (Dossetor *et al*, 1997) when the child often becomes unreachable in other ways. Neuropsychiatry and neuropharmacology provide a wealth of information in understanding neurochemical and neuro-anatomical mechanisms of the brain and brain dysfunction. The success of the drug industry is one measure of how powerful medications can be to help those suffering from the psychiatric disorder. However just like in cancer, despite active and sometimes heroic treatment, not all cases can be successfully treated.

With this preamble, it is easier to understand why young people with intellectual disability have rates of mental health problems 3 times a mainstream population at 40%, and the effect of the mental health problem has a bigger effect on the family coping resources than the in-



tellectual disability alone (Enfield *et al*, 2011). The mental health problems of children and adolescents with intellectual disability is 14% of the mental health burden of all children, although they only account for 1-2% of the population (Emerson & Hatton, 2008). However, recent epidemiology shows the rates of mental health problems for autism are even higher at 70% (Simonoff *et al*, 2008). Headley and colleagues have also identified a 4 times higher rate of suicide in people with autism with 50% showing depression and 36% with suicidal ideation (2018).

50-80% of school-aged children with autism have mental health problems, 40% have more than one. In particular, various anxiety disorders, mood disorders, and ADHD and other disruptive behaviour disorders are common. The following also have raised rates: tics (22%), tourette's (11%), enuresis, encopresis, motor coordination disorders, language disorder, psychosis NOS, bipolar disorder, schizophrenia, catatonia, self-injurious behaviour, pica, somatisation disorder, stereotypic behaviours, disorders of eating, and sensory processing disorders. In clinic populations 95% had 3 or more conditions, 75% had 5 or more (Joshi *et al*, 2010). This concurs with my own clinical audit (Dossetor, 2014). The common disorders are the spectrum of disruptive disorders and anxiety disorders, mood disorders and self-injurious behaviour, and other developmental disorders.

In Australia, a survey of adults reported retrospectively across primary, secondary and tertiary settings that 74% of school-aged young people with autism complained of being bullied, having no friends, and not fitting in; 60-75% felt they needed access to services, and 49% to mental health services (Warren, 2013); 66% of parents stated educators were not well informed whilst 72% reported they received tailored support. Indeed, Warren estimated that in Australia, 100,000 people have Autism and mental health problems. There is also considerable research that shows how stressful parenting a child with intellectual disability and particularly with autism is, often involving acute or chronic stress (Stewart *et al*, 2016). A recent example was in an autism school clinic where 7/8 of the mothers were previously unrecognised to be depressed, (and 6/8 children had untreated sleep problems) (Singhal *et al*, 2018). I find it is not uncommon, to come across parents with murder-suicide ideation, which I take as an alarming indicator of our society's failure to understand and support these families. It concerns me that I have been exposed to a series of cases which appear to have a lack of a collaborative mechanism between the National Disability Insurance Scheme and other agencies in complex cases that need such interagency collaboration.

These statistics change one's expectations when you meet a child with an intellectual disability and or autism in a child and adolescent psychiatric clinic. Any young person in a clinic with ID has a high chance of also hav-

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## “The most common presentation is a non-verbal, hyperactive, disruptive, stereotypic, anxious 7-12 year old with ASD and ID”

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ing autism and any young person with ID/ASD has a more than evens chance of having an anxiety disorder and ADHD. ADHD is clearly an additional handicapping condition on top of ID or autism, and anxiety in ASD is often highly persistent and debilitating. However, it is often difficult to distinguish between anxiety and ADHD or whether both are present.

Before thinking psychiatric disorder, consider **holistic medical needs**: any non-verbal young person with autism, with an acute exacerbation of behaviour, may well have an onset of pain or discomfort that s/he cannot describe. Accordingly, they need a full medical review and investigation, including attention to the problems that cannot be seen on routine medical examination: constipation, dental problems, sinus problems and gastric problems such as reflux, helicobacter pylori or eosinophilic oesophagitis (Dossetor, 2017). These medical risks need comprehensive assessment before considering a serious mental disorder.

- A large autistic adolescent had become dangerously violent and could not be brought to any hospital clinic, and his paediatrician *demand*ed a psychiatric opinion. This could only be provided by a school visit (not a standard practice and not generally provided by any medical service). The psychiatric team proceeded to coordinate a day admission and anaesthetic to assess and investigate him medically, including CT (a brain scan), EEG, blood tests, full examination with Dental, ENT and gastroscopy assessment. This examination under anaesthetic found a non-descript organic mass high in his nasal airways. Removal of this obstruction led to dramatic improvement. Yet it is hard to find a health service that will provide such a specialist patient-centred holistic medical assessment for one who is so hard to engage. A careful tranquillisation and sedation regimen was needed to facilitate a non-traumatic admission and such a simple, albeit a subspecialty, cure.
- A similar case went through complaint procedures until a repeat gastroscopy demonstrated that the first choice proton pump inhibitor (PPI) was failing to control gastritis, but responded to a second PPI.

The most common clinic presentation is a non-verbal, hyperactive, disruptive, stereotypic, anxious 7-12 year old with ASD and ID. (Many CAMHS services do not provide a service for those under 12, even if they have had an acute psychiatric in-patient admission previously).

**What medications to use?**

**Clonidine** is the most useful and underused medication in this situation (Jaselski *et al*, 1992). It is a second line treatment for ADHD, and a powerful anxiolytic. Its effects last approximately 4 hours. Sometimes these youngsters need 100 micrograms at first presentation in the clinic, as they are so disruptive that the interview cannot proceed until we wait for the 45 minutes from ingestion to therapeutic effect. At low doses, it is just anxiolytic and calming, at higher doses it can be used for some sedation and safety management. Dosing has to be titrated between 25-75 micrograms at 7 am, 11 am and 3 pm and 100-150 micrograms at night which is most helpful in sleep initiation. My general maximum in 24 hours is 350 micrograms. It is soluble in water for those that have difficulty swallowing, or if diluted in a 10 ml syringe, it enables precise dosing, such as 15 or 20 micrograms, for those sensitive to medications. I recommend that responsible usage can involve giving a higher dose to manage an anticipated stressful event, such as visiting the dentist, or hairdresser, or the family going out to dinner. My view is that the more profoundly disabled or younger the disabled person, the more likely clonidine is to be the answer. It is also highly helpful as an adjuvant for partially treated ADHD, and great for night time anxiety/sedation, including post traumatic anxiety. Some children do not respond well, and my suspicion is that it is in those who fight any control that comes from feeling a little sedated, as opposed to appreciating the anxiety relief. In the mainstream population, it is used to lower blood pressure and prevent a migraine. There is concern about increasing numbers of presentations from accidental overdose in children which has caused bradycardia and sedation (Cairns *et al*, 2018). This emphasises the need to keep medication safe and away from young children or developmental impaired young people.

**Guanafacine** is newly available in Australia, and has a similar mechanism but only needs to be given once a day. So far I do not consider it an alternative for clonidine, except for that reason.

**Propranolol** is another underused anxiolytic, which can be dramatically helpful in autism, where anxiety is a driver of other disruptive behaviour. I refer to it as 'like non-sedating clonidine'. I generally start at 10mg at 8am and 2pm increasing to 20mg in a week. I routinely look to increase to 30 and 40mg dosing to explore full effect. It is additive to clonidine, so cannot be generally given together, although I find that a later evening dose of clonidine is often helpful. As another anti-adrenergic

medication, it also is seen to have a role in 'intermittent explosive disorder (DSM-V)'. Propranolol is sometimes of dramatic benefit when other medications have not benefited in autism, possibly because of maintaining clear consciousness, while alleviating anxiety (reportedly used by medical students to help exam anxiety). If there is a history of asthma, then propranolol can precipitate an attack and a cardio selective beta-adrenergic blocker is safer, such as metoprolol.

**Stimulants** are the most widely used psychotropic medications and can transform life for someone disabled with ADHD. Unfortunately, in those with ID and/or autism the success rate drops from 85% to 25% on first trial and has side effects that you do not expect, such as increased violence, agitation, anxiety and sleeplessness (Stigler *et al*, 2004). I argue in those with autism that improved concentration can increase their focus on stereotypic thinking making their anxiety markedly worse. Accordingly, stimulants must be approached with caution, with no heroics for continuing, if you reach a dose that has a bad response. However, if there is a benefit, count your blessings and use it. So often ADHD has co-morbid disorders, such as tics or anxiety. In these situations, stimulants can more often than not improve the tics or anxiety as make it worse. The research shows that these developmental disorders co-occur so frequently that if stimulants makes the co-morbid disorder worse, it is only bringing out a predisposition, rather than causing it (Cohen *et al*, 2015).

It is recognised that not only do young people with autism have high rates of anxiety, but also of mood disorders and depression. Those with self-injurious behaviour may need treatment for both ADHD and anxiety/depression. My second most underused drug is **amitriptyline**, a traditional tricyclic antidepressant. In this population, I had hoped atomoxetine would become a safer modern replacement for amitriptyline, but in my own atomoxetine case series, 19/20 cases had unacceptable side effects in this population (I recognise there is still a small group that do benefit from atomoxetine, it is just not an early choice of mine). Amitriptyline is highly valued as it improves both ADHD and especially impulsiveness, and also anxiety and mood, although it is not proven for depression in children. It is also useful for problems of sphincter control, or looseness of bowel or bedwetting. I explain that the only serious risk is in overdose, where it affects cardiac conduction, and accordingly routinely I like to have an ECG to check the QT interval before starting the treatment. Some feel it can lower seizure threshold but in practice this is seldom a problem, and the advice from neurology colleagues is that this risk is not severe enough to alter therapeutic planning, and if seizure frequency increases, then one can weigh up whether to change the amitriptyline or the anticonvulsants. It is otherwise generally a problem free medication that can also improve sleep patterns. In those under 40 kg, I start at 10mg and increase to 10mg three times a day, 7am,

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“the risk of behavioural activation is approximately 40% in ASD and 25% in ID, whereby they become hyperactive, agitated and distressed”

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2 or 3pm and 7pm. If there are no side effects and if insufficient effect, I increase by 10mg/day/week, so in week 4 they are taking 20 mg 3 times a day. I often then increase to 25mg tds, as that requires fewer tablets. In the mainstream population, it is an antidepressant, but can also be used for chronic pain and recurrent headaches.

**Treating ADHD** is much more difficult in this population, and partly because of the extent of the co-morbid anxiety. I use the algorithm promoted by my colleague Prof Philip Hazel, of primary, secondary and tertiary treatments for ADHD (Personal Communication). Stimulants are primary, clonidine, atomoxetine (and amitriptyline) are secondary and mood stabilisers and major tranquillisers tertiary. Although stimulants are dopamine stimulants and major tranquillisers are dopamine blockers, in practice they regularly enhance each other in the treatment of ADHD. Similarly whereas **anxiety/depression** in ID/autism was thought to be so difficult to treat, I feel there is a similar algorithm, and it really pays to persist with trialling different options. Primary treatment is clonidine or an SSRI, the secondary is propranolol, or an SNRI and tertiary is a mood stabiliser, naltrexone or second/third generations major tranquilliser. Other medications that can be considered include 5 hydroxytryptophan, a benzodiazepine or pregabalin. The rising awareness of catatonia (Dossetor, 2018) has led to increased use of lorazepam in some highly anxious, severely disabled people with autism. In the mainstream population, fluoxetine is effective in 2/3, and a second SSRI is effective in another 2/3. I use fluvoxamine to minimise sleep problems or use sertraline out of experience. Mirtazapine is good for night sedation, mianserin for sensitivity to side effects. Ven-

lafaxine is an SSRI at lower doses and both an SSRI and SNRI at higher doses, and I feel is a stronger antidepressant for those resistant to treatment.

**SSRIs** are also challenging in ID/autism. Although SSRIs are the first choice for anxiety and depression and indeed obsessive compulsive disorder, in ID/autism one has to be more cautious. In this population, the risk of behavioural activation is approximately 40% in ASD and 25% in ID, whereby they become hyperactive, agitated and distressed (Cook *et al*, 1992). Many clinicians use an SSRI in autism for anxiety, and the patients regularly turn up in our emergency department in a state of crisis from behavioural activation, and the dose has to be reduced and often withdrawn. One has to be so watchful. Sometimes the effect is delayed, and sometimes it occurs on increase in the dose. Paradoxically there is also a group of young people with autism who present with anxiety and depression, some of whom present very early, as young as 4 or 5 years of age, who specifically require an SSRI. The meta-analysis for mainstream adolescents on SSRIs indicated behavioural activation was less with fluoxetine (Grunebaum & Mann, 2007). I feel that negative stereotypic thinking can lead to significant and severe depression at a younger age than you would expect. These cases often seem to need higher than standard dose, and one can cautiously and slowly increase to 2-3 times the standard dose, and this treatment may need to be sustained.

There is RCT evidence for benefit of SSRIs in adults with autism, while there is evidence in children but it is less strong (Accordino *et al*, 2016). Why should people with autism be split into those for who SSRIs are specifically

helpful and those who have significant side effects? I don't think it relates to the genetics of the P450 system for drug metabolism, based on my experience. Does it relate to the observation that some with Autism have high serotonin levels (on CSF fluid) and others have low levels? Is this related to their problems of maintaining optimal arousal levels for concentration and emotional attunement, or is it related to something different such as the genetics of their monoamine oxidase inhibitor enzyme or serotonin transporter system? Studies by DeLong and colleagues (1998 and 2002) of children with idiopathic ASD treated with fluoxetine (0.15-0.5mg/kg) for the duration of 5-76 months showed an excellent response in 17%, good response in 52%, fair response in 8% and poor response in 23%. In this study behavioural activation, hyperactivity, irritability, aggressiveness and agitation were primary factors for fluoxetine intolerance. Conversely a strong correlation of fluoxetine efficacy has been seen with the family history of major affective disorder such as bipolar disorder or major depression. One can speculate, but as a clinician, all one knows is that we don't seem to be able to predict the effect of these widely used medications on clinical grounds. The family history of effects and side effects of psychotropics is often a valuable indicator of what drugs may help. The other situation where I feel an SSRI is specifically indicated in autism is where aggression is precipitated by the stereotypic rigidity. It may not change the stereotypic rigidity and repetitiveness much, but does reduce the compulsiveness that leads to aggression.

**The increased rate of side effects** does need active management, and ready and regular access to the clinician to discuss developments. I am fortunate to be supported by excellent paediatric registrars, who often provide weekly telephone follow up, to provide support for understanding the effects and risk/cost-benefit, while progressively adjusting the doses. This includes trying medications in order, sticking to the golden rule of "only make one change at a time", so one can learn about the effect of this medication in this individual which is what matters. I think it is also an excellent way for the registrars to get to know these medications. They remain the independent judges of our clinical interventions, and we regularly celebrate our successes. Similarly, I expect the parents to become authorities and custodians of the experience on the way these medications work in their child, so they subsequently feel comfortable to make urgent changes in a crisis and consult the clinician later. Emergency Department attendances can be traumatic for everyone and are best thwarted by anticipating crises and having a crisis medication available.

One of the challenges in the literature is the confusion between symptoms and psychiatric disorders. There is evidence that certain drugs can help irritability, but not for aggression. Risperidone has been tested for symptoms more than disorders which creates ambiguity on when to use it. For example, much funding was spent on

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## “Bipolar disorder is often difficult to diagnose in those with ID/ Autism.”

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examining its effect on aggression and conduct disorder. However **aggression** should be subclassified into first predatorial or instrumental aggression, for which medication does not have an evidenced-based role, and in fact, the aggressor may even experience pleasure or calmness from hurting others. This is contrasted with emotional aggression for whom anger and aggression is a dysphoric and emotional reaction that may be part of problems associated with other disorders of self-regulation, for which a patient may well be looking for treatment. The reductionist literature on whether major tranquillisers work in aggression in adults with ID and ADHD cannot bring enlightenment if one doesn't subclassify aggression, report on the presence of co-morbidities and consider the developmental context including for adolescence (Tyrer *et al*, 2008 ).

Further, **major tranquillisers** are not a treatment of first-line treatment for developmental disorders, as long-term usage generally is recognised as having long-term outcome risks, particularly with the weight gain, cardiometabolic syndrome, diabetes, heart disease and many other diseases, leading to the general concern about premature mortality. There are now specific guidelines for early intervention even in adolescence and available on-line aid-memoires (Trollor *et al*, 2016). However where the consequences of not taking these medications are severe, they can also be taken safely for years. Some of the above alternative medications may be equally beneficial without these long-term consequences.

### Adolescence

In addition to my comments on the primary importance of developmental age, there is also no doubt that the chronological age of adolescence frequently stirs up difficult behaviour. There is an increase in energy, emotionality and disruptiveness. It is evident that for approximately 10 years from 13 to 23 many disabled young people's mental disorders become worse, found in populations whether disabled or not. This has been described as the age when the emotional/limbic systems become coherent, but the frontal lobes/executive function skills are still developing both capacities for judgement and restraint (Goodyer, Personal Communication). This might be described as teenagers learning to drive their emotions, whose car with a strong accelerator, but the steering and breaks aren't well developed. There is no doubt that many adolescents become a danger to others and

often especially their families, and in transition to adult services, their medications are even more unlikely to be actively managed. This is partly because general practitioners may not have been included in their management as children and adolescents and partly because young people with intellectual disability and their general practitioners are avoidant of their access to regular mainstream service and review. They frequently need an advocate to enable equitable access unless a primary health service takes it on as a routine obligation on their part and the Agency of Clinical Innovation provides a useful consumer/advocate guideline (ACI, 2017) My adult psychiatry colleagues report with concern, the cases that present on 3 or more major tranquillisers without continuity of rationale nor monitoring. Withdrawal of these medications, albeit now the patient is past the turmoil of protracted adolescence, is a slow and patient process. Nonetheless, their disapproval of the excessive use of major tranquillisers is often made post hoc, and without the experience of the family attempting to survive adolescence without feeling compelled to relinquish care. Nonetheless, major tranquillisers have an important role in the treatment of ADHD, anxiety, mood stabilising, mood elevation, and some reduction in the compulsion of stereotypic behaviour, as well as an antipsychotic. Aripiprazole is the first 3<sup>rd</sup> generation major tranquilliser with a new 'dopamine stabilising' capacity and is possibly the safest major tranquilliser with least weight gain. It clearly is valuable in anxiety, mood stabilisation and elevation as well as an antipsychotic. It has evidence of effectiveness in autism and is approved for its usage by the FDA in the USA for autism (Bristol-Meyers Squibb, 2016). The PBS has not approved it in Australia leading to a significant social injustice for people with autism who can least afford its disproportionate price. This financial obstruction on access can put them at risk of significant neurological side effects from the alternative first-line cheap major tranquillisers. This was illustrated by a recent case of life-threatening dopamine sensitivity withdrawal syndrome from haloperidol in an 8-year-old with autism (Suma Syamkumar, in press). Quetiapine and ziprasidone have some supportive evidence from open label studies (ziprasidone having the least weight gain), but psychiatrists are experienced with the full range of modern major tranquillisers and they all have a role with moderate clinically observed differences in irritability vs anxiety and in the rates of side effects, particularly for weight gain. However, I can't help but feel that part of the reason for the stronger evidence in risperidone and aripiprazole probably reflects greater pharmaceutical investment in studies of these medications.

## Disorders

**Bipolar disorder** is often difficult to diagnose in those with ID/autism. I listen for unexpected insomnia for a few nights, or a history of hypomanic euphoria, interspersed by evident misery at other times. I think the notion of a spectrum from ADHD/anxiety disorder, deteriorating into bipolar disorder with marked mood lability and altered

sleep and appetite is helpful. Some young people with autism suffer marked mood lability even from an early age, which may benefit from a mood stabiliser. The traditional **mood stabilisers** are valproate, carbamazepine and lithium. olanzapine, quetiapine and the 3<sup>rd</sup> generation major tranquillisers are also recognised as mood stabilisers, along with some newer anticonvulsants such as lamotrigine. Two mood stabilisers are generally better than one if the first is not sufficient. Valproate has more research on initiating treatment for hypomania than carbamazepine, but carbamazepine has a long track record. Lithium is still the most potent mood stabilisers and has a role in the treatment of emotion-led aggression in ID. However, its interaction with major tranquillisers needs watching. It potentiates the effect of risperidone but can inhibit the effect of olanzapine, as I found this out to my cost in a 150kgm violent autistic boy who had a fit and was started on carbamazepine. Fortunately, a switch to valproate for his uncomplicated epilepsy brought back the essential effectiveness of his olanzapine for his anxiety and stereotypic rigidity.



Trauma and deprivation lead to long-term neuropsychological brain changes. People with autism seem to be disposed to **PTSD**, as their memory for negative events may be predisposed to stereotypic repetitiveness which in turn leads to flashbacks and associated acute anxiety. Clinicians often refer to stereotypic anxious thoughts as **OCD**, but it is not distinguishable from stereotypic anxious thoughts as found in many young people with autism. I think that autism invalidates the diagnostic value of a Yale Brown Obsessive Compulsive Scale. My colleague Chris Wever, who specialised in OCD, argued that if the obsessiveness led to excessive hand washing, cleanliness and fear of germs, then one could classify the predicament as OCD in the context of autism and follow standard OCD treatment. One helpful clinical observation is that anxiety in the context of aggression can be a redeeming feature and indicative of a better long term prognosis. I sometimes have a family report that relieving anxiety for example with quetiapine in autism, makes the irritability and anger worse. So not all anxiety is bad! Conversely, non-compliance and aggression in a teenager often makes CBT ineffective and the OCD of poor prognosis.

What also needs to be emphasised is the frequency of **co-morbid psychiatric features**, for example as often seen in children and teenagers with **Fetal Alcohol Spectrum Disorder**. They may suffer mild to severe learning problems such as attention and memory problems, language or reading disorder or ID, have problems of motor coordination and therefore problems of basic self-care, eg toileting, hygiene and menses, be on the autistic spectrum with lack of theory of mind, and easily taken advantage of in their aims to have friendly relationships. They are predisposed to severe ADHD and anxiety. Additionally, they may have chronic PTSD, and major mood disorders such as severe depression, sometimes with bipolar components. They also lack many skills of executive function, such as impulsiveness in some instances and repetitive compulsions for other elements, and problems of informed consent and choice. In addition, they may have severe tics, or tourette's, worsened by anxiety and auditory and sometimes visual or other modalities of hallucination. The hallucinations can be difficult to explain but can be part of the autism, the anxiety, the depression or the post-traumatic stress symptoms. These are associated with increased risk of substance abuse, criminal behaviour and psychotic illness. Keeping someone like this safe and promoting continued development is challenging, requiring close interagency, interdisciplinary collaboration, even if they have likeable qualities and areas of competence and self-worth. Such complex problems can lead to out of home care placement, which in turn might break down.

### Other treatments

In every new case, one reviews the behavioural skills and the warmth and attachment between a parent and their developmentally disabled child. I always look for opportu-

nities to improve both **behavioural approaches and relationships as a consequence of a drug intervention**. For example, we know that children with externalising symptoms bring out different parental responses to those with internalising problems. In brief, research shows that the externalising behaviour of ADHD can also bring out an increase in externalising parenting with increased criticism and emotionality, which does not help the young person with ADHD. Conversely treatment creates an opportunity to encourage a more positive and supportive parenting style. It impresses me that parents and teachers and peers shout less at children who are on treatment of their ADHD i.e.. medication can give a second chance to love such a behaviourally disadvantaged child. We don't know in the long term how long medication is needed, but we do know that it can prevent progression to conduct disorder and substance abuse. Similarly, we know that such second order changes of medication as a

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**“I realised that these were exceptional families managing children and adolescents with exceptional difficulties”**

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change in parenting style does have a long-term impact. Conversely, we know that children with significant complex disability can overwhelm the resources of their family and parents. This was nicely illustrated in a study of families with a child with down syndrome, who are mostly affectionate and cohesive, like the child, except when that child with down syndrome also has autism (which occurs in 10-30%, Dykens, 2000). Accordingly, the parents' level of **stress, burnout, anxiety and depression** needs assessing and frequently benefits from an antidepressant, which also improves the parent-child relationship, without other changes in the stress. As my father in general practice used to say: “anxiety and depression are the disorders that nice people get, as they internalise their real life stresses, like the heroic pilots of the battle of Britain who would all suffer nervous breakdowns, without proper support and breaks from the stress”. It also emphasises for me that the parents of these difficult and disabled young people are frequently our unsung heroes, who need proper breaks and support to survive, and without which need treatment for their burnout, anxiety and depression.

### Some final thoughts on prescribing

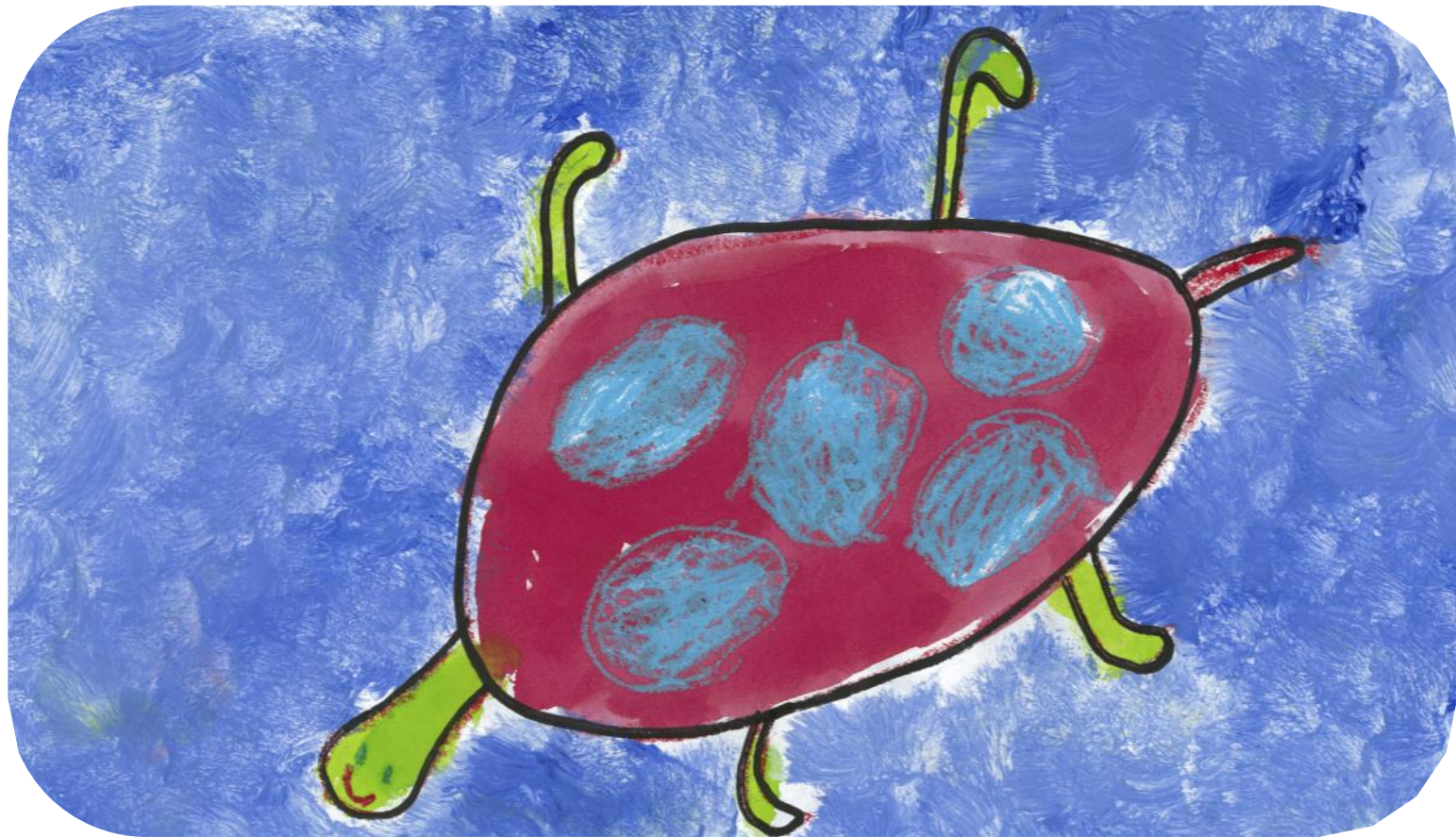
When I was a trainee and met the families of children with ID and autism, I realised through lengthy interviews that these were exceptional families managing children and adolescents with exceptional difficulties. Although UK child psychiatrists are more conservative in their approaches to medication, my mentor in the psychiatry of young people with intellectual disability taught me that to be helpful and make a difference, a clinician has to be

prepared to prescribe. In turn, I tell parents with these exceptional children and adolescents, that no amount of philosophy or ideology is sufficient and that **informed consent involves a trial of treatment(s)**. These medications are generally safe, if used responsibly and responsibly, which is why they are so widely available. The collaboration with the tertiary disability services of the state government, enabled many troubled families with such complex problems to continue to care for their children (O'Brien, Espiner, *et al*; 2014). Part of that success, without facilities for hospitalisation but with available specially skilled emergency respite, was the proactive use of medications as described above for severe co-morbid psychiatric disorder.

Lastly, as a child psychiatrist whose exclusive area of skill in a specialist multidisciplinary mental health team is psychopharmacology, I also find that I regularly contribute **innovative and novel approaches to behavioural treatment**. One 17-year-old boy had complained of nausea and an urge to vomit, associated anxiety for years which symptoms had defeated his family and many clinicians. I reformulated his symptom as a stereotypic preoccupation, which I conceptualise as a transitional object. That meant it was cruel and distressing for others to try and take it away from him, but conversely, he could be placed in charge of this preoccupation, which he should confine to his own room until this thought went away or the transitional object was settled. The improvement was dramatic over the next days and weeks, with no further anxiety CBT, or medications.

Of the articles I have written for this magazine, the one I send families away with most often is: "the management of violence in young people with intellectual disability and the importance of safety" (Dossetor, 2016). Adolescence often leads to an intensification of violence which sometimes becomes a danger to others. As this article re-emphasises, challenging behaviour should first be treated with behavioural approaches. If they do not work, it is necessary to consider co-morbid psychiatry disorder(s) that can predispose to violence and that need treating or a trial of treatment. However, particularly by the age of adolescence and a child becomes as strong as their mother, the violence may become progressively independent of behavioural interventions or psychiatric disorder. In addition, the violence in the teen may be responded with by greater physical assertion by dad, trying to protect his partner and sometimes with his own frustration/burnout, which only contributes to the teen learning to be more physical. While most intervention for emotional escalation involves multimodal approaches to learning self-soothing skills, when a youngster is hurting others, and putting themselves and others at risk, parents have an ethical and legal responsibility to stop it. However, this cannot be done with roughness or anger but, in short, anger and violence has to managed with boredom, and loss of rewards and attention by parents. It is their and only their responsibility to ensure such safety in their home, and thereby teach the teenager what safe behaviour is. A professional can only help with the authority of the parent. However if the teen hurts someone, the parent (s) have a duty to stop it with a spell of chill-out time, in a safe room, which may need to be with the door shut for as long as necessary, to keep others safe and to





teach that hurting others is wrong. In all but those with extreme disability an adolescent can learn safe behaviour from experiencing such safety and de-escalation approaches. These teens and their families can become so escalated and over-aroused that no medication can de-escalate the situation, apart from a safe room. Relinquishment is often seen as an alternative, but such behaviours generally continue for the alternative care providers. If dangerous behaviour occurs in a public place, then police or security staff will need to be involved. Perhaps the lack of a collaborative framework and a safety net of interdisciplinary/interagency collaboration is increasing the frequency of this anxiety-provoking climax and showdown. This regular crisis predicament demonstrates that parents are not just theoretically in charge but can be practically in charge for as long as necessary to re-establish safety and to teach their wards such a basic lesson of respecting the safety of others.

This last paragraph also highlights a further issue of 'restrictive practices'. A parent has the authority to manage restriction on their own child or adolescent if it is in the interest and safety of the child or adolescent. **Psycho-**

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“My creed is that any child with a disability and their family can have a ‘good enough’ quality of life”

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**tropic medications are not a restrictive practice, but for treating a psychiatric disorder**, just in the same way antibiotics to treat pneumonia, or chemotherapy to treat cancer is not a restrictive practice. If a child or teenager is becoming excessively anxious and dissociating and getting irritable, any intervention that can help modify it is psychiatric treatment. In most instances, that is the treatment that occurs and young people get on arrival with the police and ambulance in the emergency department. Such trips are highly traumatic for the young person with autism, and not so positive for all the emergency staff and a measure of failed community treatment. Accordingly, it can be necessary for parents to have some 'as needed' medications to avoid such calamities. It is appropriate to record the antecedents, behaviours and consequences to reduce the frequency of need of 'as needed' medication but a greater priority is that parents need to feel that they can be responsible for their child and keep them and the rest of their family safe. There may be limited specific research into the benefits of psychotropic medications in psychiatric subgroups of young people with intellectual disability, but there is also no doubt that the development of the subspecialty skills of child and adolescent psychiatry for children and adolescents with intellectual disability and autism has advanced dramatically in the efforts to help these young people to be managed in their families and other community settings and avoid various forms of out of home care or institutional settings. My creed is that any child with a disability and their family can have a 'good enough' quality of life. This is, without doubt, a greater and more specialised challenge than for a family with a child without disabilities. The co-morbid psychiatric and

behavioural disorders are the most difficult challenge to establishing that quality of life. Our aim is to switch distress, disruption and loss of adaptability and resilience to one of positive engagement and hope for such a 'good enough' quality of life. This requires the progressive development of adequate strong, flexible, responsive interdisciplinary, interagency community-based teams, to enable optimal developmental support and adjustment from the first day of realising something is wrong causing disability to the fulfilment of a long worthy life.

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# “Parents need to feel that they can be responsible for their child and keep them and the rest of their family safe”

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*Episode 1:* Recognising symptoms of mental illness in children and adolescents with an intellectual disability  
*Episode 2:* Deciding if, when and what to prescribe  
*Episode 3:* Instituting, monitoring and discontinuing psychotropic treatment  
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## Podcasts

*Australasian Society for Intellectual Disability Podcast Series*

A series of podcasts that reflect on a recent conference and their learning's. [www.asd.asn.au](http://www.asd.asn.au)

While you are perusing the website, download a copy of the June edition of the IDA newsletter and read about the 'Responsibility of Making Information Accessible' written by Bronwyn Newman. This is further supported with articles by Caroline Livanos (*Is it easy to write Easy English?*) and Catherine Caternich (*Accessible Information: Catherine's Experience*).

## Webinars

The Australian Disability Clearinghouse has a variety of webinars to watch in their collection.

<https://www.adcet.edu.au/webinars/>

The first webinar I watched was 'The inclusive classroom' by Troy Waller from Microsoft. Set yourself a time to regularly check their website for updated webinars, videos and blogs. This is a great resource by the University of Tasmania.

<https://www.adcet.edu.au/resource/10093/adcet-webinar-the-inclusive-classroom/>

Pain In People With Developmental Disabilities Webinar Series is presented by *Resources for Integrated Care*. There are 3 webinars that have a developmental disability focus; the mechanics of pain, the assessment of pain and pain management. <https://www.resourcesforintegratedcare.com/webinar/series/pain-in-people-tax>

## Websites

[www.idrs.org.au](http://www.idrs.org.au)

IDRS is a free service for people with cognitive impairment across NSW. You do not need an NDIS package to access the service. They provide help with legal problems, support persons at police stations and courts, advocacy, support to appeal decisions of the National Disability Insurance Agency, rights education for people with cognitive impairment, peer support and assistance for parents with intellectual disability at risk of losing care of their children. The IDRS work alongside people with cognitive impairment to promote and protect rights.

# The Medicine Cabinet: Pregabalin

Judy Longworth

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Pregabalin is an antiepileptic drug also used for chronic pain especially neuropathic pain i.e. pain from nerves and anxiety. Pregabalin is a gabapentoid which is a structural analogue of GABA (gamma aminobutyric acid) but does not act on GABA receptors or alter GABA metabolism or reuptake. It was developed by Pfizer Pharmaceuticals. Pregabalin works by blocking the alpha-2 delta calcium channels which has a presynaptic modulatory effect over the excitatory neurons and, similar to benzodiazepines, this is expected to occur rapidly. Pregabalin does not act as an antagonist at glutamate and has no effects on serotonin reuptake. This action is similar to gabapentin but better absorbed at higher doses. Pregabalin was approved by TGA in 2005 for treatment of neuropathic pain in adults and as adjuvant therapy for adult epileptics and on the PBS from 2013 for neuropathic pain. In Europe, the European Medicines Authority has licensed pregabalin as an anxiolytic in adults. There is some evidence for its use as anxiolytic in children and adolescents.

Dosing from the various adult clinical trials indicate that dosing start at 150mg/day administered in two to three divided doses and then increase to 300mg/day within 3-7 days and increase further in 1 week until maximum dose is achieved. Maximum dose varies depending on the condition, the domain for pain doses can range from 300mg-600mg/day and generalised anxiety maximum dose is 600mg/day. The dose should be weaned over a minimum of 1 week when discontinuing. Withdrawal

symptoms include insomnia, headache, anxiety, diarrhoea, flu syndrome, nervousness, pain, convulsions hyperhidrosis and dizziness may occur (Lyseng-williamson, 2014).

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#### **Pregabalin pharmacokinetic profile is;**

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Time to maximum plasma concentration	1hour
Time to steady state	24-48 hours
Metabolism	negligible
Plasma elimination half-life	6.3hours

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#### **Drug interactions**

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Pharmacokinetic	no hepatic or induction or inhibition of CYP enzymes
Pharmacodynamic	additive somnolence and sedation, cognitive and gross motor function impairment with CNS depressants
	Additive constipation with opioids
	Lower gastrointestinal function

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## Adverse effects

Clinical trials have identified many adverse effects, some are present initially but others may have long term effects and all should be reported to the prescriber. Weight gain as well as dizziness and somnolence were reported especially initially. Other adverse effects include fatigue, blurred vision including diplopia, dry mouth, headache and unsteadiness, oedema and peripheral swelling, lethargy, confusional state, memory impairment, nausea, diarrhoea and constipation. Other reported adverse effects include coordination problems such as abnormal gait, vertigo and balance problems,

## Anxiety clinical trials

A meta-analysis published by Generoso et al in 2017 compares eight studies (n=2299 patients) with a mean age of 42.38 years (range 35.6-72.3 years) with 61.6% women with pregabalin administered as the only pharmacological intervention. Primary outcome of the study showed that pregabalin was significantly superior to placebo (Generoso, 2017). There is limited long term studies identified but there was a fast onset of clinical improvement. A sub analysis including a trial of pregabalin vs benzodiazepines showed a lower dropout rate than benzodiazepines and comparable clinical response.

Montgomery et al looked at the efficacy of pregabalin in anxiety and concluded that using pooled analysis and modelling that when a reduction in the HAM-A (Hamilton Anxiety Rating Scale used to rate the severity of a patient's anxiety) of 20% or more from baseline at week 2 were predictive of a response at endpoint (Montgomery et al, 2017). Although at doses of 150mg/day were less effective than higher doses there is no notable dose response for any dose more than or equal to 200mg/day. Treatment guidelines and prescribing information recommend doses between 150mg to 600mg/day. The frequent adverse events include somnolence and dizziness as well as dry mouth and incoordination which appear to be dose related.

Boschen also did a meta-analysis of 7 randomised controlled trials in 2011 and showed that pregabalin has a greater effect on the psychic anxiety symptoms as identified in the HAM-A compared to the somatic anxiety symptoms (physical manifestations). The psychic anxiety symptoms include mental agitation and psychological distress. The overall effect was a significant advantage over placebo but size of the effect was only moderate (Boschen, 2011).

There is an overall lack of clinical trials comparing pregabalin to other forms of pharmacotherapy for anxiety (Lyseng-Williamson, 2014).

## Neuropathic pain and Fibromyalgia trials

These conditions with generalised anxiety disorder are common, chronic and complex and associated with sig-

nificant quality of life issues, Pregabalin has shown efficacy in the treatment of post-herpetic neuralgia and neuropathic pain associated with diabetic peripheral neuropathy and spinal cord injury in adult randomised double-blind placebo controlled trials in adult patients. The overall health status of patients improved with pregabalin compared to placebo. Sleep has also been shown to improve in these patients (Lyseng-Williamson, 2014).

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# “The overall health status of patients improved with pregabalin compared to placebo”

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## Adolescent and children trials

In a recent review of gabapentin and pregabalin safety and efficacy in pain by Egunsola et al there were 7 publications identified for qualitative synthesis. Although there are extensive studies in adults there is a paucity of good randomised controlled trials in pain management for children and adolescents. Problems in identifying self-reported pain measures ensure that a meta-analysis of results is impossible. The side effects reported in these trials include nausea for gabapentin and dizziness for pregabalin being the most common (Egunsola et al, 2019).

Antinew et al, reports in this pharmaceutical company trial with comparative dosing of 2.5mg/kg/d or 10mg/kg/d and placebo doses. Previous study evaluated the safety, tolerability and pharmacokinetics of pregabalin in children (N=65) with partial seizures, 1 month to 16 years. Although doses of 2.5mg/kg/d achieved a reduction in the seizure rate as measured on a 28 day seizure rate, it was not significant when compared to placebo but 10mg/kg/d was significant (Antinew et al, 2019).

In burns patients, pruritus is often indistinguishable from neuropathic pain, a review of use of gabapentin and pregabalin resulted in a chart review of 136 patients. These patients had previously failed to control the itch with diphenhydramine or hydroxyzine. If gabapentin failed to relieve the itch then pregabalin is added. Minimum effective dose for pregabalin taken together with gabapentin for 6-12 years was  $6.5 \pm 3.5$  mg/kg/d and  $4.7 \pm 1.6$  mg/kg/d for >12 years. The combination was well tolerated and reports of 88.2% response neuropathic pain and pruritus and 100% response for pruritus alone. Although the combination was well tolerated, one patient reported excessive sedation and another nausea, vomiting, and headaches which ceased on withdrawal of gabapentin (Kaul et al, 2018).

Post marketing surveillance has shown an increase in



suicidally and suicidal ideation amongst people taking pregabalin for pain and epilepsy. Thus, people taking it should be monitored and if suicidal, refer back to the treating team or seek other medical advice through GP or ED.

There has also been an increase in the use of pregabalin illegally via the illicit drug market and thus concern about diversion of products that are legitimately prescribed so ensure any medications are stored properly. Pregabalin misuse is for higher doses for its euphoric effects and thus physical dependence has been reported. This problem has been illustrated in the media and there are reports that in Europe pregabalin and gabapentin now have restrictions on the prescriptions and are being classified as controlled substances.

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# The principles of Child Aware Approaches

Child Aware principles guide community-led, innovative and practical, grassroots actions to keep children safe and well.



## Family-sensitive

**Identify and respond** to the needs of adults who are parents.

**Acknowledge and build** on family strengths while responding to family stressors and risk factors for child abuse and neglect.

## Child-inclusive

**Understand** and apply knowledge of children's needs at each stage of their physical, cognitive, emotional and social development.

**Recognise** and be sensitive to each child's unique perspective and experience.

**Include children** as active participants in decisions that affect them.

**Promote** child-safe environments.



## Strengths-based

**Enable parents** by promoting their parenting role as a motivator for positive change.

**Build children's resilience** by addressing their vulnerabilities and promoting effective, consistent caregiving.



## Culturally competent

**Understand cultural influences** on family and parenting practices and respond in a culturally sensitive way.

## Collaborative

**Develop and maintain connections** between adult-focused services and child- and family-focused services.

Source: The Good Practice Guide to Child Aware Approaches, Child Family Community Australia  
<[www.aifs.gov.au/cfca](http://www.aifs.gov.au/cfca)>

# A Pilot study of short-term outcomes of a community based weight management program for culturally diverse children with Intellectual Disability

Helen Ho, Leah Spink, Delfa Kaabi, Pankaj Garg, Denise Campbell, Gail Tomsic, Natalie Ong and Natalie Silove

## Abstract

**Aim:** To describe the short-term outcomes of a pilot, community based weight management service for overweight and obese culturally diverse children and adolescents with intellectual disability

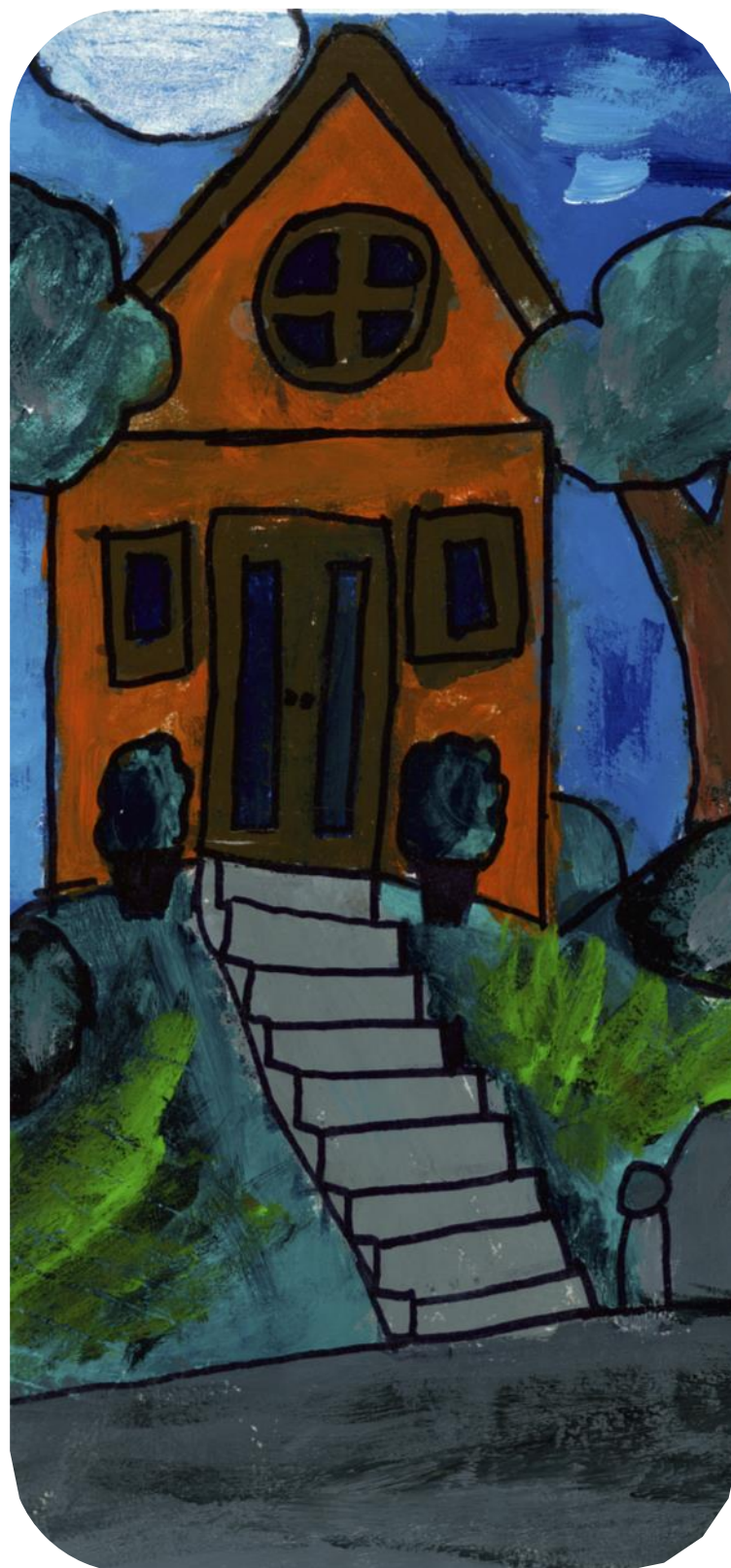
**Methods:** A retrospective review of case notes was conducted for patients seen by the dietitian and exercise physiologist over a 12-month period between 1 January 2017 and 31 December 2017. The main outcome measure was individual change in BMI z-score. Simple descriptive analysis of the data was performed.

**Results:** Of 60 patients attending the service, 41 (68.3%) were referred specifically for weight management, of which 32 patients had sufficient data for analysis. Nineteen of 32 patients (59%) achieved a reduction in BMI z-score, with a mean change of -0.1 points. Analysis showed that younger age at referral and higher initial BMI were significantly associated with a greater reduction in BMI z-score. There was a trend for patients on psychotropic medications to be less likely to achieve BMI z-score reduction. In addition, patients attending the service for prolonged periods trended towards better outcomes.

**Conclusions:** This pilot study improved access to care and demonstrates a trend towards positive short-term weight reduction in vulnerable children and adolescents with intellectual disability, and underscores the importance of early intervention. Future research should include larger sample sizes and longer study periods to understand long-term health and weight outcomes.

## Introduction

Children and adolescents with Intellectual Disability (ID) are highly vulnerable and experience a higher prevalence of morbidity compared with the general population (Cooper, Melville and Morrison, 2004). Common health problems include vision and hearing impairments, dental health issues, respiratory illness, musculoskeletal, gastrointestinal, mental and neurological health problems. People with ID are at increased risk of lifestyle related health issues such as physical inactivity, poor nutrition and being in an unhealthy weight range (Health NDo, 2006). A range of biopsychosocial and developmental



factors are barriers to accessing health services for this group of children (Cooper, Melville and Morrison, 2004).

The burden of childhood obesity is a major public health issue globally. In 2015, in the state of New South Wales in Australia, a school based survey reported a quarter of children and adolescents to be overweight or obese (Hardy *et al*, 2017). In children with ID, the prevalence of overweight and obesity is even higher (De, Small and Baur, 2008; Emerson and Robertson, 2010). Unhealthy weight issues predispose children with significant physical and psychological health consequences in both the short and long-term (Sahoo *et al*, 2015; Schwimmer *et al*, 2003; Chisholm, Alexander and Barzi, 2014). They are at increased risk of developing cardiovascular disease, metabolic syndrome and diabetes at a younger age.

Lifestyle interventions promoting dietary modification and increased physical activity are recommended as the first line treatment for weight issues in children and adolescents (Goldschmidt, 2013). There is very limited evidence, however, regarding effective weight management strategies for children with intellectual disability, particularly for culturally and linguistically diverse populations (Must *et al*, 2014; Donnelly *et al*, 2016; Ptomey *et al*, 2016).

A pilot, community based weight management service was established in a highly culturally diverse region of South Western Sydney in Australia. This service is a component of one of the pilot health teams established and funded by the state government, to increase accessibility for health needs of children and adolescents with ID living in an area with high measures of social disadvantage (SWSLHD, 2016; SWSLHDb, 2016). The rationale of this service was based on the fact that socio-economic disadvantage will compound the likelihood of childhood obesity and barriers experienced by linguistically diverse families (Wang, Patterson and Hills, 2002; Cyril *et al*, 2017).

The aims of this report is to study the profile of children referred to the dietitian and exercise physiologist component of the team and identify the factors that may impact on the achieved outcomes.

## Method

Ethics approval for the study was obtained from the quality improvement program run by the local health service (approval number 5924).

## Participants and Intervention

A retrospective chart analysis was conducted for patients seen by the weight management team during the period 1 January 2017 to 31 December 2017. Patients typically attended combined dietitian and exercise physiologist appointments with their primary carer. A family-based, individualised counselling approach as summarised in

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# “They are at increased risk of developing cardiovascular disease, metabolic syndrome and diabetes at a younger age”

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the report by Barlow, was used to promote behaviour change (Barlow, 2007). This involved education regarding nutrition and physical activity, identification of unhealthy lifestyle behaviours, realistic goal setting, and problem solving to help families implement and sustain lifestyle changes.

Patient involvement in this process was optimised as appropriate to their intellectual ability and willingness to engage. Interpreters were used for the appointments where patients and/or their families have low English proficiency. The allied health team also frequently collaborated with the service’s medical team, school staff, case managers and other allied health therapists. The majority of participants of the program also accessed nationally funded disability services, thus liaison with support coordinators for achieving health and wellbeing goals was important.

## Interventions done by the weight management team

### *Exercise Physiology*

Once the individual was cleared medically, a targeted exercise program was developed for the family and several communication, instructional strategies, activity modification and behavioural reinforcement methods such as motivational interviewing were employed. The program often started with walking or jogging for 30 minutes, followed by weekly increases in speed to promote physical endurance. Similarly riding a stationary bicycle and increasing the resistance at appropriate intervals was used using clinic appointments. Wherever, possible support workers were used for weekly walks on the weekends, and local community pools catering to programs such as swimming were encouraged. If the cognitive ability permitted, gentle lunges, and pushes and simple movement exercises of major joints were also encouraged. These were also developed in partnership with school teachers to incorporate as part of the student’s physical activities learning plan at schools. the program focussed on the suitability of exercise selection, sequence, and variety with physical fitness assessments that included the range of movements, strengths and posture.

### *Dietetics interventions*

The dietary intervention was focused on parental health education, providing individualised information on the patient’s dietary requirements for achieving a healthy balanced diet. This included education on core food groups, portion sizes, improving kilojoule intake through

balanced carbohydrate, fat and protein distribution, increasing fruit and vegetable intake, healthy snack and meal options, environmental controls and managing food seeking behaviour. For many of the patients who presented with selective eating behaviours, education and support was provided on achieving positive family mealtime experiences and consideration of their sensory food preference to assist with acceptance and tolerance of new healthier foods. Health coaching methods were used by the dietitian to facilitate lifestyle changes, though goal setting and self-monitoring. The dietitian also worked collaboratively with some of the patient's school teachers to implement these goals within the school environment.

### Data collection

Service related data and patient information was collected from the electronic medical records. This included total occasions of service, attending therapists, stage of intervention, appointment location and reasons for referral. Baseline patient data included age, gender, level of ID, presence of autism spectrum disorder (ASD), use of psychotropic medications, year of initial appointment, and whether an interpreter was required at appointments. Whenever available, pathology results were also collected, including blood glucose, insulin, lipid profile, and liver functions tests. Anthropometric data [Body Mass Index (BMI), BMI percentile and z-score using Centre for Disease Controls (CDC) Growth charts] was collected at initial and final visits (Ogden *et al*, 2002). Surveys of patient satisfaction on a Likert scale were provided to all parents who had attended at least one review appointment in 2017.

### Statistical analysis

A simple descriptive analysis of the demographic data and weight management outcomes was performed. Continuous data on age, initial BMI, number of visits and duration of involvement with the service was categorised into quantile based groups for analysis. Univariate analysis was performed using Analysis of Variance (ANOVA). The factors affecting BMI z-score change was analysed using Chi-Square test for trend. MedCalc Statistical Software version 18.6 (MedCalc Software bvba, Ostend, Belgium) was used to perform the analysis.

### Results

A total of 60 patients were seen by the service from 1 January 2017 to 31 December 2017, of which 73.3% (44) were male. The average age at initial appointment was 13.0 years (range 5.5-19.5 years). The majority of patients had moderate or severe ID as determined from cognitive and adaptive assessments by special school services.

Almost two-thirds (63%) had a diagnosis of autism, and all attended schools with significant supports. Participant characteristics are detailed in **Table 1**. The majority of appointments were conducted in English (65%) with a

Age at first appointment, mean (range)	13.0 (5.5-19.5%)
<b>Year of initial appointment</b>	
2017	24 (40%)
2013-2016	36 (60%)
<b>Gender</b>	
Male	44 (73%)
Female	16 (27%)
<b>Interpreter used during appointment</b>	
No	39 (65%)
Yes	21 (35%)
-Arabic	7 (12%)
-Vietnamese	7 (12%)
-Other	7 (12%)
<b>Level of ID</b>	
Mild	5 (8%)
Moderate	23 (38%)
Severe	22 (37%)
Profound	1 (2%)
Unknown	9 (15%)
<b>Reason for referral</b>	
Weight management	41 (68%)
Underweight	8 (13%)
Other	11 (18%)
<b>Autism diagnosis</b>	
Weight management (% of referral group)	26 (63%)
Underweight (% of referral group)	2 (25%)
Other (% of referral group)	10 (91%)
<b>Baseline anthropometry – weight management (n=39)*</b>	
BMI, mean (range)	31.2 (20.7-49.9%)
BMI percentile, mean (range)	97.0 (81.0-100%)
BMI z-score, mean (range)	2.2 (0.9-3.7%)

**Table 1: Patient profile of weight management service for Intellectual disability children, n = 60**

Unless otherwise stated n = 60, expressed as n (%),  
\*Baseline data unavailable for 2 weight management patients





Vietnamese (11.7%) and an Arabic (11.7%) language interpreter being used in other consultations. Most appointments were conducted at the community clinic (73%).

A total of 41 of 60 patients (68.3%) were referred for the management of overweight or obesity. The average BMI z-score was 2.2 points at initial appointment and 85 % had obesity. The average median weight for the overweight/obese group was 76.3 kgs (Interquartile Range 56.6- 93.7 kgs).

Of these 41 patients, 32 patients attended at least one follow up visit. **Figure 1** shows the change in BMI percentile and z-score since commencement of weight management appointments. Nineteen of 32 patients (59%) experienced reduction in BMI z-score with a mean change in BMI z-score of -0.1 (range -1.17 - 0.81). A total of 10 patients achieved a change in BMI z-score greater than 0.25. The median change in BMI for the group that demonstrated weight loss was -2.0 (Interquartile range: -3.0 to -0.87).

A younger age at referral and higher initial BMI were associated with greater negative change in BMI z-scores (p = 0.02 and 0.04, respectively) (**Figure 2, overpage**). Patients taking psychotropic medications and those

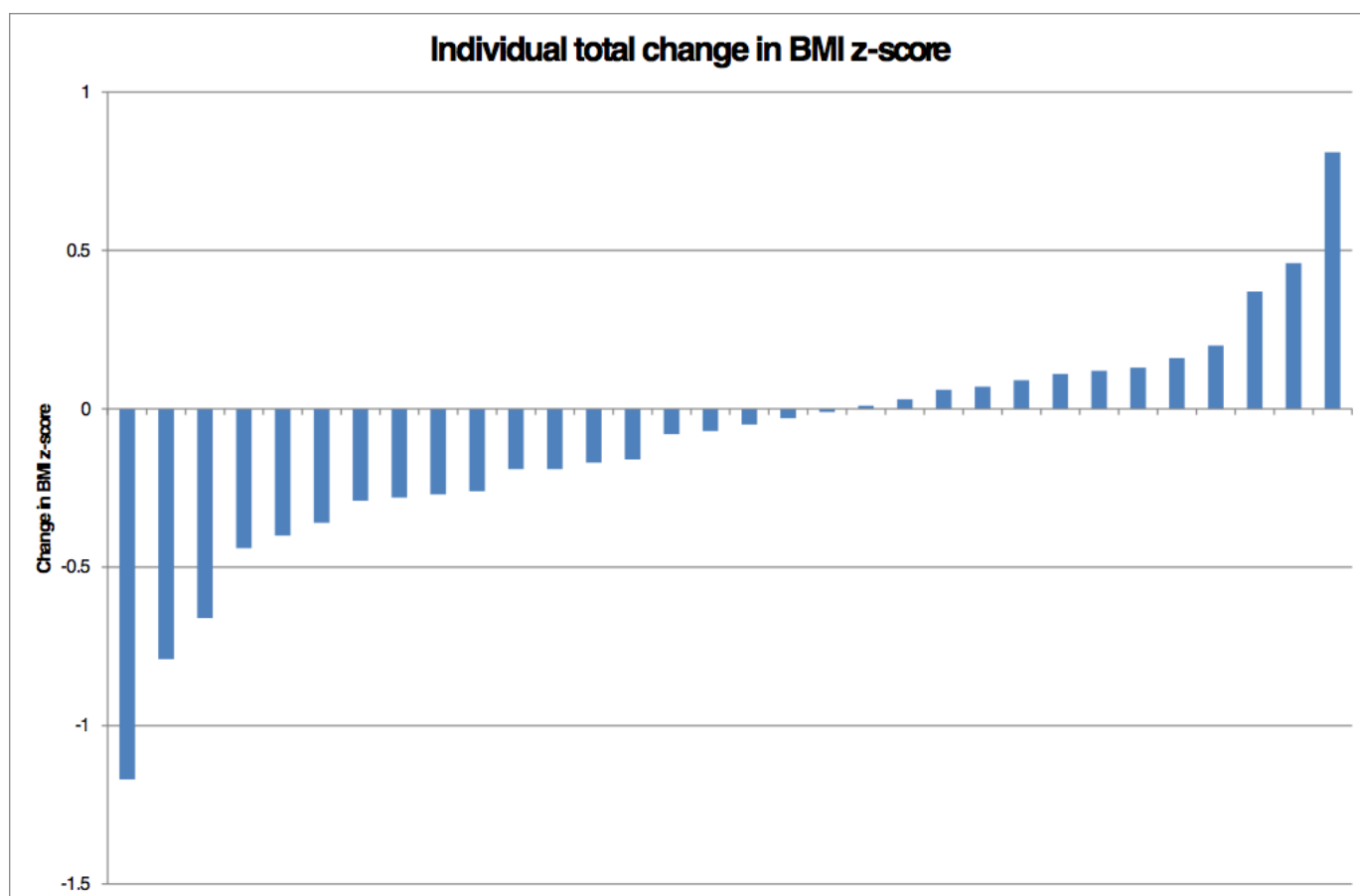
involved with the weight management program for a shorter duration were less likely to achieve a reduction in BMI z-score; however, these differences were not statistically significant. There was no association between level of ID, ASD diagnosis or interpreter use.

Six of the 32 (19%) of patient satisfaction surveys were returned. All patients surveyed indicated that they agreed or strongly agreed to the statement: *“I am satisfied with the services I have received.”*

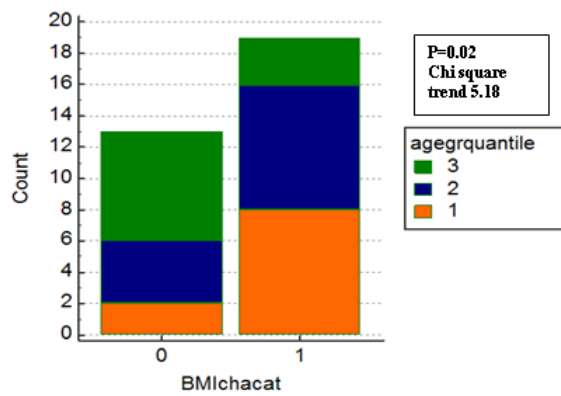
### Discussion

This study demonstrates a trend towards positive short-term weight reduction in children and adolescents with intellectual disability by a pilot weight management service in a community setting. Findings of interest include that nearly 60% of patients, who attended at least two appointments, had a reduction in BMI z-score; and that those referred at a younger age or with a higher initial BMI z-score had a greater reduction.

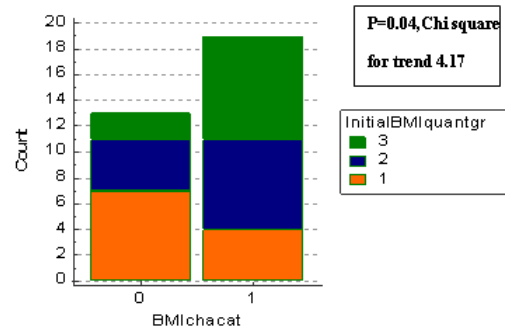
We obtained a mean BMI z-score change of -0.1 points and almost one-third of children achieved a reduction in BMI z-score of greater than 0.25 points. This is a good outcome, as a BMI z-score reduction of as little as 0.25, can result in improvements in blood pressure, total cholesterol/high-density lipoprotein ratio and insulin sensitiv-



**Figure 1: Individual total change in BMI z-score of overweight/obese children of the team (n=32)**



1=younger age quantile group, 2=older age quantile group  
 Younger Children had greater negative BMI change



1- negative BMI change, 0= no change/  
 positive change  
 Children with higher Initial BMI, greater proportion of  
 showed negative change in BMI

**Figure 2. Factors affecting weight management outcomes**

ity in obese adolescents (Ford, 2010). Unfortunately, we could not demonstrate this biochemical improvement in our cohort due to unavailability of serial measurements of blood pressure, serum lipid profile and other biochemistry, because of the challenges in obtaining cooperation of children for venipuncture and blood pressure measurements.

In the current study, younger age at initial appointment was associated with greater negative change in BMI z-score ( $p=0.02$ ). This is consistent with previous research showing younger children to have better short-term weight loss and greater possibility of modifying life style behaviours before they become more ingrained in adolescent years (Goldschmidt *et al*, 2013; Reinehr *et al*, 2009; Gow *et al*, 2016).

Higher initial BMI was also associated with greater total negative change in BMI z-score ( $p=0.04$ ) and this is consistent with previous studies in obese children and adolescents (Mameli *et al*, 2017; Braet, 2006). There was also a trend for those involved in the program for a longer duration to be more likely to achieve a negative change in BMI z-score, but this association was not statistically significant due to small size.

The majority of patients seen by the service had a moderate or severe level of ID and 63% of clients referred for weight management had a diagnosis of ASD. Our study found no significant association between severity of ID or ASD diagnosis and weight loss outcomes, however, previous studies have identified that adults with mild-moderate ID are more likely to be obese than those with moderate to severe ID (Fox and Rotatori, 1982).

Six of 39 (15.4%) weight management patients had diagnosed syndromes as the underlying cause of their ID (Lobstein, Baur and Uauy, 2004). Obesity is a clinical feature of some of these syndromes; however, again this

association could not be analysed due to the small sample size.

Centrally-acting medications such as psychotropic medications, often prescribed for managing difficult behaviours in children with ID are associated with excessive weight gain (Hellings *et al*, 2001; Leslie, Hankey and Lean, 2007). In this analysis, patients using psychotropic medications were less likely to achieve a reduction in their BMI compared with those not taking these medications, however this was not statistically significant due to sample size.

About one-third of patients required an interpreter at appointments and several English-speaking patients were from culturally and linguistically diverse backgrounds. This is reflective of the local population profile, where almost 40% of residents are born overseas, and the area is a region of settlement for refugees (SWSLHDb, 2016; SWSLHDc, 2016). Whilst the use of interpreters and the weight management service improved communication, accessibility, patient satisfaction and clinical outcomes, the families in our cohort continued to experience barriers in service engagement, due to psychosocial stressors that were not studied specifically in this report (Cyril *et al*, 2017; Karliner *et al*, 2007).

### Strengths and Limitations

This is a first report from Australia that reports the findings of a weight management service working with a vulnerable population of children and adolescents living with ID in an area of disadvantage in Sydney. The limitations of small size and unavailability of biochemical tests limited the interpretation of the findings of our study.

The study cannot ascertain the level of dietary or physical activity change in children who achieved a reduction in BMI z-score compared to those who did not. There was significant heterogeneity in specific interventions due to

the differences in patient and family characteristics, readiness for change and barriers to change (George, Shacter and Johnson, 2011). This highlights that a “one size fits all” approach for this extremely vulnerable population may not necessarily work, and further research should look at groups for targeted interventions.

Another limitation of the study is that the duration of treatment and number of visits was highly variable, which makes comparisons of BMI z-score change challenging. Ongoing data collection and analysis is planned to understand the long-term outcomes of weight management for these children.

Potential factors that may impact body weight and program outcomes, such as socioeconomic status and parental weight status were not been collected hence could not be assessed. In future studies, it would be valuable to collate other physiological data such as waist circumference, blood pressure, pathology results, fitness tests and better markers for body composition.

### Conclusions

The findings suggest that a weight management clinic run by a dietitian and exercise physiologist has the potential in reducing BMI z-scores in children and adolescents with ID who are overweight or obese. Sustained engagement and continuity of intervention is needed that has implications for resources. It has been demonstrated that earlier age of intervention and higher initial BMI z-score are factors positively associated with BMI z-score reduction in children and adolescents with ID. These findings highlight the importance of early intervention for weight management in this population, as well as the efficacy of treatment for those at the most extreme weight ranges. The current study should encourage other clinicians and researchers working with children and adults with ID to report their outcomes. There is also a

need for more collaborative research to obtain larger sample sizes. Future research in this population should include data on the level of lifestyle change achieved, multiple physiological outcomes and the impact of psychotropic medications on weight management.

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# The National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028

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The National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028 (the Plan) has been developed to provide a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia. It builds on the significant foundational work and investment over recent years made by governments, non-government organisations, family advocates, researchers and clinicians, individual champions and communities who have raised awareness and supported individuals and their families living with FASD.

The FASD Strategic Action Plan aims to improve the quality of life for children and adults who have FASD. The Plan is built around 4 key national priorities:

1. prevention
2. screening and diagnosis
3. support and management
4. priority groups and people at increased risk

## Prevention Objectives

- Reduce access and consumption of alcohol in the Australian community
- Increase community knowledge and awareness about the harms and consequences of drinking during pregnancy or when planning a pregnancy

## Screening and diagnosis

- Increase screening, diagnostic skills and knowledge in frontline professionals
- Improve capacity for screening, diagnosis and surveillance

## Support and Management

- Implement and evaluate better models of management, support and care
- Support for parents, carers and families and in education and employment settings

## Priority Groups

- Continue to support and evaluate targeted strategies and models of care for groups who are at higher risk than the general population
- Work with the criminal justice system to implement therapeutic justice interventions

## Useful FASD resources

FASD Hub  
[www.fasdhub.org.au](http://www.fasdhub.org.au)

Australian guide to the diagnosis of FASD  
<https://www.fasdhub.org.au/fasd-information/assessment-and-diagnosis/guide-to-diagnosis/>

NOFASD Australia  
[www.nofasd.org.au](http://www.nofasd.org.au)

AOD knowledge centre  
[www.aodknowledgecentre.ecu.edu.au](http://www.aodknowledgecentre.ecu.edu.au)

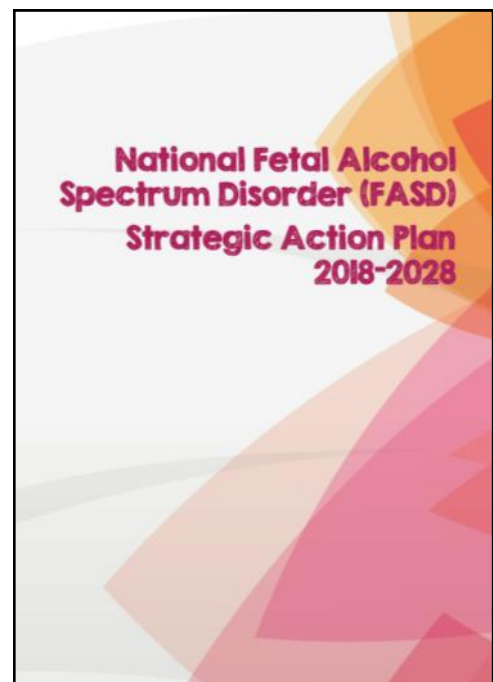
Australian guidelines to reduce health risks from drinking alcohol  
[www.nhmrc.gov.au/health-topics/alcohol-guidelines](http://www.nhmrc.gov.au/health-topics/alcohol-guidelines)

FASD in Australia; an update  
[www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/mono-fasd](http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/mono-fasd)

Understanding and addressing the needs of children and young people living with FASD – a resource for teachers  
[www.kimberleyfasdresource.com.au/pdf/FASD\\_ResourceForTeachers.pdf](http://www.kimberleyfasdresource.com.au/pdf/FASD_ResourceForTeachers.pdf)

Substance use in pregnancy resource project  
[www.ndarc.med.unsw.edu.au/project/substance-use-pregnancy-resource-development-project](http://www.ndarc.med.unsw.edu.au/project/substance-use-pregnancy-resource-development-project)

For more resources and to download the Strategic Action Plan use this link:  
<https://beta.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf>



# Group Stepping Stones Triple P in Schools: An Evaluation of a Parenting Program for Children with Developmental Disabilities in the School Setting.

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## Abstract

This study evaluated the implementation of Group Stepping Stones Triple P (Group SSTP) within Schools for Special Purposes catering for children with an intellectual disability. The intervention was a partnership between the NSW departments of education, health and disability services, and is also the first study where Group SSTP has been implemented and studied within schools. 11 schools were enrolled with a total of 56 parents recruited for the study. The study collected pre and post group data examining the areas of child behaviour, parenting style, confidence and parental mental health. Child behaviour ratings were also collected from teachers. Results found highly significant changes in parenting style, parenting confidence, parental mental health and the child's behaviour both at home and at school. The findings suggest that Group SSTP is a powerful intervention when implemented in a community setting and highlights the value of good interagency collaboration and support for children with an intellectual disability. A strength of this study is the independent measurement of behaviour by the teachers.

## Highlights:

- We trialled the Group Stepping Stones Triple P Program in Schools.
- The program was conducted by teachers, school counsellors and colleagues from disability support services.
- Significant improvements in parenting style, confidence and mental health were found.
- Significant improvements were also found in child behaviour both at home and at school.

## Introduction

Children with an intellectual disability are at increased risk of mental health and psychosocial difficulties. Kleefman *et al* (2011) estimated the prevalence rates to be between 30 to 60%. Roberts *et al* (2006) reported that behaviour problems create a significant burden, interfering with the child's social and educational skills which can lead to exclusion from community settings and effect physical health. As a result, parents of children with developmental disabilities face unique challenges in man-

aging their child's behaviour and encouraging new skill development (Roux *et al*, 2013). To address the increased risks to mental health, Steiner *et al* (2012) proposed that parent education programs designed to enhance or facilitate parental skills, are likely to be the most beneficial and cost effective method of mental health intervention for this population. One such program is the Stepping Stones Triple P (SSTP) Parenting Program which Sanders *et al* (2003) proposed can lead to significant improvements in childhood behavioural difficulties and parental mental health.

SSTP is an adaptation of the Triple P Positive Parenting Program but has a focus on families of children with developmental disabilities. Like Triple P, the program aims to improve the confidence, knowledge and skills of parents of children but specifically for a developmental disability population. SSTP encourages the use of positive parenting strategies to help facilitate a more constructive relationship between the child and parents. SSTP has five levels of intervention strength which varies from a universal media based campaign, to individual intervention, to a group based SSTP program. Evidence for SSTP has been varied and has principally focused on the individual format.

Roberts *et al* (2006) conducted a randomised control trial of individual SSTP for parents of pre-schoolers with developmental and behaviour problems. The intervention was found to be associated with fewer child behavioural episodes reported by both parents and observers. Improvements were also found in parental style and decreased parental stress. Speetjens *et al* (2010) also found from the Individual SSTP program significant improvements in parenting skills, family functioning, parental stress and well-being. Similar significant improvements in child behaviour and parenting skills have been found for families with children who have an autism spectrum disorder (Whittingham *et al*, 2006).

Regarding the evidence for Group SSTP, Harrison (2006) randomly assigned participants to either a control group or a Group SSTP condition. Children had diagnoses ranging from autism spectrum disorder (ASD), Down syn-

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## “The school setting could be a powerful environmental factor in the success of delivering a Group SSTP program”

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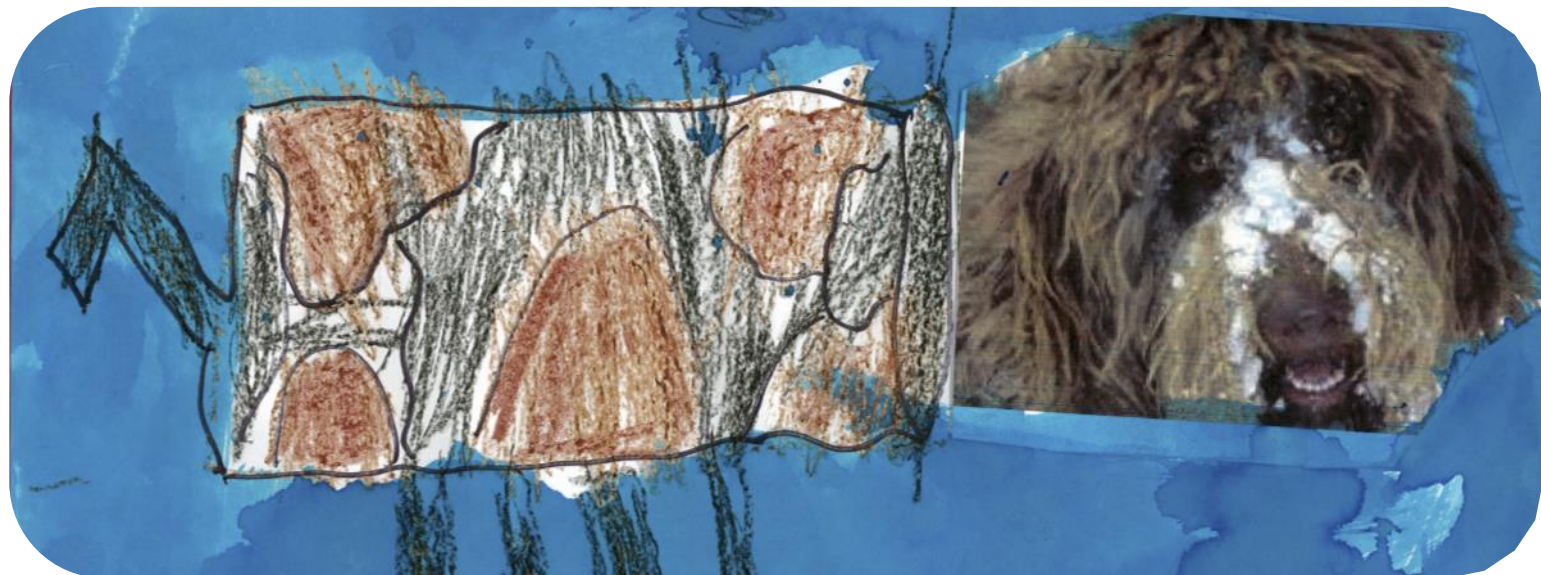
drome, intellectual disability and attention deficit hyperactivity disorder (ADHD). Parents in the SSTP group reported greater improvements in parenting style and consistency, increased confidence and competence in their parenting skills. Changes were also noted in the intensity of the child’s behaviour. However, no significant findings were found for parental depression, anxiety or stress (Harrison, 2006). Similarly, Myers (2007) found significant differences between the Group SSTP intervention and control group participants in parenting styles with decreases in laxness, verbosity and overactivity. However, there was no significant effect on the child’s behaviour.

Examining the influence of demographics, Hampel *et al* (2010) compared the outcomes of Group SSTP for children of psychosocially challenged environments to those without psychosocial stressors. Findings revealed greater significant improvements in the psychosocially disadvantaged group particularly in the areas of parental anxiety, depression, and reactivity. Similar to previous studies, actual reductions in problem behaviours were modest with mainly significant reductions in self-absorbed and disruptive/antisocial presentations. The study confirms that it is those families from more psychosocially disadvantaged areas of society that are in greater need, and are likely to benefit most, from interventions such as Group SSTP. Walsh (2008) summarises that Group SSTP shows some promising preliminary findings especially in relation to parents’ disciplinary style, sense of self efficacy and confidence however, there is a need for additional research to replicate and extend these findings.

Regarding the setting of Group SSTP interventions, previous research appeared to conduct the program in either a clinical or mental health setting, although no studies specifically state where their intervention was held (Hampel *et al*, 2010; Speetjens, 2010). In 2011, Jewell published a pilot study where for the first time, a partnership between the Parramatta Community Support Team, Ageing Disability and Home Care (ADHC), Family and Community Services, New South Wales, and Group SSTP was conducted within a School for Specific Purpose (SSP). SSP’s cater for children who require intensive levels of behavioural and educational support including children with an intellectual disability. Results from the school based program found that on the Developmental Behaviour Checklist (Einfeld & Tonge, 1994) at pre-intervention 90% of the parents gave a Total Behaviour Score in the clinical range. Post-intervention 80% of scores were below clinical range. On the Depression Anxiety Stress Scales (DASS, Lovibond & Lovibond, 1996) at the pre-intervention 50% of participants had total DASS scores within the clinical range. Post-intervention only 20% of the participants were still in clinical range. The results were extremely encouraging and suggested that the school setting could be a powerful environmental factor in the success of delivering a Group SSTP program. Close interagency work and support during the program was also likely to be a significant contributing factor to the success of the study.

From a nationwide policy perspective Mazzucchelli and Sanders (2011) discussed a public health approach to implementing SSTP but highlighted a number of barriers to its implementation, including availability and accessibility. Roux *et al* (2013) writes that any parenting program for parents of children with developmental disabilities must be easily accessible with limited demands in terms of time and travel. It was also recommended that facilitators use any available strategies to help destigmatise the program. In particular choosing the right location or venue of the program could be a significant factor in normalising participation.





The purpose of this study was to further the evidence base, to improve the availability and access to interventions for parents of children with developmental disabilities, and to provide a model of cross agency collaboration and support with this population. In 2012, group SSTP was delivered in 11 Schools for Specific Purposes (SSP's) across New South Wales (NSW) as a potential form of early intervention and prevention of challenging behaviour amongst children with intellectual or developmental disability and parental stress. This was a conjoint project across Ageing, Disability and Home Care (ADHC), Family and Community Services (Metro North and Statewide Behaviour Intervention Service; SBIS), Children's Hospital at Westmead (CHW), and NSW Department of Education Two hypotheses were proposed. Firstly, it was hypothesised that the implementation of Group SSTP in SSP's would improve the behaviour of children at home and at school. It was also hypothesised that the groups will have a positive impact on the mental health, behaviour management skills, and confidence of the parents.

## 1. Method

### 1.1. Design

The study was a repeated measures design. Pre-treatment measures were completed by the parents or carers and one pre-treatment measure was completed by each child's class teacher who acted as an independent observer. The parents or carers received the Group Stepping Stones Triple P intervention and subsequently completed the same assessment measures post-treatment. The classroom teachers also completed their assessment measure after the parents/carers received their treatment.

Due to limited resources and funds there was no control group. An opportunity sample was used as participants were recruited by schools and not the researchers.

### 1.2. Participants

The participants were all parents or primary caregivers of a child who was attending a government primary school in NSW. The 11 schools recruited were special education schools, whilst one was a mainstream school with a support class for intellectual disability. The maximum intellectual functioning of the children of the parents included in this study were within the mild intellectual disability range, they were mostly moderate or severe.

The first stage in recruitment of the parent participants was to locate interested schools that catered for children with an intellectual disability. This occurred via email advertising within the NSW SSP Principal Network and with other contacts made via the NSW School-Link mental health initiative between health, education and disability. Each school then self-directed their own Group SSTP parent recruitment campaign which included school newsletter advertisements, letters sent home to selected parents, and parent information sessions at the school.

Eighty-nine participants were recruited and completed all pre-treatment assessment questionnaires. Two participants dropped out of the program due to personal illness, one participant was administered the program in an individual format due to being the sole participant from that school, and nine participants did not complete post-treatment assessment questionnaires. In addition, 22 participants were excluded from data analyses due to missing response items on the assessment questionnaires.

The final sample consisted of 56 parents or primary caregivers of children aged between 4 and 13 years. The participant characteristics are provided in Table 1. Participants were assigned scores on the Daniel's (1983) Prestige Scale according to their occupation, where lower scores indicated higher social status or prestige.



<b>Variables</b>	<b>Participants (n = 56)</b>
<b>Age of child</b>	7.45 (S.D. = 2.18)
<b>Sex of Child</b>	
Male	42
Female	14
<b>Specific Diagnoses (by parental report)</b>	
Acquired Brain Injury	1
Specific Learning Disabilities (including ADHD)	22
ASD Spectrum	37
Developmental Delay	19
Cerebral Palsy	2
Psychiatric Disability	5
Blind or Vision Impaired	7
Deaf or Hearing Impaired	7
<b>Professional Help Sought</b>	
Sought	40
Not Sought	16
<b>Current Martial Status</b>	
Married	33
Defacto	7
Never Married/Defacto	4
Separated	8
Divorced	2
Widow/er	1
Other	1
<b>Relationship to Child</b>	
Mother	37
Father	8
Step-Father	1
Foster Mother	4
Grandparent	6
<b>Daniel's (1983) Prestige Scale (1-7)</b>	
Respondent	5.20 (S.S. = 0.76)
Respondent's partner (n = 42)	4.51 (S.D. = 1.05)

**Table 1: Participant characteristics**

### 1.3. Procedure

The SSTP school intervention was facilitated by two trained staff, consisting of one school facilitator (from the SSP) and one state government disability service facilitator (ADHC). The rationale for this was to provide a high level of interdisciplinary expertise and support leading the intervention. The school principal nominated either the school counsellor or other staff member, such as teacher, or executive to complete the three day training and accreditation in Group SSTP. The disability service (ADHC) co-facilitators were nominated by their behaviour support manager and were also accredited in Stepping Stones or Triple P before delivering the intervention. All staff were granted release time by their respective agencies.

To support the facilitators, the researchers organised three video conference link-ups over the ten weeks, pre, mid and post intervention with all schools invited to attend. A clinical research psychologist and administration team were on call should any clinical or logistical issues arise. A debrief session was offered to all facilitators at the conclusion of the study.

This study received ethical approval from the Service Improvement Unit at the Children's Hospital at Westmead and the NSW Department of Education state education research approvals process (SERAP). Both departments provided ongoing advice and support to the researchers.

### 1.4. Intervention

The majority of the intervention (6 sessions) was delivered in group format within each school, except one school which only recruited one family and so delivered the intervention individually. The researchers added an additional session ("session 0") to allow time and support for parents when completing the assessment measures. Three additional sessions were delivered individually over the telephone to tailor the intervention to each participant's needs and to report feedback from the initial assessment session. The number of participants per school group ranged from 1 to 14, with a median of 8. A summary of the sessions and delivery mode is outlined in table 2

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**“Group SSTP was delivered in 11 SSP’s across NSW as a potential form of early intervention and prevention of challenging behaviour amongst children with ID and parental stress”**

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Session	Content	Delivery Method
0	Completion of pre-assessment measures	Group or Individual
1	Positive parenting	Group
2	Promoting children's development	Group
3	Teaching new skills and behaviours	Group
4	Managing misbehaviour and parenting routines	Group
5	Planning ahead	Group
6-8	Implementing parenting routines and individual assessment feedback	Individual telephone consultations
9	Program close and post assessment	Group

**Table 2: Summary of session within the Group Stepping Stones Triple P intervention**

### 1.5. Measures

Parents or caregivers were given *A Family Background Questionnaire*, designed by the researchers, which contained basic background data such as information on the child's disability, age, gender, ethnicity and contact details etc. This was completed at the pre-assessment stage only.

Parents or carers were given assessment packs before and after the intervention which consisted of the first four measures (1.5.1 to 1.5.4) listed below.

**1.5.1. Developmental Behaviour Checklist-Parent Version (DBC-P; Einfeld & Tonge, 1994).** The DBC-P is a 96 item questionnaire which provides a parent report assessment of emotional and behavioural disturbance in children aged from 4 -18 years. Normative data are provided for children with mild, moderate or severe cognitive impairment.

**1.5.2. The Parenting Scale (PS; Arnold, O'Leary, Wolff & Acker, 1993).**

The PS is a 30 item self-report measure of parenting approaches. The scale produces subscale scores for 'Laxness' (a tendency toward inconsistent discipline), 'Over-reactivity' (displays of parental temper, anger and irritability) and 'Verbosity' (over-reliance on talking).

**1.5.3. The Parenting Tasks Checklist (PTS; Sanders & Woolley, 2001).**

PTS is a 28 item checklist designed to assess parents' task specific self-efficacy. Parents rate how confident they are in dealing with their child if they engage in difficult behaviour in common parenting situations. Confidence is rated on a scale of 0 (Certain I cannot do it) to 100 (Certain I can do it).

**1.5.4. Depression Anxiety and Stress Scale 21 (DASS; Lovibond & Lovibond, 1996)**

The DASS 21 is a self-report questionnaire for adults designed to assess levels of depression, anxiety and stress. The scale consists of 42 statements grouped into three 14-item scales of depression, anxiety, and stress. Participants are asked to respond to the statements on a 4-point Likert scale, ranging from 0 (*did not apply to me at all*) to 3 (*applied to me very much, or most of the time*).

**1.5.5. The classroom teacher of the child concerned (non-treatment participant) was given the Developmental Behaviour Checklist-Teacher Version (DBC-T; Einfeld & Tonge, 2002) pre and post intervention.** The DBC-T is a 96 item questionnaire which provides a teacher report assessment of emotional and behavioural disturbance in children aged from 4 -18 years. Normative data are provided for children with mild, moderate or severe cognitive impairment.

**1.5.6. Client Satisfaction Questionnaire (Eyberg et al, 1993).** This was distributed to participants post intervention only. Roux et al (2013) describe the Client Satisfaction Questionnaire as an adaptation of the Therapy Attitude Inventory (TAI) developed by Eyberg (1993, as cited in Sanders et al., 2003) to measure consumer satisfaction with parent-training programs. A composite score of program satisfaction ratings is given based on a 7-point scale per item. High scores indicate greater satisfaction. For the entire questionnaire a minimum total score of 13 and a maximum total score of 91 is possible.

## **2. Results**

### 2.1. Statistical Analyses

The data were screened and distributions checked. No data were deemed to be in need of transformation. All analyses were conducted using SPSS 17 for Windows. The significance level for all analyses was set at 0.05.

Planned comparisons were made between participant ratings on the pre-treatment and the post-treatment assessment questionnaires, using Paired Samples T-tests. Table 3 displays the mean and SD for pre-treatment and post-treatment ratings and differences between these ratings on each measure. Effect size for each planned comparison was calculated.

**Table 3: Means and standard deviations (in parentheses) for pre- and post-treatment ratings, and t-statistics and effect size differences between ratings.**

Variables	Pre-treatment	Post-treatment	t	Sig	Effect Size
<b><i>Parenting Style</i></b>					
Laxness	3.06 (0.76)	2.48 (0.64)	6.29	0.000	0.42
Overreactivity	2.86 (0.77)	2.36 (0.81)	4.72	0.000	0.29
Verbosity	3.49 (0.85)	2.74 (0.96)	6.53	0.000	0.44
Total	3.13 (0.56)	2.57 (0.65)	7.23	0.000	0.49
<b><i>Parenting Confidence</i></b>					
Setting Self-Efficacy	76.82 (16.09)	85.24 (12.64)	4.68	0.000	0.28
Behavioural Self-Efficacy	68.10 (16.31)	81.20 (15.22)	5.94	0.000	0.39
<b><i>Parental Adjustment</i></b>					
Depression	5.43 (4.05)	2.43 (2.46)	7.05	0.000	0.47
Anxiety	3.88 (4.12)	1.88 (2.33)	4.39	0.000	0.26
Stress	7.73 (4.05)	4.43 (2.98)	6.54	0.000	0.44
<b><i>Child Adjustment - Parent Rated</i></b>					
Disruptive/Antisocial	17.54 (9.33)	14.48 (8.18)	3.54	0.001	0.19
Self-Absorbed	23.77 (13.14)	22.43 (11.96)	1.11	0.274	0.02
Communication Difficulties	7.38 (4.56)	7.32 (4.52)	0.11	0.909	0.00
Anxiety	6.61 (3.53)	5.96 (3.07)	1.57	0.122	0.04
Social Relating	6.13 (3.10)	5.46 (2.89)	1.59	0.118	0.04
Total Behaviour Problems	63 (25.64)	56.77 (22.15)	2.46	0.017	0.10
<b><i>Child Adjustment - Teacher Rated</i></b>					
Disruptive/Antisocial	16.93 (10.79)	10.68 (10.67)	3.34	0.002	0.17
Self-Absorbed	19.36 (13.77)	14.50 (11.56)	3.67	0.001	0.20
Communication Difficulties	5.70 (4.40)	4.79 (4.23)	2.05	0.045	0.07
Anxiety	4.45 (3.60)	3.39 (2.91)	3.22	0.002	0.16
Social Relating	6.57 (3.96)	4.88 (3.40)	3.81	0.000	0.21
Total Behaviour Problems	51.71 (29.64)	38.91 (26.81)	4.2	0.000	0.24

## 2.2. Treatment Effects – Parenting Style

Using the Parenting Scale, three factor scores (Laxness, Over reactivity and Verbosity), and the Total score on the Parenting Scale were used to assess parenting style. There was a statistically significant decrease in Laxness [ $t(55) = 6.29, p < .000$ ], Over reactivity [ $t(55) = 4.72, p < .000$ ], Verbosity [ $t(55) = 6.53, p < .000$ ], and in the total score [ $t(55) = 7.23, p < .000$ ] from pre-treatment to post-treatment assessments. The eta squared statistics for laxness (.42), over reactivity (.29), verbosity (.44) and total score (.49) indicated large effect sizes for all parenting style measures.

## 2.3. Treatment Effects – Parenting Confidence

Parenting confidence was assessed using the Parenting Tasks Checklist. Setting self-efficacy scores significantly increased from pre-treatment [ $M = 76.82, SD = 16.09$ ] to post-treatment [ $M = 85.24, SD = 12.64, t(55) = 4.68, p < .000$ ]. Similarly, pre-treatment [ $M = 68.10, SD = 16.31$ ] to post-treatment [ $M = 81.20, SD = 15.22, t(55) = 5.94, p < .000$ ] scores significantly increased for behavioural self-efficacy. Effect sizes were large for both setting self-efficacy and behavioural self-efficacy.

## 2.4. Treatment Effects – Parental Adjustment

Three measures (Depression, Anxiety and Stress) on the DASS were used to assess parental adjustment. There was a significant decrease in depression [ $t(55) = 7.05, p < .000$ ], anxiety [ $t(55) = 4.35, p < .000$ ] and stress [ $t(55) = 6.54, p < .000$ ] on pre-treatment compared to post-treatment ratings. The eta squared statistics for depression (.47), anxiety (.26), and stress (.44) indicated large effect sizes for all parental adjustment scales.

## 2.5. Treatment Effects – Child Adjustment

Child adjustment was assessed using parent and teacher ratings on the Developmental Behaviour Checklist.

Parent ratings on the Disruptive/Antisocial subscale significantly decreased from pre-treatment [ $M = 17.54, SD = 9.33$ ] to post-treatment [ $M = 14.48, SD = 8.18, t(55) = 3.54, p = .001$ ]. Similarly, pre-treatment [ $M = 63, SD = 25.64$ ] to post-treatment [ $M = 56.77, SD = 22.15, t(55) = 2.46, p = .017$ ] parent ratings significantly decreased on total behaviour problems. The eta squared statistics for parent-rated disruptive/antisocial (0.19) and total behaviour problems (0.10), indicated a large effect size and a moderate effect size, respectively. Small effect sizes were found for parent ratings on self-absorbed (0.02), anxiety (0.04) and social relating (0.04).

On the teacher rating scales there was a statistically significant decrease on disruptive/antisocial [ $t(55) = 3.34, p = .002$ ], self-absorbed [ $t(55) = 3.67, p = .001$ ], communication difficulties [ $t(55) = 2.05, p = .045$ ], anxiety [ $t(55) = 3.22, p = .002$ ], social relating [ $t(55) = 3.81, p < .000$ ], and in total behaviour problems [ $t(55) = 4.20, p < .000$ ] from pre-treatment to post-treatment teacher



ratings. Effect sizes were large for all teacher ratings, with the exception of communication difficulties wherein the effect size was medium.

## 2.6. Parent Satisfaction

The ratings of parent satisfaction with Group SSTP in schools were measured by the Client Satisfaction Questionnaire. An average rating per item of 5.81 was achieved out of a possible 7. Mean total score was 74.7 (minimum total response 49, maximum total response 90).

## 2.7. Post-hoc Analysis

An independent samples t-test was conducted to compare the change scores (difference between pre- and post-treatment parent and teacher ratings) for the ASD and ID group and the ID only group.

There was a significantly greater improvement in parent ratings of Setting Self-Efficacy for the ASD and ID group ( $M = 11.70, SD = 14.62$ ) compared to the ID only group [ $M = 2.05, SD = 7.91, t(54) = 2.68, p = .01$ ]. The magnitude of the differences in means was moderate (eta squared = .11).

Similarly, there was a significant difference in change scores between groups on parent rated social relating and total behaviour problems. The ASD and ID group ( $M = 1.30, SD = 2.92$ ) were found to have a significantly greater improvement in parent rated social relating compared to the ID only group [ $M = 0.58, SD = 3.19, t(54) = 2.21, p = .032$ ]. There was also a significantly greater improvement in parent ratings of total behaviour problems for the ASD and ID group ( $M = 10.78,$

SD = 19.58) compared to the ID only group [M = 0.74, SD = 17.47,  $t(54) = 2.16$ ,  $p = .035$ ]. The eta squared statistics for parent rated social relating (.08) and total behaviour problems (.08) indicated moderate effect sizes.

There was greater improvement, which approached significance, in parent ratings of laxness [ $t(54) = 1.97$ ,  $p = .054$ ], stress [ $t(54) = 1.89$ ,  $p = .064$ ] and teacher-rated social relating [ $t(54) = 1.85$ ,  $p = .07$ ] for the ASD and ID group compared to the ID only group].

### 3. Discussion

The present research is unique in that it is the first study of the Group SSTP program to be conducted in the school environment and co-facilitated by school staff. It is also the first study to compare pre and post measure responses from an independent observer such as the class teacher. The results of the study support the hypothesis that after the delivery of Group SSTP within a school there are significant improvements in child behaviour. In addition, the findings also support the hypothesis that Group SSTP intervention in schools results in improvements in parental mental health, confidence and parenting style.

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## “Group SSTP intervention in schools results in improvements in parental mental health, confidence and parenting style”

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With regard to the first hypothesis, significant improvements in behavioural difficulties were found by teachers in the classroom after parents attended Group SSTP. Significant reductions on all scales of the DBC-T were found on the disruptive/antisocial, self-absorbed, communication, anxiety and social relating scales suggesting global improvements in behavioural and emotional problems. Parents reported likewise significant reductions on the total score and disruptive/antisocial scale of the DBC-P, however, improvements in self-absorbed, communication, anxiety or social relating indices did not reach significance.

With regard to the second hypothesis, highly significant improvements in parental mental health, parenting confidence and parenting style were found following parents' attendance at school Group SSTP programs. On the parenting scale there were significant improvements in the parent's levels of reactivity, verbosity and laxness. On the PTC the findings showed significant improvements in the parents' ability to deal with behavioural incidents and to do this across different situations. Most significantly, the parents' mental health showed highly significant im-

provements with between 43 and 56 per cent reductions in symptoms of depression, anxiety and stress. Importantly, depressive symptoms fell from the mild clinical range to the normal range. This furthers the findings of Roux et al (2013) who found significant intervention effects on the DASS although their results had to be cautiously interpreted as the pre and post intervention scores were within the normal range.

This study gains similar findings to that of Roux et al (2013) who found significant improvements in child behaviour, parenting style and parental satisfaction but with some parents reporting improvements in behaviour not reaching significance. The results also meet with Whittingam et al's (2010) study which found significant improvements in child behaviour and parenting style and supports Hampel et al's (2010) Group SSTP specific study where significant improvements in parenting skills, parental stress and child behaviour problems were found. They reported a highly positive response to the Group SSTP program by parents similar to that found by the present study through anecdotal reports (Saleh, 2012). This is also evidenced quantitatively by high average ratings on the Client Satisfaction Questionnaire.

The study provides strong quantitative evidence that the school is a well-suited environment to host and provide Group SSTP. Three-fold qualitative benefits have also been found between the parents, teacher and the child. The significant improvements in child behaviour at school also suggest that there may be benefits educationally both for the teachers', their class, and the child's ability to learn. Anecdotally, parents reported a sense of comfort with the venue being their child's school and many parents have continued to meet up long after the program has completed. Teachers and principals also expressed anecdotal satisfaction with the program with some expressing an interest in having Group SSTP as a standard part of the initial school intake package for all new children and parents. Staff from ADHC, the disability service, have also reported on the benefits of co-facilitating the groups and an enhanced relationship with the schools during and after the program.

It was disappointing that the parents compared with the teacher's findings did not observe more significant behavioural change in the children. There may be various reasons for this. In previous research, it has also been found that behavioural improvements at home can be delayed with changes still being noted at six month follow up (Roux et al, 2013). There is also a possibility that following the program the parents' enhanced behaviour management skills leads to an increased vigilance in identifying problem behaviours which were not noticed previously. This may have had the effect of increasing the number of behaviours being reported on the post intervention DBC. Additionally, the population attending SSPs are commonly highly complex with dual diagnoses

including ID, ASD and often ADHD therefore it would not be unexpected for the benefits of the parents new skills, confidence and general well-being to take time to lead to improvements in the children's behaviour.

Among the strengths of the current study is the high degree of close interagency working partnerships. Mazzucchelli & Sanders (2011) highlighted that a common barrier to the implementation and dissemination of programs such as Group SSTP in schools can be the "turf wars" that can ensue between agencies. Since 2010 this project has been the result of a partnership between Ageing Disability and Home Care, Family and Community Services NSW, the Children's Hospital at Westmead and SSP schools in NSW. Furthermore, the intervention itself was run in schools by facilitators from both education and disability services with support from a mental health service. Therefore, barriers that have impeded other studies and interventions were not present for this project.

The large sample size was also a strength of the study. During the analysis phase a conservative process of filtering was undertaken where data sets with missing data, such as questionnaires not fully completed, were excluded. Despite this process, 56 complete sets of data were included in the study. This helped maximise the validity and reliability of our findings and enhanced our ability to detect significant differences and strong effect sizes.

Another strength of the project was the use of teachers as independent observers of change. In the majority of previous research, outcomes are measured by parent responses alone. The use of teacher completed DBC-T questionnaires gained a valuable second opinion on behavioural change but also gave insight into change in the school context which has not been measured before. The program was also rolled out in both city metro and regional areas of NSW Australia therefore further enabling the generalisability of the results across the population.

Regarding limitations of the study, an opportunity sample was used where the school staff independently recruited families. In some cases, schools identified which families they would like to attend, in others the schools invited parents to apply. As a result recruitment was not standardised. However, as schools were in control of the recruitment and implementation process, the results can be considered an ecologically valid representation of clinical outcomes when Group SSTP is implemented in schools.

Regarding other possible study constraints and future directions, there was no waiting list control group as none of the schools had a second Group SSTP program planned. Diagnosis of the children relied on the parents reporting which could be suggested as being subjective information with no real independent confirmation. However, the fact that the children were enrolled in SSPs

where there is a requirement for a diagnosis of an intellectual disability for admission is a form of ratification. Finally, as post-hoc testing suggested greater improvements in children with ASD and an intellectual disability compared with children who had an intellectual disability only, it is a goal to further explore the outcomes for children with both diagnoses in the next phase of our research.

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# Differences in Side-effects in Autism

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## Introduction

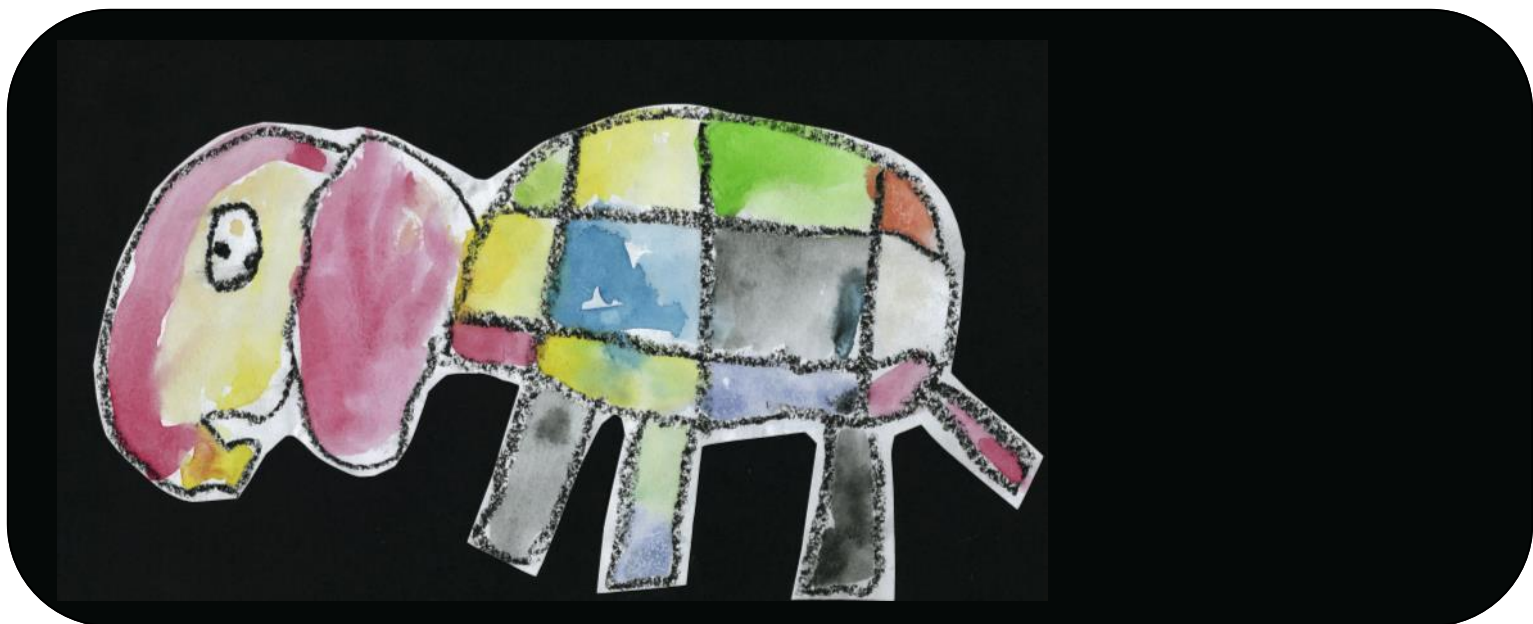
This article is written based on my training experience working in the Neurodevelopmental Psychiatry Team, at the Children's Hospital at Westmead. I came to appreciate that children with autism (ASD) with and without intellectual disability (ID) have different responses to medications to those found in the mainstream population. For those seen in the clinic, their level of behavioural/psychiatric disturbance was often so severe that other non-pharmacological approaches did not make any impact. Hence, I learned to consider a broader range of medications. As a registrar, my role included providing regular telephone follow up which gave me clinical experience on the need for attentive support for introducing medications. I met many cases in the Emergency Department, where case management had not progressed or was worse as a result of unexpected side effects. A search of the literature confirms the observation that young people with ASD/ID have a much higher rate of side effects and a lower rate of therapeutic success than a mainstream population. This article presents brief clinical case-scenarios of reported side effects and asks the reader to predict the medication used.

**Case 1.** A 14-year-old girl with a history of high functioning ASD, anxiety and previous suicidal attempts with overdoses was brought to the Emergency Department (ED) due to panic attacks which were lasting from 5 minutes to 5 hours. During those episodes, the patient described feeling shaky, palpitations, twitching,

hyperventilating, akathisia, restlessness and her mind was foggy. These episodes had started within a week from commencing on a medication for anxiety; what was the medication?

**Case 1 Outcome:** Patient commenced on fluoxetine 10mg 22 days prior to presentation to ED; 6 days into starting the medication she started experiencing the panic attacks and was initially unable to sleep or eat. Four days later, the medication was ceased, but symptoms were slow to recede. The patient was discharged from ED with the community mental health team follow-up. A week following discharge she was commenced on another selective serotonin reuptake inhibitor (SSRI), escitalopram, with a similar outcome of exacerbation of panic attacks again, and the medication was gradually weaned and ceased two weeks later.

SSRI's are activating antidepressants that are used for the treatment of restrictive, repetitive behaviours and interests, depression, anxiety and obsessive-compulsive disorder (OCD) (Williamson and Martin, 2012), (Beasley and Potvin, 1993). Due to treatment-emergent adverse effects, about 30% of neurotypical people discontinue treatment within the first month (Kaplan, 1997). SSRI use is associated with increased anxiety, nervousness, agitation and insomnia, which occur in up to 10-15% of fluoxetine-treated neurotypical patients (Chouinard, 1985, Plewes *et al* 1997, Chouinard *et al* 1999 and Gram, 1994). On com-





mencement of fluoxetine for anxiety or depression, new emergent agitation can develop in 9.2% within the first two weeks of treatment (Chouinard *et al*, 1999). Even though akathisia is a rare side effect of SSRI, a small proportion of patients have reported developing a feeling of inner restlessness and inability to stay still (Gram, 1994) (Walsh and Dinan, 2001). Activation has been described in doses between 5 and 40 mg/day (Beasley and Potvin 1993).

There are reports of fluoxetine-induced hypomania without any risk factor for bipolar disease within 3-5 weeks of treatment (Chavan, 1992; Aggarwal *et al*, 2011; Diler and Avci, 1999 and Go *et al*, 1998). Following the cessation of treatment hypomanic symptoms usually subside within 14 days (Chavan, 1992). In a cohort of 40 neurotypical youths treated for OCD and mood disorders, 30% of patients developed manic or hypomanic symptoms at fluoxetine doses as low as 10mg daily (Go *et al*, 1998). This can be more difficult to distinguish due to limited communication skills in ASD.

In comparison, side effects of hyperactivity, restlessness and agitation have been reported in up to 20-40% of patients with ASD and in 25% of patients with ID without ASD (Cook, 1992; DeLong *et al*, 1998; DeLong *et al*, 2002). This is 2-4 times as frequent when compared with neurotypical patients.

**Case 2.** A 13-year-old young man with autism (level 3) and moderate ID was brought for review due to concerns about aggressive behaviour. He was described to have a happy and caring nature, but also hyperactive, anxious, obsessive and rigid. His pediatrician had started him on a medication that helped for a short period of time, but then despite increasing doses did not improve his symptoms and caused increased weight gain of 30 kgs to 90 kg within five months of treatment. What was the treatment?

**Case 2 Outcome.** He was treated with risperidone, which was started as he entered puberty but behaviour worsened despite the gradual increase of dosing. This augmented dose caused increased appetite and weight gain. We found that hyperactivity and irritability were not the primary co-morbid problems for which risperidone was given, but anxiety, obsessions and rigidity with secondary aggression due to inability to control the situations was more likely.

Risperidone was approved by FDA in children for 6-16 years in 2007 for management of irritability associated with ASD (Williamson and Martin, 2012). For example, risperidone has been shown to reduce irritability by 57%, and this benefit maintained at 6 months



(McCracken *et al*, 2002). However, treatment is associated with hyperprolactinemia and weight gain (Anderson *et al*, 2007; Aman *et al*, 2005), which are worse in children than adults (Taylor, Paton and Kapur, 2015). Additional side effects reported in children with ASD were fatigue, drowsiness, dizziness, enuresis and drooling (McCracken *et al*, 2002). Extrapyramidal side-effects (EPS) were no more common than in placebo group (Aman, 2015); nevertheless, clinicians are noted often not to treat EPS with anticholinergics, but rather cease the medication. There is a growing appreciation that in the long term, major tranquillisers cause obesity and cardiometabolic syndrome, which is a contributor to premature mortality. Accordingly, long-term medication needs to be considered judiciously.

**Case 3.** A teen boy with ASD (level 3) and moderate ID was reviewed for aggressive behaviour in relation to rigidity, OCD and anxiety. During the initial assessment, he had been treated with a medication that improved his obsessive behaviours but contributed to the patient's significant melt-downs, anxiety and self-harm. What was the medication?

**Case 3 Outcome.** Both Case 1 and 3 demonstrate behavioural activation whilst using SSRI. Patient 3 was treated with fluoxetine of 40 mg per day with no improvement of his symptoms, except some of his obsessions resurfaced when the medication was withdrawn. On cessation of fluoxetine, his behaviour gradually improved but did not resolve.



Fluoxetine is shown to be more effective in older adolescents and adults compared to children (Williamson and Martin, 2012; Taylor, Paton and Kapur, 2015), and a strong correlation of fluoxetine efficacy has been seen with the family history of major affective disorder such as bipolar disorder or major depression. Study by DeLong and colleagues (2002) of children with idiopathic ASD treated with fluoxetine (0.15-0.5mg/kg) for the duration of 5-76 months showed excellent response in 17%, good response in 52%, fair response in 8% and poor response in 23% (DeLong, 2002). In this study, behavioural activation, hyperactivity, irritability, aggressiveness and agitation were primary factors for fluoxetine intolerance. These symptoms were sometimes seen almost immediately, but at times, a few weeks to months after 'successful treatment' (DeLong *et al*, 1998; DeLong *et al*, 2002).

**Case 4.** A 17-year-old girl with autism (level 3) and moderate ID with features of anxiety presented to our clinic. She had been treated with risperidone and fluoxetine, neither of which had improved her symptoms and therefore fluoxetine was ceased. At the time of initial review, she was managed on a small dose of risperidone. Due to on-going anxiety, self-harm and aggression towards caregivers, she was commenced on another medication which significantly improved her anxiety and rigidity leading to a cessation of further meltdowns. Since starting the new medication, she was energetic, elevated and happy at the time, but had significant problems with sleep initiation. What was the medication?

**Case 4 Outcome.** This patient commenced on propranolol with almost miraculous improvement in her anxiety and aggression. When she was faced with new and

anxiety-provoking situations, she was able to self-regulate without aggression. At the same time, she was unable to go to sleep which had become an even more significant problem than before.

Propranolol is a beta-1 adrenergic receptor blocker that has anxiolytic effects but has been shown to improve emotional, behavioural and autonomic dysregulation symptoms in ASD (Sagar-Ouriagli *et al*, 2018). Unfortunately to-date the exact mechanism in violence and aggression is not clearly established, but it is theorised that anger involves an explosive release of adrenalin from the adrenal glands. Melatonin secretion at the same time is implicated by the beta 1-adrenoreceptors as well (Munoz-Hoyos *et al*, 2001). Sleep disturbance, of difficulty with initiation and maintenance, has been shown to be caused by reduced production of melatonin through specific inhibition of beta-1 adrenergic receptors by propranolol (Stoschitzky *et al*, 1999).

**Case 5.** A late-teen with a history of level 3 autism, moderate ID and obesity presented with aggression mainly associated with food requests. Initially, risperidone did work, but with difficulty managing his appetite and learned aggressive behaviour. The trial of treatment with another obesogenic medication increased these symptoms.

**Case 5 Outcome.** This patient was commenced on olanzapine and thereafter paliperidone depot injections, in an attempt to reduce and cease the olanzapine. Despite the medications, his aggressive behaviour continued.

Olanzapine is indicated for the management of irritability in ASD (Taylor, Paton and Kapur, 2015) and has been shown to be effective in about 50% of the cases, but it doesn't improve aggression or repetitive behaviours (Hollander *et al*, 2006). At the same time, it causes significant weight gain, with a reported weight gain of 3.4 kg +/- 2.2kg in an 8-week study of 6 -14-year-old children with ASD. This reinforces the dictum that medication can only be used to treat symptoms that may predispose to aggression, and behavioural management including a safety plan is critical for aggression and violence (Dossetor, 2016). This is obviously easier to teach with a small child, but it is no less important with a large adolescent.

**Case 6.** A 9-year-old boy with autism, moderate ID and hyperactivity was commenced on treatment to manage his hyperactivity. However, this treatment caused dizziness, and he had become "out of control" every time after the medication was given.

**Case 6 Outcome.** Stimulants are indicated for the treatment of inattention, over-activity and impulsiveness. However, the efficacy in ASD is limited with the response rate being reported to be around 50% in children with autism (Research Units, 2005; Aman *et al* 1997). For example, only a quarter of patients have been shown to respond to the first stimulant trial, in comparison with 60-70% of neurotypical children. Furthermore, 57% of children with ASD showed adverse effects: 36% developed agitation, 14% depressed mood and 10% aggression (Stigler *et al*, 2004). Another study showed that 49% of children with ASD on treatment with methylphenidate showed side effects such as reduced appetite (37%), insomnia (26%), irritability (15%), tics (7%) and lethargy (7%) (Aman *et al*, 1997). This provides some explanation for why clonidine is the first line treatment of ADHD in ASD and/or ID in our clinical team.

**Case 7.** A pre-teen boy with autism, moderate ID and hyperactivity was commenced on treatment to manage his hyperactivity, but it was discontinued as it increased his irritability and in higher doses caused sedation.

**Case 7 Outcome.** As a second line treatment for hyperactivity, this young man was commenced on clonidine. Due to undesired symptoms, treatment was ceased, and his ongoing management of hyperactivity was effectively managed non-pharmacologically with organised activities – walking, running, and playing. Clonidine is indicated to be used to manage hyperarousal, hyperactivity, irritability, anxiety and insomnia in ASD (Doyle and McDougale, 2012). Treatment with clonidine has been shown to improve attention deficit,

hyperactivity, mood instability, aggressiveness, sleep initiation and night awakening in children with ASD (Ming *et al*, 2008). Interestingly, if clonidine worked within the first week for sleep, the dose did not need to be increased in the first year. Main reported side effects were sedation, decreased activity, and paradoxical patient irritability (Ming *et al*, 2008), which may be explained by the patient fighting the sedative effect of the clonidine. Rarely reported side effects to include pallor, tachycardia, hypotension and depression. This case illustrates that there is no single answer for ADHD in autism.

**Case 8.** A 12-year-old boy with autism level 3 and epilepsy was already treated with sodium valproate. His main problems on presentation were anxiety and meltdowns lasting for hours in relation to indecisiveness. He was commenced on a medication which improved his anxiety and therefore meltdowns but also concentration. However, it caused increased appetite, increased seizure activity requiring augmentation of sodium valproate dose and initially slight drowsiness which could have been because of the medication or increased seizure activity.

**Case 8 Outcome.** This young man was commenced on aripiprazole (Abilify) with good effect on his anxiety and therefore also a significant improvement of his meltdowns which prior to treatment caused problems in daily living.

Aripiprazole is a third-generation antipsychotic that has been approved by the FDA since 2009 for use in 6 -17-year-old children with autism who have irritability and stereotypies such as repetitive, purposeless actions (Hirsch and Pringsheim, 2016). Short-term intervention with Aripiprazole has also shown to improve hyperactivity in children and adolescents. Ari-

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“Sleep disturbance, of difficulty with initiation and maintenance, has been shown to be caused by reduced production of melatonin”

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piprazole has a smaller effect on weight than risperidone; on risperidone, 76 % of subjects gained weight (mean +2.7 kg, range -3.3 to 8.1 kg) (Stigler *et al*, 2009) versus 1.13 kg on aripiprazole compared to placebo (Hirsch and Pringsheim, 2016; Ching and Pringsheim, 2012). A 14-week prospective trial in children with mild ASD, 5-17 years showed a 3-fold decrease of prolactin level (Stigler *et al*, 2009). The most common adverse events were mild tiredness (21 -56%), cough (48%), increased appetite (44%), nau-



sea/vomiting (40%), rhinitis (40%), drooling (9%) and tremor (10%). There are rare reports that aripiprazole can reduce seizure threshold when there is underlying seizure disorder.

**Case 9.** A young teenager with autism, average intellect, bipolar type 1 and ADHD was commenced on treatment to improve arousal and aggression. He had refused oral treatment, and he was therefore started on intramuscular preparation of the same medication. The medication caused postural hypotension described as lightheadedness during exercise, tachycardia, increased tiredness and stiffness of lower limb muscles. What was the medication used?

**Case 9 Outcome.** This patient was commenced in intramuscular paliperidone with improved agitation and hyperarousal.

Paliperidone is a second-generation atypical antipsychotic with limited studies showing its effectiveness. Studies have shown an 84% response rate in improving irritability, but it has caused mild-to-moderate EPS (in 16%), an average weight gain of 2.2 kg and 8-fold prolactin increase (5.3 to 41.4 ng/mL) (Stigler *et al*, 2012). Furthermore, paliperidone can cause dizziness, sedation, hypotension and motor side effects (Taylor, Paton and Kapur, 2015). If there is concern about side effects, it is recommended to be patient allowing the patient to accommodate the medication. Anticholinergics like benztropine can be used to improve motor

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“Patient persistence with a broader range of medications was helpful in the vast majority of cases”

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side effects, and early enrolment in lifestyle interventions for exercise and weight management with monitoring is recommended.

**In summary:**

Although psychotropic medications are less efficacious and have more side effects in young people with ASD, I found that patient persistence with a broader range of medications was helpful in the vast majority of cases. It is important to use safer medications rather than resort to major tranquillizers early in treatment. Warnings about the main side effects at the start of treatment and telephone support for other side effects is vital to maintain the confidence of the patient and parents and find the right combination of medications with minimal side effects. Further to establish the impact of each medication, it is important to change one medication at a time. Some medications, such as SSRI's list large numbers of side effects that one seldom sees. It is valuable to warn patients and parents of common side effects, and suggest that if any other new symptoms arise, they should be in touch to review the importance of such symptoms.

SSRIs are more efficacious in adults and older adolescents for the treatment of repetitive behaviours and may exhibit behavioural activation frequently in children particularly with ID and ASD. Whereas activating side-effects are reported in 10-15% of neurotypical children, these are reported in up to 40% of children with ASD. SSRI's can be valuable in some instances of co-morbid anxiety and depression, and where aggression is driven by the stereotypic rigidity of autism. We recommend using these medications with caution and titration of doses should be done more slowly.

Atypical antipsychotics are efficacious for the treatment of irritability in children, adolescents, and adults with ASD. It is a significant health inequity that aripiprazole is not approved on the Prescriber's Benefit Scheme even though there is evidence of efficacy and fewer side effects than traditional major tranquillisers. Even though olanzapine and risperidone have been reported to work in about 50% of the time for irritability in ASD consideration of significant side effects should be paramount.

For hyperactivity and inattention, psychostimulants may be beneficial but are less efficacious and associated with more adverse effects compared to neurotypical individuals with ADHD. Unfortunately, the first trial of stimulants works in about 25% of cases with ASD in comparison with 60-70% of neurotypical children. Furthermore, the rate of side effects has been reported to be over 50% in children with ASD. Due to this, clonidine is a preferred first-line treatment for autism with ADHD and/or anxiety.

Although the literature helps guide choices, the only trial that matters is identifying if this medication actually helps in the case. Sometimes the constellation of symptoms may help select a medication choice, and sometimes the effects or side effects help further understand the nature of the presenting problem. Finally, psychotropic medication is only indicated for a co-morbid psychiatric disorder, and not for the core symptoms of ASD or challenging behaviour.

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# Girls and Autism: Educational, Family and Personal Perspectives

Editors; Carpenter B, Happe F, and Egerton J. 2019, 1-189.  
Routledge: London. A review

*Book review by Dr David Dossetor, Child Psychiatrist,  
The Children's Hospital at Westmead*

*The failure to recognise autism in girls has been a significant professional discourse, so I was attracted to this new book on the subject by well-known British authors. It provides a powerful overview with both scientific evidence along with accounts of personal experience. It is primarily targeted at appreciating the challenge in the UK educational system, and provides a strong advocacy for teachers and clinicians to sharpen their awareness of the differences in presentation of autism in girls. They often present with other problems and it takes a discerning clinician/teacher to pick up the autistic deficits behind these problems. I have tried to capture the main themes of the book- Dr David Dossetor*

“For people with autism, trying to understand the rest of us is like travelling to a foreign country, which allows you access but not acceptance. For women and girls with autism it is more like sneaking in under cover of darkness, wearing a disguise, hoping no one will blow your cover.” Autism has a male stereotype, shored up by Simon Baron Cohen's theory of an extreme male brain with systematising male brains vs empathising female brains, related to prenatal testosterone levels. Many females with autism *mimic* neurotypical behaviour, adopting social stereotypes of being quiet and biddable, creating an unbearable strain for themselves, often later being diagnosed with various mental illnesses, while their autism remains undiagnosed. The book aims to break the barriers to these stereotypes.

A forum in 2016 provided a booklet 'flying under the radar' ([www.nasen.org.uk](http://www.nasen.org.uk)) to increase awareness. Baroness Sheila Holland put girls with autism within the wider issue of the protection of minors and vulnerable adults to both on-line and off-line abuse (Child Dignity Alliance 2018). She hosted a forum in the House of Lords which enabled people to speak out, illustrating the struggles in school, problems of sensory overload, the unfathomable dynamics of friendships, feelings of isolation and the anxiety of the fast paced classroom. This led to 'the big shout 2016 conference' and a call to action.

It is the quality, intensity and co-occurrence of the behavioural-cognitive features that lead to a diagnosis of autism. However, the sex differential may not be 1:10 or 1:4 as has been reported in the past but nearer 1:2. In a

2012 study, 41% of girls with autism had experienced misdiagnosis compared to 30% males. They also experienced late diagnosis whereby only 8% were diagnosed by 5 years versus 25% of boys, rising to 20% vs 50% by the age of 12. Many aren't diagnosed till their 20s and 30s. Whereas boys with autism tend to externalise their stress, girls are more likely to have emotional disorders such as anxiety, self-harm, depression, personality problems, eating disorders and school refusal. These girls need early diagnosis, individualised needs assessment, and personalised interventions for education, social skills and relationships. Without scaffolding they are at risk of a lack of diagnosis, unemployment, lack of social contacts and dependency on their parents.

The book is presented in five parts; I the scientific evidence. II the lived experience. III education. IV adolescence and identity in relation to sex, gender, friendships and mental health. V looking to adulthood and the future.

**Chapter 2 Francesca Happe:** Although autism was always there, the awareness of autism has grown since Kaner's description in 1940s, with increased recognition in those with high IQ, and a widening of diagnostic criteria with aspergers syndrome in the 90s. It was thought if it occurred in girls, it was a more severe presentation.

There is evidence of a female protective effect. For example, looking for ASD in the siblings of ASD subjects, brothers are more likely to be affected than sisters. However, active surveillance with screening instruments finds a higher proportion of girls, compared to clinical cohort studies. As a consequence, females are under-represented or excluded in much research. Diagnostic overshadowing is where one diagnosis is overlooked by another: e.g. one study found 23% of women hospitalised for anorexia nervosa also had ASD on an ADOS. Additional features include: girls may present differently with lower levels of rigid and repetitive behaviours; narrow interests may appear neurotypical, such as horses or boy bands, art or literature and not trains, dinosaurs and astronomy; social differences may be more 'clingy' rather than aloof and therefore they appear less isolated on the playground. Many girls describe 'camouflaging' behaviour through copying, although this is experienced as exhausting which leads to other mental health (MH) prob-

lems. Research is a circular problem: if girls aren't diagnosed, how can you research the features that would help with diagnosis?

**Chapter 3. Katie Buckingham**, 'The Advantages of autism: a personal journey'. Diagnosed at 16, to her parents relief and her disbelief: she thought her life was over. She had already had MH intervention most of her life, but this diagnosis enabled her to start to see herself differently. Not fitting in had led to intense anxiety disorder, somatic anxiety and OCD. Challenged to participate in school outings etc, she started to find advantages, such as thinking independently, working out strategies before events and being able to focus. These helped her to write about coping with MH problems and become a MH advocate. It also helped her to be innovative in work and business. Despite these strengths it was still important for employers to understand autism. Too often autism is seen as a disability. Even though it can be tough, it is better to be told that you have a 'condition that enables you to think differently, inspires specific interests and expertise, you have an eye for detail and a logical mind. Autism causes problems but you can be supported to face challenges and you can still succeed in life. Her supportive father described it: some cars are petrol and others are diesel, but they can all get to where you want to be.

**Chapter 4. Carrie Grant**, 'Raising the voice of the lost girls': "all behaviours, good or bad, are communication: so what are you trying to tell me?". Most people find an earlier diagnosis helpful to understand who and how they are to themselves. Because her

autistic children were so different, each had to be parented differently. A parent group for girls with autism was intensely helpful. She adapted 'non-violent resistance' as a form of parenting to help any two parties in conflict (derived from Haim Omer). Schools only provide adjustments if a child is a problem to them. They only listened when her daughter started talking about suicide. Carrie helped the school learn to support friendships. Teachers need to consider: 1. The classroom from a sensory perspective. 2. The teacher-child relationship, so the child feels understood. 3. Adapting the subject to individual needs. 4. Watching the child's friendships. This chapter indicates that parents may need to appeal the 'Education, Health and Care Plan' (or Statement of Special Educational Needs). Schools are institutions that find it difficult to change and adapt and so often respond with rigidity and lack of empathy. Adjustments can take months or years to be implemented. Her daughter loved school, till threats of detention caused acute anxiety and school refusal. The lack of intervention for the bullying was devastating, re-evoking suicidal risk and the need for constant suicide watch. One daughter learned to blend in and mask her problems, the other couldn't mask her problems and blurted things out at school. How do we get schools to cater for children with such individual differences? Yet the cost of not educating them in terms of unemployment and mental health needs is infinitely greater. Investment, a change of mindset and policy are all needed to allow such girls be included and contribute to the community.

**Chapter 6. Vanessa Bobb**, 'Black girls and autism: the spectre of diverse communities on autism'. Being black





or part of any diverse community can add to the delay of diagnosis. They are more likely to be mislabeled as attachment disorder or low self-esteem and the parents are more likely to be blamed. Her intelligent daughter became very angry for professionals failing to understand her. "Oh she looks normal!" The black communities tend to reject labels of illness or disability because of the indication of shame or weakness which in turns isolates the family. As black people are diagnosed less often with autism, then professionals believe black people are less affected by autism. Even at autism conferences black families feel isolated from the white majority of autism families. We know autism affects all cultures similarly, but in minority groups there is more taboo, denial, concealment and distress. Diagnosis may be overshadowed by other stereotyped views: socio-economic difficulties, drugs, addictions, gangs, crime, teen mothers, mental health and sexual abuse. Her daughter's teen pregnancy redoubled these views, rather than appreciating the failure of sex and relationship education. Such prejudices influence schools' responsiveness to special need

considerations. Sometimes it leads to denial in professionals and sometimes in parents. It is also a worry that girls with autism are 3x more likely to be exposed to coercive sexual victimisation, including from partners. We need specialised 'staying safe' programs and recovery programs for the traumas. Think about how traumatic being stopped and searched by police is for someone with autism. We need autism champions amongst the police. Those with autism are often guilty by association with criminal friends and suffer major trauma in prison. Other institutions may be highly rejecting of autism. What if a Muslim women cannot wear her hijab because of sensory sensitivity? Some Christian churches attribute autism to demonic spirits, or the parents' lack of faith. In all cultural settings people with autism and their families have to fight stigma and prejudice. Some organisations recognise the cultural challenges and they need to reach out to other institutions and cultures to help deepen the wider education of autism.

**Chapter 7. Sharonne Horlock** a special educator writes on a girls with autism support group and issues they face of identity.

### **Part III: 'Girls, Autism and Education'.**

**Chapter 8. Rona Tutt** '*Leadership issues*'. Education providers need to listen to the individual girls and their parents better, as well as the professionals, in resolving special educational needs. This challenge conflicts with government focus on raising academic standards by set ages in keeping with the UK National Curriculum. Special educational needs and/or disabilities (SEND) reports often need a written statement of action, because of the weakness of implementation found on audit inspections. It is not just a question of whether the school can cope with the child, but also whether the child can cope with the school environment. Inclusion does not mean mainstream for everyone. It is a process rather than a place tested by "where can this pupil be most fully included in the life of this school community?"; this needs a range of educational placements. The mental health green paper: 'transforming children and young people's mental health provision' (2017) expects schools to play a key role in prevention and early intervention and SENDs should nominate a designated senior lead for MH. These changes need an inclusive ethos, coming from the principal.

**Chapter 9. Sarah Wild**, '*a specialist curriculum for autistic girls*'. The whole school culture should celebrate autistic girls with awareness and understanding. This can include: understanding the problems of masking, focus on the multiple contributors to anxiety and how to manage it, ensure safety especially while experimenting with relationships, clarifying communications and emotions, and reducing vulnerability by promoting independence.

**Chapter 10. Jane Friswell and Jo Egerton**, '*included or excluded?*' Exclusion from school encourages problems



to be solved by giving up and walking away. Rather, these kids need more support not less. In the UK, exclusion rates are going up slowly as is the permanently excluded number. Boys are excluded 3x more than girls. Exclusion rates for autism are increasing eg by 25% in the last year and 36% of the permanently excluded. Young people with Special Educational Needs account for about 50% of these.

The number of parents opting for home schooling has doubled in 5 years. 22% of teachers mistakenly recommend parents to 'informally withdraw' their children from school. There is little research on exclusions. One study in the UK found 45% of families with a child with autism had 'illegally been put on a reduced timetable, sent home early or asked not to come to school on days of tests or outings'! Exclusion law requires the school to comply with the Equality Act (2010). The principal has to investigate, taking account of special needs and be subject to an independent panel. Gill (2017) reported 50% of diagnosed conduct disorders and 33% of those with emotional disorders are recognised as having special needs. The proportion of excluded children with MH problems approaches 100%.

Research on girls with autism is scarce, but exclusion is often due to 'self-exclusion', prompted by feeling isolation and distress in school. In special education settings, 98% are boys, which recreates marginalisation for the girls. Girls with autism often present with anxiety which leads them to be sanctioned for bad behaviour. But fewer than half of teachers feel confident about supporting a child with autism. Honeybourne's study of girls with autism found they felt lonely, isolated, social misfits, and suffered related anxiety and depression. They wanted time alone and lacked the opportunity, struggled to meet like-minded people, had difficulty maintaining friendships, were teased and bullied, and struggled with group work. They needed structure brought to the unstructured, provision of a range of activities in breaks, clear guidelines for groups, specific roles and clear expectations, and make it normal to have a quiet space and time alone.

A study from the Institute of Public Policy Research found half of all pupils permanently out of school have a recognised MH problem; only 1/100 get 5 GCSEs, the majority end up in prison; exclusion is part of a downward spiral of underachievement. These figures are followed by some case histories of exclusion. Yet Kannadasan (2016) identifies that autistic girls are: non-judgmental, honest, rarely boring, special, logical, loyal, interesting, wonderful, diverse, imaginative and unique; and as Temple Grandin says 'different, not less'.

**Chapter 11. Ruth Fidler** provides a readable summary on *Pathological Demand Avoidance in girls*. This controversial syndrome first proposed by Elizabeth Newsom in the 1980s, is used in some services and not in others. The

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“Without scaffolding they are at risk of a lack of diagnosis, unemployment, lack of social contacts and dependency on their parents”

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chapter provides a helpful summary, and while some feel the diagnostic description helps describe some children, there remains a lack of research to help determine validity.

#### Part IV:

**Chapter 12. Meng-Chuan Lai**, *'the neuroscience of autism in girls'*: doesn't replace other sorts of knowledge such as cognitive styles and behaviour preferences and patterns. Sex refers to biology and gender to socially constructed characteristics which are affected by multiple factors but these are not distinct in maleness or femaleness. Generally, similar processes of brain development is seen in male and female autism, but females tend to have (or need) a greater degree of brain changes; both qualitative and quantitative. Restricted and repetitive behaviours involve motor regions of the brain (male autism) but camouflaging is associated with orbitofrontal cortical activation in women when thinking about comparing themselves (but not found in men). The 'female protective effect' may mean they need a stronger genetic load for autism, as illustrated by male siblings of an autistic child are more likely to show autism than female siblings. Conversely, infant girls siblings of an older autism child show enhanced attention to social scenes compared to infant boys, suggesting this social screening may have a protective effect.

**Chapter 13. Tina Rae and Grace Hershey**, *'MH in girls with autism'*. Failure of diagnosis of autism in girls increases MH morbidity and prevents engagement in necessary learning, affecting future potential in cognitive skills, social skills and emotional wellbeing. The core features of autism affect the ability to gain emotional resilience which in turn affects health, longevity, education, and lifestyles such as smoking and drinking. On-line social connection can be positive but also stressful, abusive and addictive.

Despite limited research there appears to be increased self-harm in girls with autism. Impairment of social communication is associated with depression and substantially mediated by bullying associated with an increase in suicide attempts. Schools need to screen for risks and have good pastoral care. CBT can be adapted for autism,

but is limited by the delay in development of meta-cognitive skills. Work can be done to improve self-esteem, and reduce exposure to sexualised images. Teaching teens to play sexualised roles diminishes their academic success. Unrealistic attitudes to thinness contributes to sexism, sexual harassment and violence against women. They discuss a model of an adolescent social group intervention that they piloted, but it was important to be aware of the vulnerabilities of the participants with and without autism beforehand. Connection between young people, parents, teachers and clinicians depends on having a common language.

**Chapter 14. Felicity Sedgewick and Liz Pellicano, 'Friendships'.** Difficulties in social development is associated with maladaptive behaviours and poor adult outcomes. But how does this apply to girls with autism? Boys tend to share activities and focus on achieving social status, whereas girls have fewer closer friends based more on cooperative pretend play. Some autistic children are desperate for friends and some not so. Girls with autism 10-16 years rated friendships of higher quality, often with neurotypical girls, and showed higher social motivation than boys, which may be protective. Conversely boys were more likely to be rejected by peers. Autistic girls often have interests around people and animals, whereas boys are more focused on objects. Autistic girls rated friendships similarly to neurotypical girls, which was very different to autistic boys. Autistic girls are more interested in people, what they were doing and what they like. Autistic boys were more interested in activity than affect. Autistic girls' friendships were closer and trusting, even if it was limited to a few best friends. However, in conflict they would tend to see things as their fault, or entirely blame the other. In some ways they cope better with on-line relationships with type-written communication. However whether autistic or not, girls had high levels of insecurity in their friendships creating anxiety. Autistic girls tended to interpret neutral situations as negative or sarcastic. Autistic girls lack conflict resolution skills and nuance, with an 'all or nothing approach'. Often having friends becomes more important than having the right friends.

**Chapter 15. Gillian Loomes, 'approaches to adolescence and sexuality as a special educator and advocate'.** Autistic girls absorb adolescent discourses to construct their identity. Loomes describes the dialectical jigsaw for adolescent girls with autism. These discourses are often socially and politically charged but autistic adolescent girls deserve to be offered an autistic-feminist political identity in order to escape socially enforced conformity of silencing narratives that discredit our autistic experiences.

**Part V: 'Autistic girls for the future'**

**Chapter 16. Jo Egerton, Helen Ellis and Barry Carpenter, 'transitions and employment'.** Ellis presents a nice description of her experiences of transitions, but the world



of work is so unlike anything that school prepares you for. Offices have their management structures and unofficial social hierarchies which are challenging for someone with autism. Temple Grandin described the transition from school to college: to deal with such a change she needed a way to rehearse it, acting out each phase of her life by walking through an actual door. Employment is a predictor of social inclusion, economic independence and cognitive, physical and mental health and wellbeing and promoted by schools as a positive outcome. Only 32% of autistic adults are in some kind of paid work, and only 16% in full time work. 51% were over skilled for the job, and 40% were working fewer hours than they liked. 79% on out-of-work benefits wanted to work. Employers need to understand autism better. Girls with autism face a double discrimination with similar additional disadvantages to female neurotypicals. Autistic people need support throughout their lives to help the access and preparation for employment opportunities (National Autistic Society, 2017). Under identification of girls with autism leads to a lack of this support. Developing career aspirations is linked to forming a vocational career identity and gained from experiences and self-discovery. It in-

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*“Reversing her mental health and social trajectory is a slow complex process”*

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volves developing a vocational identity from interests and skills, and addressing the skills for workplace expectations.

### Final thoughts on the book

*This summary of science and experience pushes us to look more closely for autism in girls. Credit goes to the authors and other leadership figures who have evidently challenged the clinical, educational and therapist sectors in the UK to recognise the problems of autism in girls and act! Schools not only need to actively engage in the mental health of their pupils, but in doing so they may find the girls who not only need an autism diagnosis, but face a challenge of a complex combination of problems of mental health, social problems, self-esteem, stigma and exclusion. This fits my clinical experience. I recall one case of a 7 year old girl, sister of a patient, but who also needed help. Getting to know her was like a process of peeling off the layers of the onion of problems as I got to know her and she matured, trusted me and opened up, starting with a clinging maternal attachment, severe anxiety, non-compliance, lack of communication, school refusal and over few years going on to find the autism, the learning difficulties, deteriorating motor skills, problems of trauma and ADHD as well. Conversely, I also recently met a chronically depressed and recurrently suicidal 14 year old, who had not had her autism diagnosed by several mental health clinicians. Although diagnosing the autism brought new light to her problems, and may help understand why she was so difficult to treat, it was no immediate solution to her chronic mental health problems. Reversing her mental health and social trajectory is a slow complex process.*

*For the last 25 years, all schools have been challenged to look for and recognise the prevalence of autism mainly in boys and provide for their needs. The depth and complexity of the problems of girls with autism is a new frontier, needing awareness, advocacy and intervention for their autism and their comorbid issues. This book increases one's awareness which is the first step to earlier recognition, but needs progress towards establishing intervention and tackling the weight and complexity of their co-morbid problems. Do we have that leadership and skills to recognise these needs and make a difference in Australia?*

Further information:

Tony Attwood on **Autism in Females** lighthearted podcast  
<https://vimeo.com/122940958>





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

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