

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

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

Description and purpose

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

On our Website:

www.schoollink.chw.edu.au

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

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

Editorial

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What a year! It has been extremely difficult and yet somehow inspirational. We have watched while borders and countries shut down, while disease has ravaged the world. We have also been inspired by the courage and resilience of people to get back up, learn a new way of living and working together for the sake of the world and the health of our own communities. The challenges have been immense, more so in the world of health and mental health. We encourage you all to take time for yourself and your families, acknowledge the years challenges and plan for a brighter future. As the year winds up, check in with each other. If you find no one around when you need it, find strength in your own self and please make use of the services available on the phone numbers below; always reach out when you need it.

Lifeline: Call 131114 or Lifeline Text: 0477 13 11 14
Kids Helpline: 1800 551 800

Headspace: 1300 737 616
Reachout: Reachout.com.au
Parent line: 1300 1300 52

In this edition there is a strong focus on self-injurious behaviour as we have found a need amongst professionals to understand **more about why it occurs**. Dr Dossetor's article gives insight into many cases that have resounding messages in practice. It really is a useful guide to understanding the variety of self-injurious behaviours and what to do. Dr Vinita Bansal gives us some background information about a medication that can potentially be used in treating self-injurious behaviour.

Other articles in this edition include *Transforming the Mental Health and Disability Interface for Children and Young People with Complex Needs through Interdisciplinary Education*, a book review of: *Exploring Giftedness and Autism, a study of differentiated educational program for autistic savants* and the *Medicine Cabinet* written by Judy Longworth.

Have a safe and happy holiday season and we look forward to hearing from you in 2021. Enjoy reading this edition of the journal and please send any feedback or your own contributions to schoollink@chw.edu.au

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Self-Injurious Behaviour: Challenging the cycle of distress! Multi-disciplinary, multi-modal models of examining behaviour.

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Self-injurious behaviour (SIB) is defined as a severe, recurrent and chronic form of aberrant behaviour that poses serious risks to people with intellectual disability **and produces injuries to an individual's body** (Matson et al, 2008). It is a different problem to self-harm or suicidal intent which is commonly seen in neurotypical teenagers and young adults. SIB is much more common in young people with autism (50%) compared with those with intellectual disability alone (12%).

The most common forms are head banging or face punching, self-biting or pinching, self-scratching, or pulling out hair. It can last for a few seconds, be episodic or go on for hours. It is problematic to family members, carers, teachers and professionals because of the psychosocial stress it causes (Oliver et al, 2017). Parents are most likely to be stressed as evidenced by them being more likely to rate the SIB as severe (19% versus 5% for other carers and professionals). When the level of behavioural disturbance is recognised to be so severe it can also impact on home/social/institutional placement. However, in the most serious cases, it can result in permanent tissue damage, bone fractures e.g. to the skull with brain damage, enucleation of the eye, dismemberment and

even death.

SIB is associated with severe and profound intellectual disability and communication deficits. Within this population it is also associated with overactivity, impulsivity, stereotypic and repetitive behaviour (Lavery et al, 2020). These symptoms of overactivity and impulsivity may be indicative of deficits in behavioural inhibition as a causal mechanism. They are also features of ADHD. These features are also predictive of self-restraint, such as restricting an individual's movement with clothing, objects or their own body.

The longest epidemiological study (Lavery et al, 2020) showed in a sample of 67 that 44% had persisting SIB 10 years later. This study showed that persistence was associated with overactivity and impulsivity but also stereotypic behaviour and repetitive behaviours and decline in the latter behaviours predict a decline in SIB. Severity of autism, co-morbid low moods, anxiety and behaviour disturbance are also associated with persistence. SIB is also associated with significant costs in care and intervention. SIB over the age of 20 is particularly prone to persistence and the authors suggest that early intervention and persistent interven-



“It is also associated with overactivity, impulsivity, stereotypic and repetitive behaviour...”

tion in childhood and adolescence may be important to prevent problems persisting in adulthood. SIB is associated with some recognised genetic disorders, and also with medical problems particularly causing pain. There is a consistent finding of considerable paucity of access to services. It has been suggested that a lack of access to multidisciplinary multiagency services is a contributor to persistence. Overactivity and impulsivity are the biggest secondary risk factors and perhaps those with these risk factors should have intervention even before the onset of SIB.

Matson and colleagues’ study (2008) showed that SIB in those with intellectual disability was associated with challenging behaviours of aggression, property destruction, sexually inappropriate behaviours, and stereotypes when compared with a control group without SIB. In fact, the level of behaviour disturbance on an Aberrant Behaviour Checklist predicted the SIB group in 73%!

Genetic conditions: often account for the most serious/dangerous cases. Huisman and colleagues (2017) specify 12 genetic conditions with different patterns of SIB. Amongst the more distressing images are people with Lesch Nyhan Syndrome who may chew their lips or cheeks severely (Oliver et al, 2017). Those with Smith Magenis may stick objects up orifices e.g. ear or anal. They also may pull whole nails off and head bang. Fragile X tend to head bang. Those with Prader Willi are prone to skin picking and have also been shown to have a special vulnerability of **challenging behaviour due to rigidity to ‘cognitive shift change’**, i.e. if asked to do something unexpected they can get angry or self-injurious. These differences in presentation indicate there are evidently complex genetic factors to even different types of self-injury.

Those with Cornelia de Lange’s Syndrome are prone to SIB but systematic research has identified that many have self-injurious behaviour secondary to painful medical problems, specifically gastro-oesophageal reflux, sinus and ear problems, dental problems, not to mention constipation and gastric ulceration (Moss et al, 2017). **Moss’s team found that medical intervention**, such as antacids for reflux, reduced the SIB. This illustrates that such medical causes of SIB behaviour,

particularly of non-observable causes of pain, need to be considered in all cases. Health services need to provide facilities for coordinating multidisciplinary assessment under anaesthetic for holistic care of the patient.

Whereas Applied Behaviour Analysis has more reports of intervention, they are mainly single case studies, and are therefore the recommended first-line intervention but often lack long term data of outcome. A functional analysis, over different conditions and locations is indicated to identify if there is a consistent meaning to the SIB, but frequently this is not the case. Further there has been a lack of widespread implementation, which, particularly in families, can have problems of translation. As one might expect from the above review there is an evident failure of benefit because any single approach is likely to fail across a case series, as multiple causes and mechanisms are likely to be at stake in different cases. It is recognised that family factors have only a minor causal contribution to the emotional and behavioural disturbance and parents should not feel blamed for these problems (Fitzgerald, 2020). However, I would suggest that high quality and persistent behavioural parenting skills can alter the behavioural trajectory of a case and this is best started in early life. For me, this is illustrated by the change in presentations of children with Smith Magenis Syndrome with earlier diagnosis and the support of the **parents’ organisation. 20 years ago, the cases of Smith Magenis Syndrome I met were amongst the most catastrophic and such cases don’t seem to come my way anymore.** The account by Yasmin Eris (2011) illustrates how the biological trajectory was altered by persistent, calm behavioural modification.

The association of SIB with such a range of factors indicates there is no single mechanism, but SIB needs to be seen within a holistic approach to understanding the presenting symptom, any possible functional role, associated emotional and behavioural disturbance and psychiatric disorder, as well medical or pain-causing disorder. Some of the developmentally related issues include understanding in terms of the **individual’s sensory issues, such as overload or under stimulation**, their capacity for moderating arousal levels, their communication capacity, their self-worth and self-esteem, (including hate of self or another), and the quality of their relationships. In autism, emotional and behavioural disturbance is specifically related to a lack of awareness of emotions in self or others, such they are expressed in extremes of explosive emotionality. Where feasible, specific intervention of building emotional recognition skills leads to better self-control (Personal communication, M Wong). However, for those who are severely delayed in intellect, communi-

“Each case needs to be considered as an individual in an environmental and social context ...”

tion and autism, there are limited recognised interventions. The norm would be to expect a complex combination of these factors contributing to SIB.

Accordingly, it seems evident that any single approach to treating SIB or challenging behaviour in the context of Autism or intellectual disability is likely to be an excessive simplification of a complex human predicament. Each case needs to be considered as an individual in an environmental and social context with developmental, medical, temperamental, genetic, communicative, relationship, cultural, neuropsychological, neuropsychiatric models of examination and understanding. Further, causal mechanisms may not be the same as those available and helpful in treatment. Frequently, multidisciplinary and multimodal approaches are needed. Disability Services need a triaging structure bringing more multidisciplinary skills and resources, as many cases are resistant to treatment, as was provided by state disability services previously (Dossetor, 2011).

While it is regularly a sign of distress, such as due to discomfort or pain due to a medical problem, a large proportion have persisting and even chronic SIB, which indicates that they are basically resistant to treatment. While a functional analysis can be viewed as an initial investigation assessing the communicative intent of self-injury, often there is no evident communicative intent or interpretation, or a changing or multiple communication. Andrew Frakes (Personal Communication) from Giant Steps Autism School developed a questionnaire to provide a functional analysis, whereby their specialist skilled teachers could evaluate the communicative intent of SIB without protracted assessments taking weeks. Most common intents suggested are:

- to get attention,
- to avoid a task,
- to avoid social engagement/pressure
- environmental factors such as sensory or
- lack of control over their environment and its changes.

The emotional communication is often important to

understand, not just the cognitive function or intent, to attempt to modify this cycle of distress. An excess of parental/carer emergency emotions is likely to contribute to a sense of emotional insecurity for the young person hence parental/carer emotional response can be a source of maintaining dysfunctional behaviour.

Serious persisting cases need a full medical work up and a multidisciplinary psychiatric team are frequently required, without which family breakdown, in all its forms are at risk, which in turn often causes exacerbation of the SIB. Huisman and colleagues (2017) go so far to recommend that an interdisciplinary approach should be considered *mandatory*.

A few anonymised cases from my experience are presented in brief to illustrate some of the principals outlined above. Successful outcomes are a good evidence base on which to demonstrate causal processes and illustrate the wide diversity of causal mechanisms. Sequential clinical hypotheses can be tested, and the process is repeated until a solution is found.

Case 1. A 10-year-old non-verbal autistic, moderately intellectually disabled boy presented with recurrent head banging and pinching of thighs and arms so they were red and acutely bruised. He was referred by his paediatrician after he had failed to respond to SSRIs and Risperidone. He had been treated with fluoxetine as his parents felt he was unhappy and stereotypic,



suggestive of depression. He was treated with Risperidone as it is a third line treatment of ADHD, that also improves irritability in autism.

Family assessment revealed that at the time of onset of the SIB, that family had been faced with his mother's diagnosis with late stage carcinoma. This presentation was too late for a surgical treatment, and the first chemotherapeutic approach failed to work. However, 13 rounds of a second chemotherapy approach, with significant toxic side effects, halted the disease and gave the family some hope of her survival. However further family assessment revealed that both parents were severely depressed. Treatment of both parents with anti-depressants led to improvement, not just in their well-being and suffering but also improved their son's SIB by 80%.

Message: The importance of parental emergency emotional communication. Depression is a cause of SIB, but treating parental depression demonstrated that their emotional state and communication was sufficient to cause persistent SIB in their disabled son. This improvement occurred despite the family continuing to fight his mother's cancer, albeit with greater optimism. Young people often suffer from witnessing their parental distress. This scenario has been a not uncommon presentation in my practice.

Case 2 was a 12-year-old non-verbal autistic moderately intellectually disabled boy who presented with significant SIB. He had been seen 3 years previously when he was felt to be depressed and responded to SSRIs. He was re-referred by his paediatrician with a recurrence of his problem which had already been resistant to behavioural interventions for 4 months. He would stay in his bedroom self-injuring and groaning unhappily. This time he failed to respond to antidepressant treatment, although he still seemed depressed.

He was also agitated and had features of ADHD, for which he was treated with clonidine, and amitriptyline and then risperidone. He had had failed treatments with stimulants with unacceptable side effects in the past. Still, considering the presence of depression, the mood stabiliser, valproate was tried. During this time multidisciplinary multi-agency review was re-activated. He was attending a specialist autism school whose expertise in all manner of behavioural and sensory intervention had failed and he had been placed on short days attendance because of the severity of his behaviours. A re-examination of sensory processing profile did not help.

Both parents were very caring and committed, and the family lived in a small high-rise apartment. We at-

tempted to institute behaviour activation therapy, a recognised depression treatment for people with an intellectual disability, getting his parents to persist in getting him up and taking him out, but this was without benefit.

Although no one felt he was sick or in pain, he was admitted after a few months of failed treatment for an extensive medical review with an examination under anaesthetic including brain scan, sinus x-rays, gastroscopy, dental review, general examination and wide-ranging blood tests. This revealed no indication of an underlying medical problem that might be causing pain.

Early in the course of a year-long clinical contact, with reviews each month, recommendations were regularly made to suggest that the parents should trial protective head gear, but this recommendation was not heeded. Over the year of treatment and in the absence of progress, there was increasing frustration from different stakeholders raising the pressure to find a solution. This led the clinician to become more and more insistent on trialling various forms of helmets, with discussions ranging from a rugby scrum helmet, to bicycle helmet to cricket helmet, with or without plastic visor to prevent head and facial injury from the SIB. In the meantime, there was a small degree of improvement with high doses of olanzapine, as a treatment for agitation, low mood, anxiety ADHD and stereotypies.

Following the Christmas break the family returned with C2 wearing a bike helmet, reporting that he was so much better that they were ready to reduce all his major tranquillisers. He would sleep without a helmet, but start hitting himself each morning, until his bicycle helmet was fitted. He did not strive or struggle to take it off.

Why the SIB had returned in this last year and more severely than previously? In retrospect his parents felt this was due to C2 entering puberty and the associated intensification of his predispositions due to adolescent hormones.

Message: Always consider the role of protection as a treatment. Treatment of SIB requires multimodal approaches, and efforts to prevent injury are one such empirical and sometimes the critical treatment. There is undue philosophical blindness to this important modality of treatment, which should regularly be examined and tested empirically.

Case 3. A 14-year-old with autism level 3, severe intellectual disability and low adaptive functioning was so aggressive and violent to himself that he could not be

brought out of his home to see any doctor or hospital. Both siblings also had ASD and mother suffered anxiety disorder. They had moved because of domestic violence but the moves made C3 worse. A generous member of the treating team agreed to do a home visit. C3 was initially treated for depressive disorder and increased anxiety due to change in routines leading to increased self-injurious behaviour. He was started on Mirtazapine, and had his major tranquillisers transferred from Risperidone to Quetiapine with the introduction of Aripiprazole, partly because of weight concerns on his Risperidone. His mother remained worried about constipation that needed an enema but was also worried about him not breathing through his nose. Accordingly, as he was more settled, a day admission was arranged for examination under anaesthetic, including a CT head scan, dental examination, ophthalmology examination, blood tests and general examination. The ENT registrar questioned the need for a routine ENT examination, but this revealed a mycetoma, i.e. a large submucous membrane infected swelling, that needed surgical removal. He subsequently settled down and was able to resume school.

Message: The importance of specialist multidisciplinary medical examination under general anaesthetic. Any SIB that fails to respond to first approaches needs a full multidisciplinary medical examination and investigation which requires a general anaesthetic. GPs so often do an amazing job scanning for intermittent medical problems without specialist medical back up, but they need active support of specialist hospital services.

Another case with a similar presentation after a complaint to the minister was admitted. He was also on omeprazole, a proton pump inhibitor (PPI) for helicobacter pylori. His mother was still concerned he had **gastric pain, but the gastroenterologist didn't think a** further endoscopy was indicated. Fortunately, a second opinion from another gastroenterologist showed that the ulcers were resistant to omeprazole and did much better when changed to a different PPI, esomeprazole.

Yet another case was diagnosed with bipolar disorder because she could go 10 days without sleep in state of continued agitation. Having tried a number of medications, she improved on lithium carbonate, with olanzapine. However, following a delay of access to a gastroenterologist she was also found to have a gastric ulcer caused by helicobacter pylori and may well have been suffering pain especially at night. Patients with pica, or recurrently putting their (dirty) hands in their mouth, are at high risk of helicobacter pylori, and if a gastro-enterology opinion is not forthcoming but

gastric symptoms may be causing pain, it is sometimes necessary to treat on presumption of helicobacter infection with the triple therapy antibiotic treatment and PPIs.

Case 4. A 14-year-old girl with Cornelia de Lange Syndrome had had distressingly severe, persistent and repetitive self-injurious behaviour for 10 years. She had the difficult temperamental features of Cornelia de Lange Syndrome, including being non-verbal, autistic, hyperactive, impulsive, and repetitive in her behaviours. Her behaviour had led to breakdown of family and substitute family care and she was institutionalised. Numerous and persistent efforts by all disciplines had failed to achieve improvements over a number of years. She was assessed for her sensory needs and found to enjoy tactile experience. Regular massage sessions were instigated 2-3 times a day for 30 minutes as a treatment. The use of massage oil and talcum powder became a source of engagement with the nurse and developed into a playful to and fro game. Over a few months the intensity of her self-injury declined and she became happier (Dossetor et al, 1991).

Message: Sensory experience is important; look for creative ideas in treatment. There is a professional consensus on the importance of sensory processing in those with autism and or severe intellectual disability and consideration as for potential therapeutic intervention. Although there is a lack of empirical evidence of the therapeutic benefits of sensory intervention, it is frequently found to contribute to wellbeing and improved behaviour in case reports such as this.

Case 5 was a girl with profound intellectual disability with a rare genetic disorder (Pyruvate Dehydrogenase Deficiency), micro-cephaly, a seizure disorder with blood curdling screaming of a stereotypic and repetitive nature. The severity of this screaming is difficult to comprehend unless you live with it. All siblings had left home and, although her parents were skilled articulate and committed after years of trialling treatments, including multiple psychotropics, they were at the end of their tether. As this screaming was so painful to others, I postulated that it may constitute a form of SIB, and therefore trialled her on Naltrexone (50mg 8am and 2pm). This medication made a dramatic difference to the screeching for the next 5 years, until she was transitioned to adult services.

Message: The Endorphin theory of SIB: There is an interesting literature on the value of Naltrexone, on the theory that SIB gives an endorphin high, which is compulsive, which is blocked by Naltrexone (Bansal, 2020). In my experience, it is significantly helpful in 30-50% of cases in which I trial it, as a third line pharmacological

“Often SIB is part of a wider picture of severe disturbance, especially in ASD....”



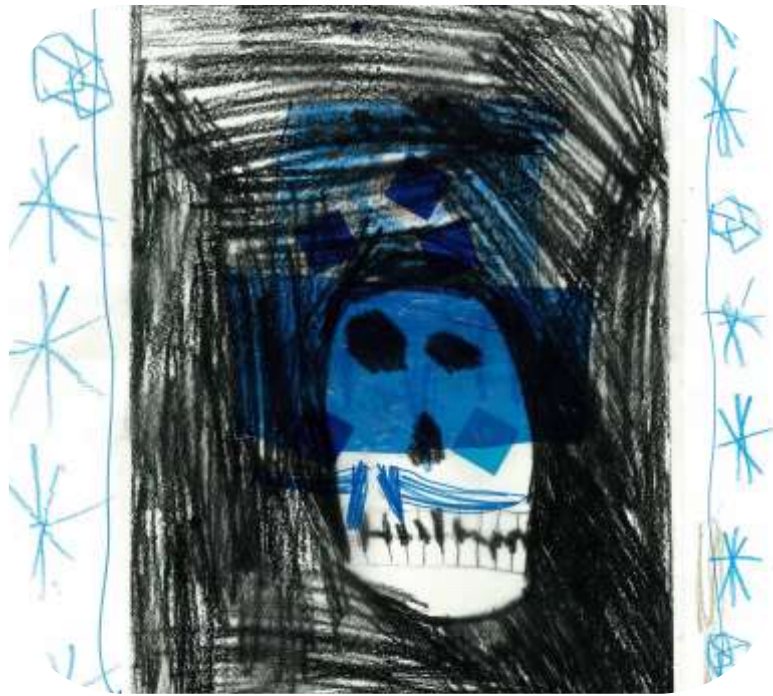
treatment for SIB.

Case 6 was 9 at presentation with severe intellectual disability, autism, hyperactivity, and later was thought to have significant anxiety and depression. His presenting problems were aggression, destructiveness and head banging. He presented to the consultation **‘howling with agitation and needed to be sedated with clonidine to continue the interview.** He lacked all concentration and would climb the fence and run away. He also had breath holding attacks and on occasion this led to fits. He also had a twin with the identical developmental problems who was more anxious than **his hyperactive brother (who didn’t cope without 0.5mg of risperidone a day).** They had a dedicated and proficient mother but were estranged from their father who subsequent to separation developed mental health problems. C6 was treated with a range of medications and behavioural approaches. The medications focused on ADHD, anxiety, depression and SIB and included: clonidine, stimulants, amitriptyline, risperidone, quetiapine, propranolol, fluoxetine. With a focus on treating a mood disorder in the context of a possi-

ble family history of bipolar disorder he was trialled on valproate to supplement the fluoxetine. We subsequently established that the valproate was the critical medication to alleviate both aggression and SIB. He continues to do well on risperidone and valproate 300mg bd. His breath holding has also ceased but he has now had a few epileptic fits independent of breath holding being reviewed by a neurologist.

Message: Always consider a differential diagnosis of co-morbid psychiatric disorder and persist with treatment trials for them. C6 illustrates how often SIB is part of a wider picture of severe disturbance, especially in ASD. It illustrates the need for successive treatment testing for different components of the presenting picture. Perseverance in treatment (he was re-referred after a 2-year break) was one key and resulted after 5 years in a good outcome. Was this a former fruste Bipolar Disorder, or did the mood stabilising qualities of valproate have a special effect on him?

Case 7. 7-year-old with autism level 3, moderate to severe intellectual disability, presented with hyperactivity, excitability, tantrums, defiance, lashing out, risk taking, running away and self-injury. His motor and independence skills were 3-4 years developmental age, whereas his language and social development were 18-24 months developmental age equivalent. His parents had shown unusual resolve in exploring wide range of alternative treatments including extensive ABA, and other behavioural interventions, oxytocin, treatment for immunological problems and stem cell treatment overseas. His mental health co-morbid diagnoses included Anxiety Disorder, ADHD, Tourettes, and Motor Dyspraxia. Trials of many psychotropics over a number of years were not felt to be consistently helpful but side effects were commonly reported. Yet he had a number of presentations to the emergency department and even a long supportive admission under neurology. He was taking a mixture of clobazam, fluvoxamine, clonidine, cannabinoids and quetiapine with mild improvement. In the context of a failure of progress, his SIB was reformulated as a reflection of attachment behaviours: his head banging left his parents feeling helpless and depressed and brought out



feelings of blame with conflict over differing parenting approaches, shame at not having helped him more, and guilt e.g. from post-natal depression, and this was associated with an attachment which was insecure in style. Mother was interested to learn more about childhood attachment and difficulties with the aid of the Circle of Security Framework of counselling. This led his behaviour to be understood as a communication to be reflected on rather than respond with more parenting behaviour. This led mother to feel calmer and better able to set limits. She was able to emphasise moments of closeness and slowly was able to help him to move from a sense of danger to one of greater security. He was able to tolerate wearing a helmet, and his parents were better able to tolerate their inability to stop his headbanging but calmly give him chillout time until he settled. His behaviour improved and he was able to be positively settled in school.

Message: Attachment and Relationships still matter in Autism. Although the literature on attachment styles in autism is not clear; it is clear that autistic behaviour is significantly traumatising to family relationships and parenting skills (Mukhejee et al, 2019; Fitzgerald, 2020). The deficits of emotional recognition and reciprocity skills makes attachment more difficult for a child with autism and also with intellectual disability. These autistic qualities mean that attachment behaviour is developmentally related, and like that of a much younger child, rather than chronologically aged related. Successful treatment of the severe problems of autism often also includes repair of the family **attachment and relationships, as it is this 'belonging'** that is critical to the emotional survival of the young person with autism and their family. Awareness of attachment is important and sometimes can be therapeutic, but not used as a basis of blame for the behav-

iours.

Another case of a 4-year-old presented with autism, severe intellectual disability, ADHD, severe tantrums and self-injury. He had also suffered multiple additional adversities: prematurity, a difficult temperament, gastro-oesophageal reflux, feeding problems, hydrocephaly of unknown origin that needed surgery, and recurrent otitis media with deafness and needing recurrent grommets. His ADHD was treated with clonidine, amitriptyline and a small dose of risperidone. The key intervention was providing his mother with insight as to why he had become so vulnerable, sensitive, attention seeking and reactive in his temperament, secondary to these adversities and supporting her calm engagement and limit setting. This skilled and now confident parenting cured his SIB and steadily improved his emotion and behavioural disturbance and development over a 9 month period. This illustrates the competition between adversity and biology versus confident skilled parenting.

Case 8 presented at 6 years with severe intellectual disability, autism, ADHD, anxiety, aggression and SIB **since the age of 5 years when 'he became an aggressive monster'. I saw him over a 6-year period** whereby he needed several psychotropics including major tranquillisers, his mother recovered from anxiety and depression and became determined and effective in behavioural management. He required a specialised helmet, including a visor (which needed regular replacement from damage), particularly after he had severely smashed his face on a concrete corner at school. He had a specifically built sensory room, supported by an OT, in which he could self sooth and provide safety from his violence. He required specialist behavioural support to be maintained in school. One challenge was **supporting his mother's challenges to maintain adequate funding from the NDIS for the therapeutic services, as well as for in home support/respite and his sensory room and protective equipment.** When all these components were in place, the level of his SIB was reduced by 50% and containable in his home and his school.

Message: Interdisciplinary multiagency multimodal intervention support may be all that can be done. One **couldn't say this long hard road was a success story,** but his mother is so committed to him and, with this level of support, he maintains family and school placement and such high-level support is still so appreciated by such special families.

These cases illustrate some similarities of developmental context but differences in the cause of SIB as indicated by successful management. SIB is a key and frequent problem in autism and related neurodevelop-

mental difficulties. Fundamentally, a developmental understanding of autism means the young person with autism is not able to understand our thinking, feelings and motives, but as adults, armed with this framework and knowing the individual with autism we are able to have some inkling of what it is like to be that autistic child. They are not different from us but delayed in their emotional and social development. Behavioural intervention is a sophisticated form of non-verbal communication, not a specific treatment. Although it is in many ways intuitive, it can be enhanced by expertise.

However, we also need to take account of other models of understanding, which can include motor and sensory processes, alternative and augmented communication, emotional understanding and theory of mind, temperamental and neuropsychiatric qualities, as well as their interactions with the environment and relationships.

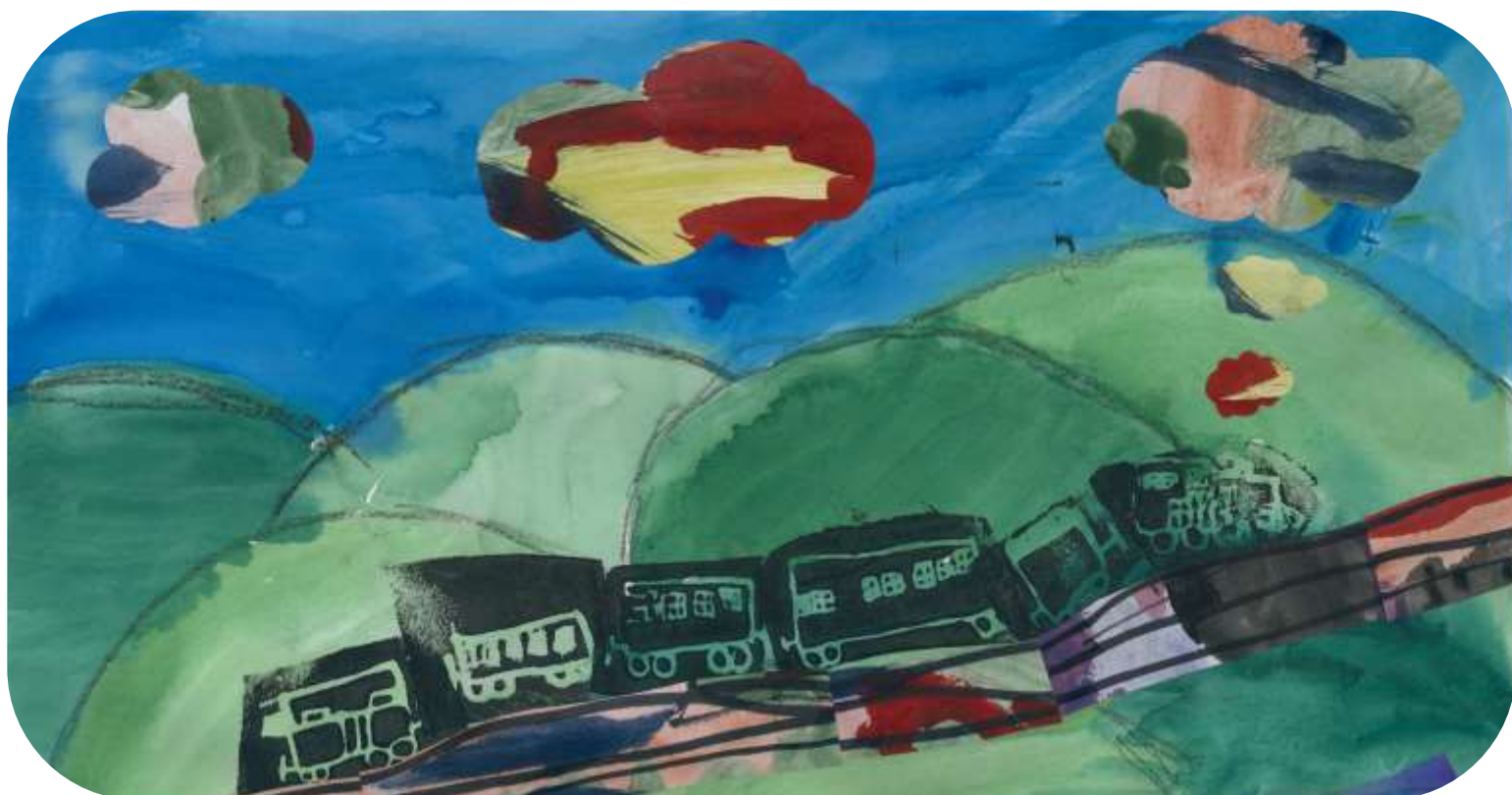
History and learning are also impactful. Yet multidisciplinary, multimodal child psychiatry intervention can make a large difference to the level of disability that arises from the emotional and behavioural difficulties. Early intervention remains important, as well as psychosocial context. These case scenarios are a shorthand of how much concern and effort goes into helping such complex cases that are so resistant to treatment. However, they also testify that the whole range of modern child neurodevelopmental psychiatry skills can make a difference. We are necessarily talking about a small, minority population with huge problems of developmental and emotional and behavioural impairments, where much scientific funding and exami-

“These case scenarios are a shorthand of how much concern and effort goes into helping such complex cases ...”

nation is still in its infancy, but those with clinical experience share important skills and expertise (Dossetor et al, 2011). Successful treatment therefore requires different disciplines and skills from different agencies to have mutual respect and collaborate and work together from the same framework, supported by funding, and infrastructure to enable such tertiary services

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Reading List

Working in collaboration with high school teachers to better understand how to support the social emotional needs of autistic adolescents.

The Westmead Feelings Program is the first emotion focused evidence-based program designed for autistic children (both with and without an intellectual disability). The program aims to develop the emotional competence skills of the child, as well as the confidence and skills of parents and teachers who will be the main emotion coaches beyond the therapy room. The current Westmead Feelings Program has been demonstrated to be successful in both a clinical and a school-based setting for children, however high school settings can often present a range of different barriers which require additional consideration. Furthermore, while mental health concerns continue to rise in adolescents on the autism spectrum with co-occurring ID, there are no evidence-based interventions designed for this population.

In 2017 Anita Gardner was employed to work on an adolescent adaptation of the Westmead Feelings Program, one that is designed to meet the social-emotional needs of autistic adolescents with a mild ID. Conducting a literature review, it became evident that there was a dearth of research that aimed to understand the social emotional learning needs of autistic adolescents from the perspective of **high school teachers. As context is crucial in a program's success, the team conducted its own research to explore the high school teacher perspective.**

This year, the results of that study were published in the Australasian Journal of Special and Inclusive Education (Gardner, Wong & Ratcliffe, 2020). In the focus group, lead by Jodie Caruana and Kim Eisler and held at Kids Research, 8 experienced teachers from mainstream and special needs settings shared with us their experience and thoughts on some of the social emotional needs and barriers faced by autistic adolescents in their school setting. A thematic analysis identified 3 themes: (a) Social emotional learning needs of students on the autism spectrum, (b) teaching social emotional learning in high school settings, and (c) gaps in social emotional learning. The study also revealed suggestions for how a program such as the Westmead Feelings Program could be developed so that it best meets the needs of the teachers who might be implementing it. Outcomes from this study provided important insights into our understanding of the development of emotional competence in adolescents on the autism spectrum in special education and have practical implications for intervention models.

Gardner, A., Wong, M., & Ratcliffe, B. (2020) Social-Emotional Learning for Adolescents on the Autism Spectrum: High School Teachers' Perspectives. *Australasian Journal of Special and Inclusive Education*, p1-16. doi: <https://doi.org/10.1017/jsi.2020.13>

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Respite Care, Short Term Accommodation and the NDIS <https://planpartners.com.au/ndis-respite-care-sta>

Supporting yourself- Carers <https://headtohealth.gov.au/supporting-yourself/support-for/carers>

Learning with Lili

Margaret Meaker
STaR CEO

I stepped into the world of disability services 30 years ago having studied Social Welfare at TAFE. I had no idea what an influence working for a small non-government organisation would have on my professional and personal life. I learnt to never make **assumptions about what people can and can't do**, the importance of a positive image, both physically and socially, and how powerful language and terminology can be. I was in a role supporting adults with intellectual disabilities to move into the community and support them to become active participants and access services they needed. Unfortunately, they were categorised by a label or diagnosis that had been placed on them, often incorrectly, and I witnessed the enormous consequences of this. I also experienced the power and control that services and/or organisations have over people they are meant to support. At times, practices were questionable and I left after seven years, disillusioned and vowing never to work in disability services again.

My daughter, Lilian, was born a healthy baby in 1998. At 8 weeks Lili contracted bacterial meningitis. She deteriorated quickly, and soon after being admitted to **Westmead Children's Hospital Paediatric Intensive Care Unit** was placed on life support. It was a traumatic experience that will never leave me; I was broken in **mind, body and spirit. Yet Lili's determination to live** led to her unexpected survival. We were told that that **Lili would be "profoundly disabled physically and intellectually", as she had sustained significant brain damage.** Little can be compared, in scale or scope, to that life-changing moment when we received that prognosis and became the parents of a child with a disability.

I left the hospital with an 11-week-old baby, a strong belief in the human spirit and the name and number of a physiotherapist to contact. It was at that point that I became a service recipient, NOT a provider.

This unknown path was stressful financially and emotionally. The merry-go-round of therapy and medical services, trying to find affordable services that would **best meet Lili's needs and recognise her abilities** was exhausting. The focus was often what was wrong with her, and there was no time to celebrate the small achievements as we moved onto the next problem. The advice and information was often conflicting and



at times I simply didn't know what to do.

Lili smiled her way through intensive therapies that helped her to crawl at 17 months, walk at 2 years and develop her fine motor skills. It was all-consuming; **everything I did became a form of therapy. Lili's ability** to communicate was significantly delayed, and stepping outside her familiar environment was very traumatic. I was fortunate to have a then DADHC (Department of Ageing, Disability and Home Care) caseworker who worked closely with my therapists. She gently encouraged me to accept respite as my second daughter, Ella, arrived. At first I resisted help because it felt like I was admitting failure, not coping. I thought I should cope because I had a professional background in disability. Finally, I accepted in-home respite, and from then I have never looked back!

Suffering "therapy fatigue" and wondering whether that was the only answer, I sought early education op-

"I found myself on this merry-go-round of therapy and medical services..."

tions. I had resisted having Lili formally assessed, feeling strongly that a formal label would only serve to segregate her and place limitations on her, but I went ahead when I learnt we needed it to get her into preschool and attract funding. It was a difficult and confronting day. Lili was diagnosed with a mild-moderate global developmental delay. I felt she had been placed in a box.

My search for a suitable preschool for Lili was extensive - I went to six in my local area. I was desperately searching for acceptance, skill and resources. A sense of urgency consumed me. I was told by my caseworker that people from Macquarie University Special Education Centre (MUSEC) were establishing a program for children with disabilities at a Meadowbank childcare centre. I look back on that referral as life changing.

Lili was enrolled in the STaR (Special Teaching and Research) Associations Childcare Placement and support program. STaR assists families of children with disabilities to find placement in regular early childhood services where their special educators coach and mentor the childcare educators to ensure these children are learning and included. She had a 3 wonderful years with STaR and together, with other STaR families, I worked to fundraise to ensure the program continued. I knew my child was being stimulated and meaningfully included, not just minded. Lili began to lose her fear of the unknown and decreased her dependence on me. Her language skills developed dramatically. **Discovering special education so early in Lili's life** changed my thinking from trying to fix Lili, to teaching her.

Unfortunately, at that time Lili began to have seizures. We were forced back onto the medical treadmill as we tried to manage a diagnosis of uncontrolled epilepsy. Over the next 12 years we experienced some very traumatic seizures, and Lili fought for her life again, several times.

Transitioning from the early year's sector to school was somewhat terrifying but could not be avoided. We needed another formal assessment for the school application. This time Lili was assessed as having severe global developmental delay. I was devastated as at that time I knew a mainstream school was no longer an option.

There is so much anxiety associated with starting school. Although I took comfort knowing Lili would be understood in the non-government special school that had accepted her, I still felt she was vulnerable because of her uncontrolled epilepsy. After 18 months, I received a call from the principal asking me to find **another school, as they simply couldn't cater for her** needs. I was shocked and began to wonder if there was a place for her. We moved her to a special school with a very holistic approach to education. Changing schools is not always a bad thing and Lili was embraced for all she could do and contribute. School was a place where Lili was at her happiest as she was surrounded by her peers and people that understood her and recognised her potential.

Things started to fall apart in year 10 as hormones and mental health reared their ugly head. We barely managed to cope as a family despite being surrounded by an amazing network of school, medical, family and community supports. Recognising that we could





no longer provide Lili with the care she needed, we made our hardest decision ever, to move Lili into supported living.

Good things seem to always happen when you hit your lowest, and for us, that was meeting Barbara Lewis, Manager of the Carers Support Unit Northern Sydney LHD and her promise to help has remained steadfast. Together, with Barbara and another family in the same situation we were unrelenting in our pursuit to secure a home for our daughters. We have established a home where Lili and her house mates (both school friends) live a good life. It is a place where they are safe and comfortable, where they know they belong and where they are treated with kindness and respect. This is achieved through strong relationships between the housemates, their families, the team of amazing staff and our provider under a family governance model.

Initially funded by ADHC (Ageing, Disability and Home Care) we transitioned to NDIS funding as Lili left school in 2016. Like most parents, I have found navigating this new funding system somewhat confusing and challenging. Despite this I am so grateful as this scheme, fought for and engineered by some extraordinary advocates for all Australians living with disability, means my daughter is living a good life. I used to beg

for services for Lili and suddenly we became sought after customers.....we were given choice and control.

Leaving school is something all parents dread. It is alarming that the assumption that learning is ending is commonplace. I am appalled by the lack of quality learning programs in post school settings. Expensive adult minding is not what I seek for my daughter. To date, our post school experience has been a very frustrating one and it alarms me that Lili's learning has diluted. Lifelong learning is a human right and I am proud to work for an organisation that is working to deliver lifelong learning to adults with disability.

As Lili has become older and her difference more obvious, we have learned to accept that we will be noticed wherever we go. There have been many wonderful moments when children, encouraged by their parents, try to communicate with her. There also continues to be times when people stare or laugh or parents pull their children away. I have become very resilient over the years realising that I need to be prepared for these moments and have a selection of interesting and informative responses ready to go, depending on the circumstances!

A network of wonderful people, including professionals, has always surrounded Lili. This remains fundamental and over the years I have become more confident to "flick" the people who are not adding value to Lili's life in both a personal and professional sense. Disability is a family issue and we rely on this network to stay strong and together! Keeping good records of reports and medications etc has always assisted me to ensure the stressful, expensive and time limited medical consults and therapy sessions were efficient, informative and effective. This has enabled me to make good decisions with clarity and confidence.

As Lili's mum I have witnessed the triumph of the human spirit time and time again. It is ironic that Lili has led me back to disability services. As CEO of the STaR Association, I am now comfortable with the dual role of provider and recipient, in fact, they give me balanced insight.

“As Lili's mum I have witnessed the triumph of the human spirit time and time again...”

Lili is a beautiful woman who has touched the lives of so many with her sheer determination to survive and **achieve. She doesn't have a malicious bone in her** body or any desire for material goods, and she accepts all people for who they are regardless of race, age or appearance. Whilst having a child with a disability is not something I would choose for my family, in no way is it a disaster. Lili has lead me to know many extraordinary people and a career that I never imagined. I continue to learn from her.

All views are the authors own.



Counselling and Support

Counselling and support is available to help you and your family through difficult times.

Every family is different, and everyone responds differently to challenges in life. It's a healthy positive action to seek help and talk about things with someone you trust. This can happen informally by talking with other parents and friends, or more formally by speaking with a health professional.

How can I get counselling and support?

You can get free counselling and support to help with depression and anxiety, parenting, financial pressure and relationship stress.

Talk to your Maternal and Child Health nurse or GP to find out what type of support would best suit you. This could include face-to-face counselling, telephone support, joining a group or accessing support online. Your GP can also tell you if you can access support through a Mental Health Care Plan where some of the cost is covered by Medicare.

Parents of children with disability can get counselling support through:

Carer Gateway

Call [1800 422 737](tel:1800422737) or visit the [Carer Gateway website](https://www.carergateway.gov.au)

How else can I get help?

A number of helplines also provide counselling support:

Parentline

Call [132 289](tel:132289) (8am to midnight, 7 days a week)

Maternal and Child Health Line

Call [13 22 29](tel:132229) (24 hours)

Family Relationship Support for Carers

Call [1300 303 346](tel:1300303346) or visit the [Each website](https://www.familyrelationships.gov.au)

Relationships Australia

Call [1300 303 346](tel:1300303346) or visit the [Relationships Australia Victoria website](https://www.relationships.com.au)

Lifeline

24-hour telephone and online counselling.

Call [131 114](tel:131114) or visit the [Lifeline website](https://www.lifeline.org.au)

MensLine Australia

Call [1300 789 978](tel:1300789978) (24 hours) or visit the [Mensline website](https://www.mensline.org.au)

National Debt Helpline

Free financial counselling.

Call [1800 007 007](tel:1800007007) (Mon-Fri) or visit the [National Debt Helpline website](https://www.nationaldebt.org.au)

1800 RESPECT

National Sexual Assault Family Domestic Violence Counselling Service

Call [1800 737 732](tel:1800737732) (24 hours) or visit the [1800 RE-SPECT website](https://www.1800respect.org.au)

This is a excerpt from the Association for Children with a disability website. [Please visit https://www.acd.org.au/counselling-and-support/](https://www.acd.org.au/counselling-and-support/) for more resources.

Transforming the Mental Health and Disability Interface for Children and Young People with Complex Needs Through Interdisciplinary Education

Donna White, David Dossetor, and Lesley Whatson

Introduction

The launch of the *Intellectual Disability Mental Health Core Competency Framework* (Department of Developmental Disability Neuropsychiatry, 2016) for mental health professionals is a reminder of the existing Interdisciplinary Practice Framework of Core Interventions for children and adolescents with intellectual disability and mental health issues (Dossetor, Whatson, & White, 2015; White, Dossetor, & Whatson, 2008; 2010a; 2010b; 2010c). This was developed as part of the Training Curriculum Project that used a phased approach to develop a comprehensive interdisciplinary education program for professionals working in the disability, education and health sectors (White, 2011). The program consisted of a framework of core interventions, an evidence based two-day training seminar, and a published book, *Mental Health of Children and Adolescents with Intellectual and Developmental Disabilities: A Framework for Professional Practice* (Dossetor, White, & Whatson, 2011). Implementation and evaluation of the training seminar resulted in increased knowledge, confidence and collaboration of professionals in meeting the mental health needs of children and adolescents with intellectual disability (Dossetor, Whatson & White, 2016; White, Dossetor, Whatson, & Farah, 2009).

The Training Curriculum Project was established as the result of a long standing partnership between the Statewide Behaviour Intervention Service, Ageing Disability and Home Care (ADHC) and the Department of **Psychological Medicine at The Children's Hospital at Westmead (CHW)**. This partnership has resulted in the integration of positive behaviour support, education, neurodevelopmental perspectives and psychiatric expertise to address the complex needs of young people with intellectual disability and mental health needs through the Developmental Psychiatry Clinic. A review of the clinic and other partnership projects recommended that the Training Curriculum Project educational program be reviewed to determine **enhancement possibilities in the future (O'Brien, Espiner, Arnold, Riches, & Roberts, 2014)**. This paper revisits the Training Curriculum Project outcomes achieved through an interdisciplinary approach to practice, and shares ideas for future directions.

Background

Young people with intellectual disability have an increased risk of developing emotional, behavioural and mental health issues when compared to the general population (Emerson, 2003). Review of the prevalence



research indicated that 30 to 50% of children and adolescents with intellectual disability have diagnosable mental health disorders (Einfeld, Ellis & Emerson, 2011).

Signs of mental health problems in young people with intellectual disability can be difficult to distinguish from behaviours of concern that are the result of developmental, biological, psychological, family and social-ecological factors (White, 2011). It requires people **within the young person's support system to recognise** what signs and changes in behaviours indicate a possible mental health disorder and then seek support (Costello, Bouras, & Davis, 2007). However it can be difficult to ascertain mental illness in a young person, not only due to their cognitive and communicative limitations in conveying their psychological needs, but also due to the lack of adequately skilled specialists to identify and diagnose them.

Research found that only 9% of young people with intellectual disability and significant psychiatric diagnoses accessed specialist services (Einfeld & Tonge, 1996). Literature reviews suggested that lack of expertise and confidence of professionals, compounded by inadequate training and poor interagency collaboration undermined the effectiveness of service delivery to young people with intellectual disability who required mental health care (Torr, 2013; White, 2011).

There was evidence that suggested that interprofessional training programs for staff from mental health, intellectual disability, allied health and education backgrounds, resulted in increased confidence and knowledge when working with people with intellectual disability who have a mental health problem (e.g., Mohr, Phillips, Curran, & Rymill, 2002; Whitehurst, 2008). Unfortunately these studies were small scale and their findings had limited utility due to a lack of methodological rigour (Farah, 2010, as cited in White, 2010).

The aims of the Training Curriculum Project were:

1. To address workforce issues and meet the ever-increasing demand for education and clinical skill development in the dual disability of intellectual disability and mental illness in child and adolescent services.
2. To develop a professional learning and development program for the child and adolescent mental health and intellectual disability workforces within New South Wales.

Method

Development of the interdisciplinary education program

“The Training Curriculum Project aimed to build the capacity of professionals working in child and adolescent mental health and intellectual disability...”



The Training Curriculum Project aimed to build the capacity of professionals working in child and adolescent mental health and intellectual disability. The phased approach to the project enabled the development of a framework of core clinical interventions that was based on a literature review, review of clinical and **training data, expert opinion of “what works”, review of existing resources and curricula** and a clinical forum of experts in the field.

The framework was further refined through a stakeholder survey that obtained a consensus of the most important core interventions to be included (White, Dossetor, & Watson, 2008). These core components were separated into four domains within the practice framework:

1. Understanding the issues and integrating scientific approaches
2. The impact of disability and family well-being

3. Individual emotional and behavioural well-being
 - a. Interventions to promote skill development
 - b. Understanding and managing mental health issues
4. Integration of service systems

Additional analyses of the stakeholder survey data was used to prioritise the topic areas for inclusion in the two-day seminar and decide on the presentation methods (White, Dossetor, & Watson, 2008). This resulted in the inclusion of core topic areas from each of the four domains in the two-day seminar as lecture style presentations and workgroup/ practical activities (see Table 2). The seminar titled, *A Framework for Professional Practice: Seminar for Disability, Health and Education Professionals*, aimed to **increase participants'**,

1. *Knowledge* about the core clinical approaches in the framework;
2. *Confidence* to apply new knowledge in their workplace; and
3. Understanding of the need for *collaboration* with other professionals when working with young people who have intellectual disability and mental health care needs.

Implementation

The target group for the interdisciplinary education program was professionals working in government and non-government agencies from a range of professional backgrounds including health, mental health, education, disability, behaviour support, allied health and management. The goal was to train 400 professionals. Five training events were held over a two year period that included two pilot events in NSW regional areas (TE1 and TE2), two additional events in metropolitan

Sydney (TE3 and TE4) and one event in a NSW regional area to assess sustainability of the educational program (TE5). Each training event included lecture style presentations and work group activities covering 14 core components of the framework (see Table 2). The work groups were engineered prior to the training events to ensure that each group had 7-8 professionals from multiple disciplines, in effect creating interdisciplinary teams in order to encourage active involvement in problem solving, focused discussion and clinical application around case studies.

Preliminary review of the evaluation from the first two pilot training events (reaction data from the feedback surveys for TE1 and TE2) allowed for modifications to be made to seminar presentations for the following two training events (TE3 and TE4). The fifth training event (TE5) involved a mixed media delivery of the seminar, using both face-to-face presenters and pre-recorded videos to explore sustainability options of the educational program.

Table 2: Outline of 2-day training seminars

Evaluation

A quasi-experimental design was used to test both the impact of the training program, and changes in **participants' level of knowledge, confidence and collaboration** in the area of mental health and intellectual disability. Evaluation measures were piloted prior to delivery of the training events and revised by the training team to ensure item validity and to assess logistical issues. Measures were collected for all five training **events based on Kirkpatrick's (1959; as cited in Kirk-**



Title of Presentation	Format
Introduction	
A Framework for Professional Practice: Development of the educational program	Lecture
Section 1: Understanding the issues and integrating scientific approaches	
Aiming for a quality of life: What makes for a 'good enough' life for a child or youth with intellectual disability and their family?	Lecture
A common language for understanding intellectual disability, development, emotions and behaviour	Lecture
Section 2a: The impact of disability and family well-being	
Family adjustment from a cultural perspective	Lecture
Parent stress, parenting competence and family-centred support	Lecture
Section 2b: Maintaining parental and family mental health and well-being	
Formulation and intervention planning	Group work
Challenging behaviour in intellectual disability: A systemic approach	Group work
Section 3a: Individual skill development and emotional/ behavioural well-being	
Communication for life: Strategies for children and adolescents with intellectual disability	Lecture
Developing emotion-based social skills in children with intellectual disability and Autism Spectrum Disorder	Lecture
Building life skills for children and adolescents with intellectual disability: A case-study	Group work
Section 3b: Understanding and managing mental health issues	
Understanding and responding to challenging behaviour: Contributions from attachment theory.	Lecture
Transition: More than an event	Lecture
Risk management during crisis: Promoting safety and resolution	Lecture
Mental illness and intellectual disability: The context, the evidence, the art and the challenge.	Lecture
Section 4: Integration of service systems	
Interagency collaboration	Group work
Conclusion	
A Framework for Professional Practice: Epilogue	Lecture
Questions and discussion	Interactive

Table 2: Outline of 2-day training seminars

patrick, 1996) theoretical model for training evaluation. This model was a goal-based approach that involved four levels of evaluation, i) reaction (level of satisfaction); ii) learning; iii) behaviour (transfer of learning); and, iv) results (impact of training on the organisation). Measures for the first three levels of Kirkpatrick's model were collected in various combinations across the training events (see table 3). The evaluation process was used to measure the key objectives of the training program in the following ways.

Level 1 Reaction

An 11-question feedback survey was used to determine participants' reaction and satisfaction with the training events. The questions were adapted from the evaluation study of Curran, Sargeant, and Hollett (2007) and included eight statements that participants were asked to rate on a 9-point likert rating scale (1 = strongly disagree, 9 = strongly agree) and three open-ended questions. The feedback survey

aimed to measure both utility reactions (judgments on the applicability of training) and affective reactions (satisfaction with training components) of the participants (Alliger, Tannenbaum, Bennett, Traver, & Shortland, 1997). Data in relation to this measure was collected at the end of Day 2 for all five training events.

Level 2 Learning Outcomes

Measures were collected immediately before and after the training seminar. This occurred for the pilot training events (TE1 and TE2) and the last training event only (TE5). Measures included,

1. Knowledge measures: Participants were given 40 true/ false questions that were linked to the training curriculum and were evidence based.
2. Confidence rating scale: Participants were required to rate their level of confidence pre/post training on a 7-point likert scale across 6 topic areas. The confidence intervals ranged from 1 = Not at all confident to 7 = Very confident, for example, "How con-

“Five hundred and twenty-six professionals from multiple disciplines attended the five training events ...”

... confident do you feel in your work in relation to *understanding quality of life issues* for children and adolescents with intellectual disability?”.

3. Collaboration rating scale: Participants were required to rate their attitude to collaboration pre/post training on a 9-point likert scale for 5 statements. Item intervals ranged from 1 = Strongly disagree to 9 = **Strongly agree**, for example, “*I believe that the collaborative process is essential in my professional practice*”.

Level 3 Behaviour

A survey with twelve open-ended questions (adapted from Curran, Sargeant, & Hollett, 2007; Mohr, et al., 2002; Tsiantis, Diareme, Dimitrakaki, Kolaitis, Flios, Christogiorgos & Costello, 2004; Whitehurst, 2008) aimed to measure the transfer and application of learning from training events to the work place for knowledge, confidence and collaboration. The follow-up surveys were sent to all participants from the two pilot training events (TE1 and TE2) three months post-training.

Results

Participants

Five hundred and twenty-six professionals from multiple disciplines attended the five training events (31% more than the target number of 400). Of these, 30 professionals assisted with facilitation of group activities and 496 participated in the collection of demographic information and evaluation measures. Participants provided informed consent through the act of participation (see Table 3).

Table 3: Collection of evaluation measures from training events

	Number of participants	Learning Outcomes completed	Reaction Surveys completed	Behaviour Measures completed
TE1 Regional NSW	88	65 (74%)	67 (76%)	45 (51%)
TE2 Regional NSW	88	65 (74%)	55 (63%)	41 (46%)
TE3 Metro Sydney	151		101 (67%)	
TE4 Metro Sydney	113		83 (73%)	
TE5 Regional NSW	56	35 (62%)	32 (57%)	
	496	165/232 (71%)	338/496 (64%)	86/176 (49%)



Participants were relatively experienced with approximately 70% of participants having 6 to 25+ years of experience working with people with intellectual disability. Participants from a case work or social work background and psychology made up 40% of all professionals who attended, with a reasonable proportion of professionals from allied health, behaviour support, education and management, also attending (see Table 4). The lowest proportion of participants came from nursing, psychiatry and paediatrics. This may be more reflective of the participants' employing agencies rather than interest in this area, as government disability services (ADHC) were the employing agency of 46% of participants, compared to 14% who were employed by health and mental health services. Participants from non-government disability services 21%, education 16%, and other government services 3% were also represented.

Evaluation Measures

Level 1 Reaction

Analyses of responses to the open-ended questions in the feedback survey revealed that participants' reactions to the training were generally positive and that there was a high level of agreement across all five training events (see Table 5). Strong themes affecting participants' immediate reaction to the training program included the seminar structure and content; the performance, style and knowledge of presenters; attitude towards knowledge gain, the opportunity to collaborate with other professionals and agencies, and the importance of inclusion and feeling represented in the interdisciplinary training (White et al, 2009).

A particular strength of the seminar was identified in participants' reactions to content elements, applica-

Table 4: Participants area of work

Area of work	%
Case work/ social work	20
Psychology	20
Speech pathology, occupational therapy, physiotherapy	12
Management	12
Behaviour Support	11
Education	11
Nursing	4.5
Psychiatry	2
Paediatrics	0.5
Other (not specified)	7
	100

tion to the workplace and delivery modes. The group activities in the workshops, where there was application of new knowledge and skills to case studies, were perceived to be effective in terms of facilitating active learning. The group activities also stimulated a positive **response from participants' due to the deliberate orchestration of mixing professionals and agencies for the workshops.** Participants found this approach to be very effective in establishing meaningful collaboration and in recognising the useful contribution of others to achieving a successful outcome. This was also effective in building positive interdisciplinary relationships that extended beyond the training event.

Presenters' style and performance also influenced participants' reaction. Participants valued the knowledge and experience of the different presenters. However, participants reacted more positively to presenters who were passionate and interactive. Further analyses revealed sub-themes and areas for improvement (see Table 6).

Note: 1 = strongly disagree, 5 = neither agree or disagree, 7 = agree, 9 = strongly agree

Level 2 Learning Outcomes

The data from the pre and post learning measures were entered into SPSS (Version 15) for analyses. There were no significant differences between the first two training events, therefore data on these measures were combined and analysed as a single sample. The data from the fifth training event (TE5) was analysed separately. Paired sample t-tests were conducted on measures of knowledge confidence, and collaboration.

For the two pilot training events (TE1 and TE2), data analyses revealed statistically significant increases in **participants' knowledge, confidence, and attitude to collaboration post-training** (White et al, 2009).

Knowledge: There was a statistically significant increase in knowledge from pre training (M = 32.23, SD

	1. Presenter knowledge	2. Teaching methods	3. Met objectives	4. Presenter enthusiasm/responsiveness	5. Met participant objectives	6. Training applicable to practice	7. Enhanced participant knowledge	8. Training influence change at work
TE1	7.84	7.06	6.97	6.95	6.32	6.68	6.92	6.71
TE2	7.95	6.89	6.92	7.05	6.16	6.94	6.74	6.71
TE3	8.07	7.49	7.47	7.57	7.31	7.56	7.58	7.41
TE4	8.28	7.48	7.55	7.6	7.28	7.48	7.52	7.38
TE5	8.19	7.05	7.32	6.85	6.86	7.4	7.53	7.47
Average	8.07	7.19	7.25	7.20	6.79	7.21	7.26	7.14

Table 5 above: Participants ratings of satisfaction with the seminar across training events

Table 6 below: Themes and sub-themes of reaction measures (from the Feedback Survey)

Themes	Sub themes
Training structure	Great variety of topics; lots of information in short amount of time; well organised and structured.
Presentation format	Good mix of delivery modes (lectures, workshops, videos); group activities were a highlight that reinforced learning and sharing of ideas; more interaction and less reliance on PowerPoint presentations
Presentation content	Balance of topics covered; specific topics noted; in-depth; practical examples; case studies; relevant and applicable to workplace; evidence based practice
Presenters	Style; knowledge and experience; passion and enthusiasm
Training resources	Resources and handouts; practical tools to take away
Attitude towards knowledge/ learning	Perceptions that training was a consolidation and expansion of knowledge and skills, refresher/ revision, and entry level
Collaboration	Networking opportunities; multidisciplinary; interagency; holistic approach; need to include education perspective
MH and ID	More on mental health aspects of intellectual disability

= 2.78) to post training (M = 34.23, SD = 2.40), $t(130) = -8.64$, $p < 0.0005$ (two tailed). The 95% confidence interval ranging from -2.39 to -1.50. The eta squared statistic (0.36) indicated a large effect size.

Confidence: There was a statistically significant increase in overall confidence levels from pre training (M = 4.48, SD = 1.41) to post training (M = 6.10, SD = 1.20), $t(130) = -1.83$, $p < 0.0005$ (two tailed). The 95% confidence interval ranged from -1.42 to 1.83. The eta squared statistic (0.66) indicated a large effect size.

Collaboration: There was also a statistically significant increase in attitude towards collaboration from pre training (M = 6.70, SD = 0.99) to post training (M = 7.56, SD = 0.85), $t(130) = -11.99$, $p < 0.0005$ (two tailed). The 95% confidence interval ranged from -0.99 to -0.71. The eta squared statistic (0.53) indicated a large effect size.

For the final training event (TE5), data analyses revealed statistically significant increases in participants' knowledge, confidence, and some aspects of collaboration post-training (White, 2010).

Knowledge: There was a statistically significant in-

crease in knowledge from pre training (M = 32.37, SD = 3.07) to post training (M = 33.80, SD = 2.32), $t(34) = -2.98$, $p < 0.005$ (two tailed). The 95% confidence interval ranging from -2.40 to -0.45. The eta squared statistic (0.09) indicated a moderate effect size.

Confidence: There was a statistically significant increase in all confidence ratings, as outlined in Table 7.

Collaboration: There was also a statistically significant increase in three out of five collaboration ratings from pre training to post training (see Table 8). **Participants'** perceptions of the importance of collaboration in their professional practice and the use of one client plan across professionals and agencies was already exceptionally high before training and only slightly higher post training which did not result in statistical significance.

Level 3 Behaviour

Forty-nine percent of participants from the two pilot training seminars (TE1 and TE2) completed the 3-month post-training questionnaire about the transfer of learning to the work place. Analyses of the responses revealed the following (Farah, 2010; as cited in White, 2010).

Table 7: Statistical analyses of pre and post-training ratings of confidence for TE5

Confidence Ratings	Mean	N	Std. Deviation	t	95% confidence interval		Sig. (2-tailed)
					Lower	Upper	
Understanding quality of life							
PRE-training confidence	5.37	35	1.41	-7.78	-2.09	-1.22	0.0005
POST-training confidence	7.03	35	1.01				
Integrating scientific approaches							
PRE-training confidence	3.97	35	1.70	-8.25	-2.31	-1.40	0.0005
POST-training confidence	5.83	35	1.31				
Understanding impact of disability							
PRE-training confidence	5.20	35	1.72	-4.97	-2.21	-0.93	0.0005
POST-training confidence	6.77	35	1.35				
Interventions for skill development							
PRE-training confidence	4.69	35	1.71	-8.76	-2.35	-1.47	0.0005
POST-training confidence	6.60	35	1.33				
Understanding mental health							
PRE-training confidence	4.09	35	1.93	-8.81	-2.91	-1.82	0.0005
POST-training confidence	6.46	35	1.19				
Integrating service systems							
PRE-training confidence	4.74	35	1.80	-8.96	-2.48	-1.56	0.0005
POST-training confidence	6.77	35	1.16				

Collaboration Ratings	Mean	N	Std. De- viation	t	95% confidence interval		Sig. (2-tailed)
					Lower	Upper	
Collaboration is essential to my practice							
PRE-training collaboration	8.31	35	0.90	-0.88	-0.56	0.22	0.384
POST-training collaboration	8.49	35	0.78				
One plan across multiple agencies							
PRE-training collaboration	7.24	34	1.30	-0.76	-0.75	0.34	0.451
POST-training collaboration	7.44	34	1.48				
Know when to seek collaboration							
PRE-training collaboration	6.74	35	1.57	-3.38	-1.46	-0.36	0.002
POST-training collaboration	7.66	35	0.90				
Knowledge and skills to contribute to collaboration							
PRE-training collaboration	6.06	35	1.60	-5.36	-1.81	-0.81	0.0005
POST-training collaboration	7.37	35	1.26				
Know role, responsibilities and limitations in collaboration							
PRE-training collaboration	6.37	35	1.28	-6.31	-1.73	-0.89	0.0005
POST-training collaboration	7.69	35	0.86				

Table 8: Statistical analyses of pre and post-training ratings of collaboration for TE5

- The most useful aspects of the training:* Participants noted that most useful aspects were the opportunity to network and collaborate with different professionals and agencies; discussion of case studies and the work group activities; and the practical strategies presented.
- Change in knowledge post training:* Some participants felt that the training seminar refreshed and consolidated their skills and knowledge, and validated their work practices. These participants also felt the training increased their knowledge base in intellectual disability and identified that the holistic nature of the framework and the training methods (case studies and workshops) contributed to this. To a lesser extent, some participants felt that the information presented in the seminar was more appropriate for participants new to the field of intellectual disability.
- Change in confidence post training:* The majority of participants reported an increase in confidence when working with clients with intellectual disability. However some participants reported no differences in levels of confidence or reported decreased levels of confidence due to not being able to apply what they had learnt or they had more **awareness of their limited knowledge (e.g., “made me more aware of what I don't know”).**
- Change in intervention strategies used:* Participants

commented on how they had incorporated different interventions into their practice such as augmentative and alternative communication (e.g., comic strip conversations, video social story), teaching levels of emotions, genograms, and attachment theory.

- Change in how work was done with clients:* Participants noted that they were more holistic in their work, and also had more awareness and understanding of the impact of mental health issues on clients with disability and their families. Participants also noted the importance of reflection and how they were able to reflect on their current work behaviour and incorporate different approaches learnt at the training to meet the needs of their clients.
- Change in teamwork and collaboration with other agencies:* After training, participants reported an increased willingness to engage in collaboration with other team members and services whose expertise would further benefit their clients. The training program also reinforced the importance of interagency collaboration, and increased their **awareness and understanding of others' roles in the process.** Some participants commented on how collaborative practice was already established in their workplace, while others noted that the training highlighted the difficulties in establishing collabora-

tion between mental health and disability services at a local level.

7. *Aspects of the training applied in work:* Participants had applied some strategies learnt at the training into their work including communication and visual supports for routines, emotions, and behaviour; the practical aspects of working together; and the networking and building partnerships with other professionals and agencies
8. *Workplace factors that assisted in application of learning:* Managerial and supervisor support, a supportive flexible workplace environment, information sharing opportunities and peer supervision were important in facilitating transfer of learning into the workplace. Having the opportunity and autonomy to implement ideas and interventions from the training was also highlighted by participants as important factors in applying learning to the workplace.
9. *Barriers or challenges to application of learning:* Resource constraints were the greatest challenges for participants in applying their learning to the workplace. This included the negative impact of financial limits on the continuity of care and service funding, time pressures and role demands,

and the impact of staff shortages and consequent waiting lists for clients to access services.

Discussion

The goals of the Training Curriculum Project were achieved and resulted in the development of a framework of core interventions, implementation and evaluation of a 2-day seminar and the subsequent publication of a book to support the interdisciplinary educational program (Dossetor, Watson & White, 2015; White, Dossetor, & Watson, 2010b). In this way, the workforce issues for clinical skill development in this area were addressed with 526 professionals throughout NSW attending the 2-day seminar across five training events (White, 2010).

Analyses of the evaluation measures revealed that there were positive reactions to the seminar immediately following each training event. There was also statistically significant improvement in the majority of learning outcomes for knowledge, confidence and attitude to collaboration, and transfer of learning to the workplace occurred for some participants (White, Dossetor, Watson, & Farah, 2009). The results of this evaluation study were in line with previous research that found that training programs had a **positive impact on professionals' knowledge of psychopathology**, confidence in working with individuals, attitudes to services and transfer of knowledge into clinical practice (Costello, Bouras & Davis, 2007; Gibbs & Priest, 1999; Mohr, et al., 2002; Tsiantis, et al., 2004; Whitehurst, 2008).

This evaluation study had several strengths, firstly the sample size of professionals was large enough for results to be considered statistically reliable, and secondly, this study is thought to be the largest interdisciplinary training program focused on the mental health of children and adolescents with intellectual disability to report evaluative findings. The development and use of such an interdisciplinary education program is an essential first step in being able to develop, assess, and refine best practice in mental health and intellectual disability. However, this study had weaknesses, in **that the evaluation only focused on professionals' responses to training and short term behaviour change** but did not measure the impact that training had on the outcomes and quality of life of children and young people with intellectual disability and mental health issues. This is a common failing in other studies on training programs (MacDonald & McGill, 2013).

The sustainability of any education program is always of concern to project teams following the extensive amount of resources that goes into the training needs analyses, development, implementation and evalua-



tion of such programs. The educational program developed as part of the Training Curriculum Project was no exception. Investigation of sustainability options revealed that the core framework and 2-day seminar provided the participants with a foundation level of knowledge for working with young people with intellectual disability and mental health needs. There was varied feedback to the modified format of the seminar (video vs. live presentations at TE5) however most of the satisfaction ratings were comparable to those achieved for the two metropolitan Sydney training events (TE3 and TE4, see Table 5).

Qualitative data on the modified seminar format and individual video presentations were also diverse with suggestions made for improvements to this approach. Importantly, the modified format had no impact on learning outcomes with statistically significant improvements being made for knowledge and confidence measures, and most aspects of collaboration. The most interesting outcome of the evaluation however was that to enable transfer of learning from the seminar, whether it included an e-learning component or not, required some face-to-face contact with professionals with content expertise to allow for both knowledge and skills transfer to the workplace.

Implications

The outcomes of this educational program have highlighted a number of implications for curriculum design and implementation that may be transferable to other interdisciplinary programs for professionals, notably;

- A variety of teaching and learning strategies need to be employed to assist with the learning needs of adults, for example, lecture-style presentations, workshops with interactive and practical activities, written material to support topic areas, DVDs.
- Program content needs to have a good balance of theoretical and practical information that is relevant and meaningful to the participants' clinical context. This will assist in ensuring transfer of learning from the training environment to clinical practice.
- Interactive group activities and opportunities for networking help establish local connections between participants and their organisations. This is important for collaboration across agencies and for peer support in the workplace.
- Supportive supervisors and an understanding of the value of reflective practice in learning may enable participants to change work practices and implement new strategies when supporting young people with intellectual disability and mental health issues.
- Having a sustainability plan for use of the training materials (i.e. seminar manual, handouts, DVD of videoed seminar presentations) needs to be con-

sidered from the outset of any curriculum development project.

Future Directions

Since the completion of the Training Curriculum Project, the partnership between the Statewide Behaviour Intervention Service (ADHC) and the Department of Psychological Medicine (CHW) has continued and resulted in additional service development activities. This has included joint work through,

- School-Link Initiatives, for example, contributions to the Journal of Mental Health for Children and Adolescents with Intellectual and Developmental Disabilities: An Educational Resource (www.schoolink.chw.edu.au), the "Meet Jessica" Animation Project, and the Promoting the Mental Health of Adolescents with Intellectual Disability Project ;
- Extension of specialist skills, for example, the Westmead Feelings Program (formally known as Emotion-Based Social Skills Training, Ratcliffe, Grahame, & Wong, 2010); and,
- Integration of framework domains and project outcomes into work practices, for example, Practice Improvement Framework (Turner, 2015).

Additionally, the recommendation from O'Brien, et al. (2014) to review the Training Curriculum Project outcomes led to a small scale survey being conducted at the 2016 World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). An adapted stakeholder survey from the Training Curriculum Project was used to determine whether the Interdisciplinary Practice Framework of Core Interventions (on which the Training Curriculum Project educational curriculum was based) reflected current thinking by multidisciplinary practitioners in the sector.

Preliminary analysis of survey results indicated that the framework had withstood the test of time and that most components continued to be seen to have a high level of importance within the framework. Although it should be noted that there had been a shift in the level of importance that practitioners assigned the different components of the framework. It is envisaged that any future revision of the Training Curriculum Project educational curriculum will need to take into consideration the emergence of new research, shifts in referral trends and patterns, the availability of new resources and training curricula, and the evolution of clinical practice.

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A Review of: Exploring Giftedness and Autism, a study of differentiated educational program for autistic savants.

By Trevor Clark, National Director, Education and Research at Autism Spectrum Australia (ASPECT). Routledge: London. 2016.

Reviewed by Associate Professor David Dossetor

Introduction: Darold Treffert, an authority on savant syndrome and exceptional abilities sets the scene in the foreword: How is it possible for extraordinary ability and giftedness to co-exist with incapacitating disability in the same individual. The best known example is from the movie “Rain Man”? What does this say about dormant potential? How do islands of genius impact on our theories of overall intelligence? What brain changes account for the differences in Savants?

The focus of this book, which was based on Trevor Clark’s PhD, is: **Can these seemingly non functional traits be used in a strengths based approach to better communication, functional skills and independence?** The book provides a specific Savant Skills Curriculum (SCC) in a control study to look at outcomes and then measures the strategies that improve the critical skills for life. Secondly he examines school-age students with autism who display savant skills with psychometric measures to standardise and document their skills. He documents their obsessive nature, their high levels of challenging behaviour as well as high levels of interest and motivation, using the Savant Skill Nomination Form and the Family and Teacher Savant Skill Questionnaires. He documents the early onset of skills without training and a familial link with superior performance of giftedness in family members. The students with savant skills show imaginative and creative skills, high-level memory and showed multiple savant skills rather than a single talent. These skills did not diminish with intervention. The challenge is to find them valued roles as adults and in employment.

Clark’s PhD explored savant and splinter skills in the autistic population through a differentiated educational ‘Savant Skill Curriculum’ (SSC) over 2 years, using a multiple-replication case study research design in a group of 22 children aged 4-16. In the context of low IQ, the students with savant skills showed skills in: memory, hyperlexia (the ability to read, write and spell), art, music, mechanics, spatial skills, calendar and mathematical calculation, sensory sensitivity and athletic ability. This study continues to be a ‘world first’. The study focuses on strengths rather than defi-

cits, and as such they should be seen as gifted students, not disabled children with freak talents. The book is rich with case stories. This study was done while studying at the Gifted Education Research, Resource and Information Centre at the University of NSW under Emeritus Professor Miraca Gross. For this study Clark was awarded the International Award for Excellence in Education and Psychology for the Gifted.

Bringing the challenge alive with case stories:

Patrick (14yrs) will not greet you with a hello but with what is your birthday or your car registration, etc and will recite these to you every time he sees you subsequently. He has loved numbers since he was 2 and can do 6 digit calculations faster than his teacher can on the calculator. He prefers to spell words than speak them. He is hyperlexic being able to decode words without necessarily knowing their meaning. He also loves computers and can use many software programs **without training, such as removing his brother’s files** from the computer.

Bradley (6yrs) loves words and reads street directories, the telephone book and encyclopedias for leisure. He could read and write at 2 years. He constructs electronics with lego, making traffic lights, stereos and computers. He is 2 years ahead on reading and numbers, including number concepts.

Terry (5yrs) could recite 12 times table by 5 years, and knows the location of every street hole in Northern Sydney and draws complex marble mazes. His father is in finance, and grandfather and great grandfather are gifted in mathematics.

Yet all these three have autism. Patrick has mild Intellectual Disability (ID), while the others are of average IQ.

Challenging behaviours include: Patrick will bite himself or others, tantrums, running away from class, running through traffic with no road sense. His communication skills are delayed to the first centile, his social skills are delayed, he has low self esteem, and his behaviours are in the severely disturbed range.

“Innovative programs that focus on strengths are demonstrating some research results...”

Bradley easily stresses if a piece of Lego is missing, or if he has to change class, when he throws tantrums. He also is extremely anxious, crying, and demanding that routine be followed. Terry also tantrums, screams and refuses to cooperate and becomes aggressive if he doesn't get his own way. He is solitary but can cooperate with structured interactive games like snakes and ladders. He gets distressed and anxious if someone disagrees with his viewpoint.

Those with savant skills can be of any IQ, although it is rare in those with severe ID. Some are remarkable in contrast to their IQ (categorised as Talented Savants or Savant I) others are spectacular even in a normal IQ

(categorised as Prodigious Savants or Savants II).

Although Rimland found savant skills in 9.8% of children with autism, Howlin found about 30% of adults with autism had savant skills; yet in her study of 137, only 5 were in employment. 95% (of 81,000 people with autism) reported restrictions to their education in the 2014 Australian Bureau of Statistics survey. 86% reported school difficulties, 6% were not attending school at all and 81% had not completed a post school qualification. In the ASPECT 'We belong too' survey 65% of parents felt their child's teacher didn't understand autism and 70% felt their child's educational needs were not being met. There has also been a lack of autism educational research, with the available research emphasising early intervention. There can also be a gap between research and practice.

Innovative programs that focus on strengths are demonstrating some research results, such as in finding post school employment and quality of life. One student described was sensitive to noise and was found to have perfect pitch. He was introduced to making music on an Ipad, which he used for social engagement, and created songs for emotional regulation, and subsequently composed some top 10 popular songs

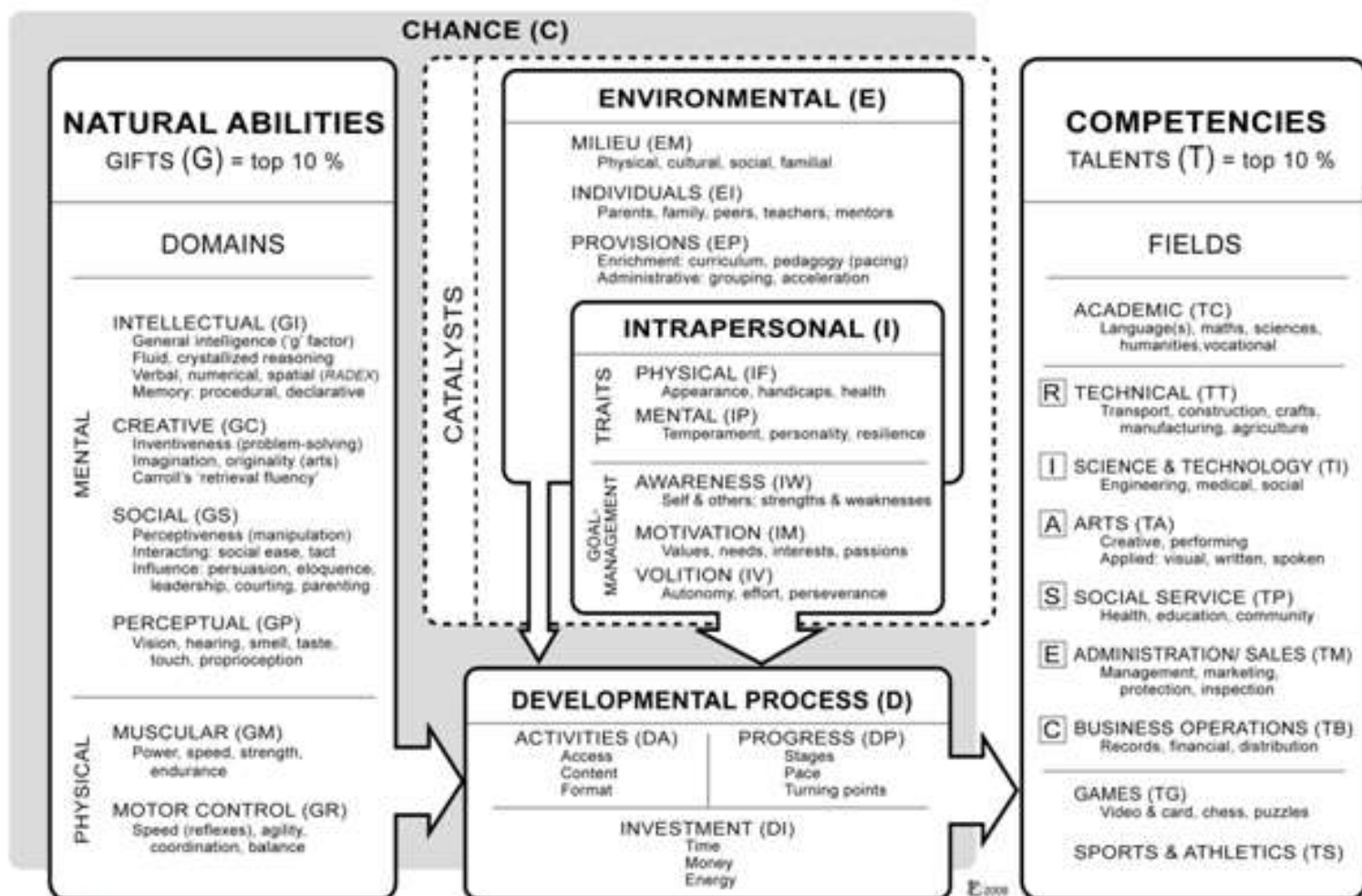


FIGURE 3.1 Gagne's Differential Model of Giftedness and Talent (2009)

Model for Savant Skill and Talent Development – Clark, 2011

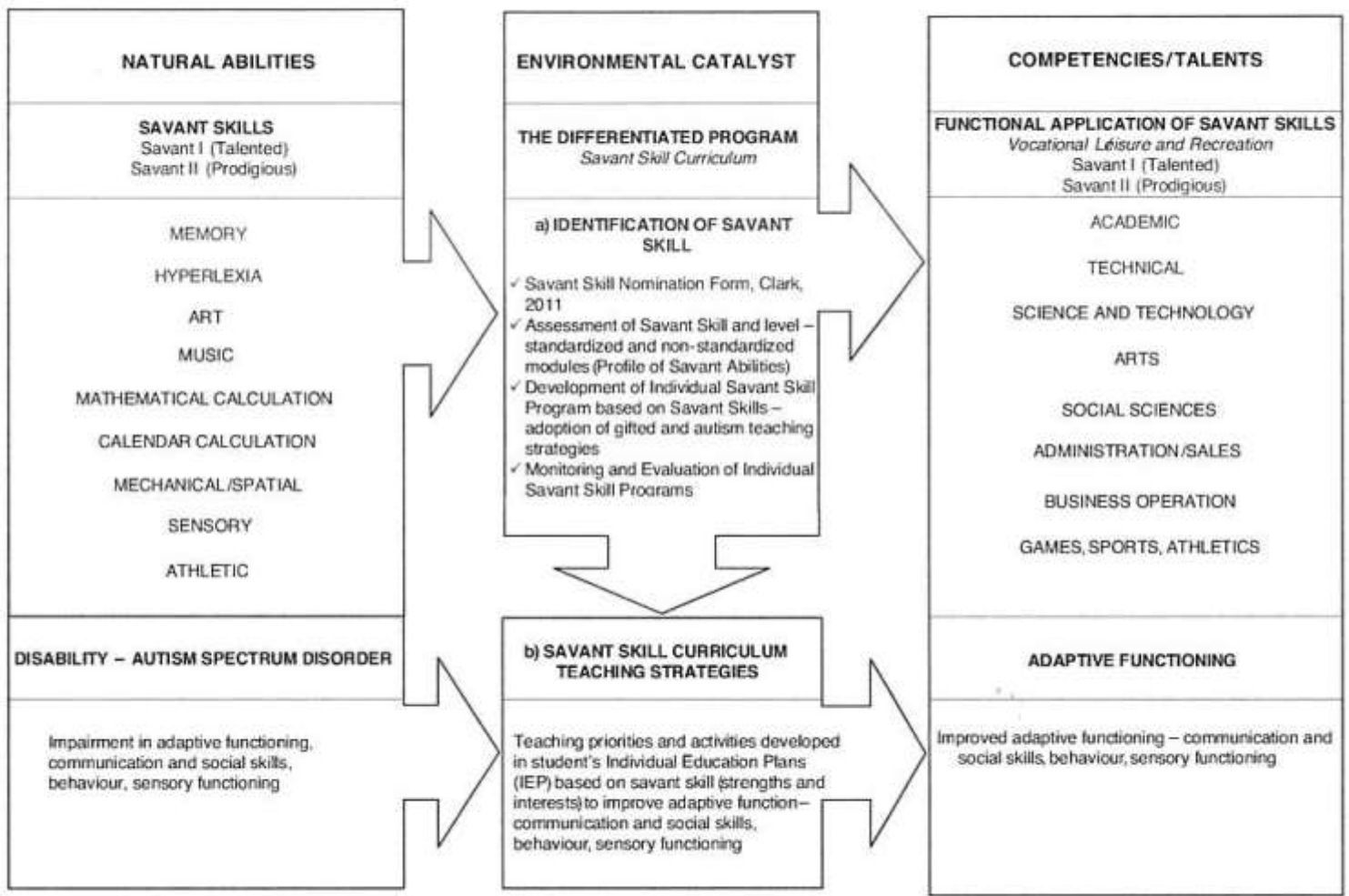


FIGURE 3.2 Model for Savant Skill and Talent Development – T.R. Clark, 2011

becoming a musical superstar. Using a special interest is the way to honour a child and motivate them to learn. One 24-year-old non verbal man with autism with special skills in Lego became an Ikea furniture assembler!

The SSC underpins practice with research, draws on the skills of autism education combined with that for the gifted, and suggests that *identifying savant skills may transform their education*.

Patrick was impossible to engage in class as he ran around flicking through books and magazines and running away. Clark provides clinical scenarios of a further 3 students to scaffold the account of the intervention. Their challenging behaviour was partly due to frustration and boredom in the absence of education of their gifted skills. While savant skills are frequently observed to be self taught, they are also dismissed as the product of relentless practice and overlearning.

Clark's research review suggests there are a discrete number of savant skills: memory generally for narrow

fields of interest; hyperlexia or pseudo-verbal skills with limited understanding; artistic ability mainly drawing or painting; musical ability for singing or an instrument; mechanical/visual spatial ability for taking apart or assembling mechanical objects, or maps; calendar calculation; mathematical calculation; athletic or coordination ability, e.g. balance (walking on the top of fences); and some include hyper or hypo sensitivity, but this may be a failure in sensory processing (this can include knowing the time without a watch, or hearing a conversation others can't hear). Young people with autism may have a talent for systemising, which requires an attention to detail. All these features were found in the study, the most frequent being: memory (100%), hyperlexia (87%), mechanical/spatial (81%), calendrical (25%), number (18.25%) and athletic (6.25%). Over 50% had sensory abilities. Patrick had the most skills at 7 years old and the details of all are provided. Some still argue that savant skills are independent of IQ. Testing these skills on psychometric measures is described: it has been suggested that those with savant skills do no better than expected for IQ. For example in memory, their memory skills have

“There is also a relationship between restricted interest and motivation for practice....”

been described as similar to artificial intelligence, not geared to everyday problem solving, and they may have these skills at the expense of efficiently accessible and coherent memories. This proved to be incorrect. In this cohort they all had superior memory skills **on memory testing**. **Treffert's book 'The complexity of Greatness' (2013) it is argued that innate talent is linked to genes for memory and that neuroscientists have discovered neurones that make connections independent of experience, indicating genetics underlie such skills. There is also genetic evidence of domain specific gifts in non-disabled populations e.g. in absolute pitch. However, the research evidence also shows that rehearsal and practice also contribute. All of the subjects spent hours on their interest each day. Conversely these skills can be lost if not supported. There is also a relationship between restricted interest and motivation for practice. Weak central coherence and problems with abstraction/perspective as a deficit of executive function appears to be part of the picture. There remains dispute on savants' creativity which may be related to IQ, yet some certainly achieve originality, for example in music. Treffert suggests savant skills involve pathological events forming exceptional neuronal structures in prenatal brain development, and this rewiring is associated with restrictive thought processes and reduced abstract thinking. He backs this with EEGs, brain scans and neuropsychological testing and has found a number of cases with right hemisphere imbalance. Functional brain imaging suggests increased recruitment of memory areas. Savant skills in ID tend to be seen as curiosities, but Clark's aim is to make this skills of functional value through developing the Savant Skill Curriculum. Some of the savant success stories are well worth reading on their own.**

The SCC is a framework to merge the fields of giftedness and autism education. Clark works from the Gagne differentiated mode of giftedness and talent and developed a modified Model for Savant skill and Talent Development (see figures above).

The SCC is planned as an **Environmental** catalyst involving key **Individuals (EI)** (parents, teachers and

mentors) and **Provisions (EP)**, enhancing **Interpersonal Motivation (IM)** using Autism education skills. The natural abilities are considered against other skills (Savant I) and the Developmental Process has a strong emphasis in transferring gifts into talents for these disabled students. This includes an emphasis on improved adaptive function: communication, social skills and behaviour, which in turns improves competencies and talents. *Acceleration, enrichment and mentorships* were borrowed from gifted student teaching. Lastly 1 to 1 *mentors* were incorporated. There was also a focus on integration into mainstream classes. A longitudinal multiple-replication case study design was used which is a powerful method for rare phenomena. Various standardised and non-standardised measures before and after along with



qualitative information. The study measured: functional application of savant skill, communication ability, social skills and behaviour, academic self-esteem, and degree of Autism. Follow up was at 12 months and a waitlist control group of 6 was also included as a comparison.

Results of Clark's research included the finding that all child participants were highly motivated in working on savant skills. These skills develop from an early age between 6 months and 2 years. They had not received previous specific training. 72% had giftedness in family members. This confirmed they are 'twice-exceptional' in giftedness and autism. All participants showed special memory skills but didn't necessarily perform well on formal memory testing. This does suggest that memory may be a contributor to other savant skills.

There was a substantial improvement in the functional use of savant skills compared to controls enabling productive talents for many children, which was attributable to the design of the SCC. Communication skills improved more in the control group, which may reflect the focus of the curriculum in the control group. There was a lack of significant change in behavioural/emotional disturbance, or self-esteem although there were improvements in both. There was definite reduction in the degree of autism which seem to reflect changes in adaptive communication, behaviour and social skills. Some showed a decline in their savant skills, e.g. improved comprehension was associated with a decline in hyperlexia. Temple Grandin, an adult savant with autism, has suggested that savant skills decline with improved social development. This change may reflect a reduction in the obsessive nature of a savant skill, not a decline in the skill itself. Overall the SCC led to a decline of the deficits of these savants.

Clark's book also provides a 'how to' on how to assess a child for savant skills, how to develop the SCC for a child and then how to evaluate the changes at one year.

Changes in the example cases are described following SCC implementation: Patrick can now use the computer independently and writes the school newsletter. He showed improvement in communication and behaviour and an increased interest in social relations. Bradley had peers who were interested in his electronics and won popularity and self-esteem and an improvement in social language. He also helps the school caretaker with the school electrical systems. They both have a decline in autistic behaviours. Terry also remains with savant skills. He uses his spatial skills to

“Intellectual skills that can be developed and harnessed to reduce other areas of functional disability...”

help his mother navigate in the car. He has gained some appropriate computer skills. More improvements are generally found in practical accounts than necessarily reflected on some of the objective tests. Clark suggests that children with autism need to time to think about their special interests and one girl with autism expressed that teachers need to include them in the design and implementation of educational programs. One example was a teacher designing an examination on classroom air conditioners, which of course the relevant girl with autism won, with consequent enhancement of self-esteem.

In conclusion, these are not just 'freak talents' but intellectual skills that can be developed and harnessed to reduce other areas of functional disability. The Australian Advisory Board on Autism Spectrum Disorders position paper (2012) has two governing principles. Every child with Autism should have access to an educational service appropriate to their needs; and all educational sectors should provide services to cater for the needs of Autism. The SCC is therefore an appropriate intervention for all such 'twice exceptional' students.

As this study remains a first, there is still a need for replication, and further research on the nature of savants and giftedness, for example is the importance of IQ and communication skills. Finally, we need to examine the role of such specialised curricula for post school options that prepare for transition to adulthood and employment.

This text is enhanced by the personalised elements of **the account, from the case studies, the Clark's learning experience, and the influence of his supervisor and mentors.** Clark also testifies to the dedication of the parents and teachers involved. His accounts of the long term follow up of some of his students illustrates the long term benefits of the increased functionality of **savants' skills to both the young men in their 20s and 30s and indeed their families.** The book includes useful a range of useful resources to enable others to ap-



proach the 'how to' for themselves.

I found the text the best summary on this interesting subject of autistic savants that all those who work with autism encounter. It illustrates the importance of developing educational research for young people with disabilities. I also think that studying savants and their education may become increasingly important, as authors like Tanzi and Chopra suggests, growing intelligences and skills, and improving our capacity for using our brains, is key to the development of our species (Superbrain, 2012).

Further Reading

Rudolph Tanzi, Deepak Chopra. 2012. Super Brain: Unleashing the Explosive Power of Your Mind to Maximize Health, Happiness, and Spiritual Well-Being.

Naltrexone for the treatment of self-injurious behaviour

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Self-injurious behaviour (SIB), or self-mutilation (SM), is a potentially dangerous and anxiety-provoking condition. SM was recognised as early as the 5th century BC, there are some variations in definition, and Favazza **described SM as “deliberate, direct destruction or alteration of body tissue without conscious suicidal intent”**.^{1,2} It can present in various forms including head-banging, self-cutting, self-choking, self-biting, self-scratching, hair pulling, hand mouthing and many others.³ The extreme forms described were eye enucleation and castration.¹

SIB can be a manifestation of a wide variety of psychiatric disorders including intellectual and developmental disability (IDD),⁴ schizophrenia,¹ borderline personality disorder,⁵⁻⁸ pervasive developmental disorder,⁹ stereotypic movement disorder¹⁰ and Tourette disorder.^{11,12} It is also quite commonly found in people with specific genetic conditions or syndromes such as fragile X syndrome, Prader–Willi syndrome, Cornelia de Lange syndrome, Smith–Magenis syndrome and Lesh–Nyhan syndrome.¹³⁻¹⁶ SIB is seen more frequently in individuals with communication deficits, restrictive adaptive skills, and severe or profound intellectual disability (ID).¹⁷⁻¹⁹

The prevalence of SIB varies depending on the meth-

ods and criteria used; for example, a community survey of SIB among developmentally disabled children and adolescents done by Griffin found that 2.6% of the students exhibited at least one type of SIB during the preceding 12 months.²⁰ The studies have found higher incidences of SIB (27.7- 50%) in children with comorbid autism. Risk factors for SIBs included lower chronological age, associated perinatal conditions, a higher level of autism and greater impairment in self-care skills.²¹

Untreated SIB has a major effect on various domains of quality of life, including self-care, vocational opportunities, social involvement and learning experiences.^{22,23} Untreated SIB can also lead to an increase in the rate of institutionalisation²⁴ and multiple medical issues, including death.²⁵

Self-injurious behaviour in those with intellectual and developmental disability is often a complex and chronic condition that is challenging to treat. Treatment depends on the examination of the causal contributors including a behavioural analysis and consideration of the aetiology of SIB and other risk factors. In those who are non-verbal this includes full medical examination, including examination under anaesthetic for **‘silent’ causes of pain. A comprehensive psychotherapeutic treatment plan may include various behavioural interventions such as social skills training²⁶ and reinforcement-based strategies to increase more appropri-**

“Self-injurious behaviour in those with intellectual and developmental disability is often a complex and chronic condition that is challenging to treat...”

ate behaviours.³ Extinction and punishment-based strategies, for example, aversive procedures,^{2,3,27-30} have been used especially for people with intellectual disabilities and extreme self-injury. Some aversive treatments need ethical review to be appropriate to consider the impact of self-injury versus the impact of treatment.^{2,23}

Pharmacological interventions are commonly used alone or with behaviour therapies. Antipsychotic medications are the most frequently used.³¹⁻³⁵ Other medications which have been used in treatment of SIB include selective serotonin reuptake inhibitors,³⁵⁻³⁷ lithium,^{35,38} tricyclic antidepressants,³⁹ beta-blockers (propranolol and pindolol),⁴⁰⁻⁴² tryptophan,⁴³ L-dopa,^{14,44} buspirone,^{45,46} clozapine,⁴⁷ clonidine,^{35,48} guanfacine,⁴⁰ monoamine oxidase inhibitor inhibitors⁴⁰ and the opioid antagonists (naloxone and naltrexone). Naloxone and naltrexone have drawn attention due to positive results in severe cases of SIB unresponsive to multiple modalities of treatments.^{3,9,10,24,49-65} In a very severe refractory case of SIB, psychosurgery, including cingulotomy and limbic leucotomy, decreased the severity and frequency of SIB in an adolescent boy with Tourette disorder after the failure of other treatments.¹²

What is naltrexone?

Naltrexone is a specific, competitive, long-acting, non-addictive oral opiate antagonist that highly binds to the mu-receptor, followed by kappa and delta receptors, thus hindering the activity of opiates.^{8,66} Although naltrexone was first synthesised in 1963 and was approved for medical use in the United States in 1984,⁶⁷ it was not reported in the literature as a treatment for SIB until 1985.⁵¹

Pharmacology and pharmacodynamics

After absorption from the gastrointestinal tract, naltrexone is extensively metabolised in the liver.⁶⁶ It has a major active metabolite (6- β -naltrexol) which may also have weak opioid antagonist activity.⁶⁶ Peak plasma concentrations of naltrexone and 6- β -naltrexol occur about 1 hour after oral dose. The elimination half-life of oral naltrexone is about four hours, and of 6- β -naltrexol is about 13 hours.⁶⁶ However, Verebey et al. reported a possible prolonged pharmacological effect (24–96 hours) which may be secondary to the slow release of tissue-bound naltrexone and partial reabsorption by the kidney.⁶⁸

The side effects reported with naltrexone include increased or decreased appetite, oedema, toothache, ejaculatory difficulties, reduced potency, depression and suicidal ideation.⁶⁶ Reversible hepatotoxicity has been reported after the use of higher doses (e.g.



300 mg/day or more) for extended periods.^{66,67} Naltrexone is contraindicated in patients who have been treated with opioid analgesic for a painful condition as naltrexone will decrease analgesia.⁶⁹ Naltrexone is also contraindicated in acute hepatitis, liver failure or with elevation of liver enzymes (>3 times). Dose reduction may be required with mild renal impairment but naltrexone should be avoided if impairment is severe as risk of hepatotoxicity may be increased.⁷⁰ There has been safety testing in children down to the age of 2-3 years.^{10 71}

Clinical use

In Australia, naltrexone hydrochloride (ReVia) requires an authority prescription and is only available under the Pharmaceutical Benefits Scheme⁷² for alcohol dependence. However, naltrexone has been used effectively for other clinical conditions, for example, opioid dependence, obesity, ASD,^{10,51} SIB that is unresponsive to pharmacological and behaviour treatments,^{24,51,73} and pathological gambling.⁷⁴ Naltrexone may improve hyperactivity and restlessness in children with Autism⁵⁵. Interestingly naltrexone is used as modified release preparation in the management of obesity in patients with BMI of 30 kg/m² or greater with antidepressant Bupropion along with exercise and dietary modification.⁶⁶ There is also some evidence of improvement in dissociation and SIB in borderline per-

sonality disorder.^{8,51,66,75,76} Naltrexone is preferred over naloxone due to its high potency, ease of oral administration and longer duration of action.^{51,66} As naltrexone is a potent opioid blocker naltrexone should not be given prior to surgery where opioids may be utilized for pain relief. The effects of naltrexone are still present up to 3 days after ceasing to take.

Physically the naltrexone tablets are bitter tasting which can be a problem for some children. The taste can be masked by using a product called GLOUP which can help lubricate the throat and help the tablet slide down. Commercial flavorings from a Compounding Chemist can be added to a solution of the dispersed tablet in water. The tablets can be dispersed in 20ml and takes up to 2 minutes to dissolve and also Compounding Pharmacies will make up bespoke mixtures. Recent literature supports the use of naltrexone in adults with SIB.^{24,73} However, there is a lack of up-to-date evidence to guide naltrexone safety and efficacy for SIB in children and adolescents (the most recent review was done in 2004 in the 7–67-year age group).

Previous reviews evaluating the safety and efficacy of naltrexone

Buzan et al.⁵¹ performed the first published literature review for the use of an opiate antagonist for recurrent SIB. They included 31 case reports with a total of 98 patients (5–67 years) and reported a dose-dependent improvement up to 1.5 mg/kg/day. Of these 98 patients, 89 were developmentally disabled or autistic.⁵¹ No hepatic or significant adverse effects were noted in SIB patients.⁵¹

Symons et al. conducted the first quantitative synthesis of peer-reviewed literature from 1983 to 2003 on the efficacy of naltrexone treatment on SIB. The review included 27 research articles involving 86 subjects (7–67 years) with 85% of them double-blind, 9% open-label and 6% single-blind studies. SIB reduced in 80% of subjects, and in 47% of subjects, SIB reduced by 50% or greater. The most common dose evaluated was 50 mg (1 mg/kg).²⁴

A systematic review by Roy et al. in 2015 evaluated the efficacy of opioid antagonists for SIB in adults

with ID. They included ten RCTs with a total of 124 participants (91 males, 33 females). Eight of the 10 studies reported a reduction in the frequency of SIB, and 61 of the 124 participants showed statistically significant improvements. The naltrexone dose varied from 0.25 mg/kg/day to 2 mg/kg/day, and 9% of the participants reported minor side effects including nausea, tiredness, sedation, loss of appetite, weight loss and mild liver abnormalities.⁵⁰

Some individual studies in children and adolescents:

The Bernstein et al. study was the first documented single-case trial using naloxone and oral naltrexone, in an 18-year-old intellectually impaired adolescent. Oral naltrexone reduced SIB by 33%. The reduction in SIB persisted despite no further naltrexone treatment.⁶⁵ The study by Barrett et al. was the first double blind placebo controlled (DBPC) study, which showed positive effects on SIB even with smaller doses of naltrexone (at doses of up to 50 mg/day) after an initial increase of SIB with naloxone.⁵²

Walters et al. investigated naltrexone in a 14-year-old autistic and IDD boy (DBPC). Results indicated a marked decrease in SIB and increase in social relatedness.⁵³

Benjamin et al. found naltrexone useful for severe SIB of a nine-year-old boy with IDD and Prader–Willi syndrome. The combined treatment of naltrexone with a behavioural intervention yielded marked improvement in weight control, skin picking and oppositional behaviour. The associated weight loss raised the hypothesis that obesity may be related to excessive endorphins and that opioid antagonists may therefore have a role in treating obesity.⁵⁸

Johnson et al. compared the effects of behavioural treatment and naltrexone to reduce the SIB of a 7-year-old boy with severe IDD and autistic disorder, and found that the combined use of naltrexone, splint-fading, differential reinforcement, and a brief hand restraint was effective in reducing severe SIB to zero.⁵⁷

In conclusion, although the research is limited in the child and adolescent population, due to the relatively benign side-effect profile of naltrexone and the reported benefits in the previous studies, clinicians may consider this as an option for severe, refractory SIB. Such consideration would require rigorous assessment and treatment of medical and psychiatric comorbidities, and exhaustion of other treatment modalities, including behavioural treatments. Clear documentation of any off-label use is recommended, including noting the limitations of the current evidence and a record of informed consent obtained from the patient or caregiver

“Clinicians may consider this as an option for severe, refractory self injurious behaviours...”



after explanation of the purpose, side effects, risks and benefits of naltrexone treatment.⁷⁷

Note: This brief report is derived from a comprehensive literature review by Vinita Bansal, which is available on request.

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The Medicine Cabinet: gastrointestinal disorders and autism

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It has long been recognised that there may be a link between gastrointestinal (GI) disorders such as reflux and autistic spectrum disorders (ASD) as well as other developmental disabilities. These disorders can include functional diarrhoea, functional constipation and gastrointestinal reflux disease. In one study comparing ASD subjects with unaffected siblings found significantly more GI symptoms (42% to 12%). Another study has found increased severity of autism increased the odds of having GI problems.²

In a 1999 study looking specifically at gastrointestinal symptomatology in autistic disorder or pervasive developmental disorder found nearly 70% patients had reflux oesophagitis and 88% had symptoms including night time awakening with irritability, signs of abdominal discomfort.¹ This study further showed on histology there was chronic inflammation of oesophagus, stomach and duodenum – high prevalence of reflux oesophagitis, hyperplasia of duodenal cells as well as intestinal carbohydrate digestive enzyme deficiencies. Children with developmental delay are three times more likely than children with typical development to experience frequent sensitivity to foods, pain on defecating, diarrhoea, constipation as well as difficulty swallowing and vomiting.² This study also concluded that children with ASD had not only the highest reports of food dislikes but also highest odds of reporting GI symptoms not explained by other factors.

Although some individuals with ASD may respond to dietary intervention such as removal of milk for symptoms of lactose intolerance, these need to be assessed empirically as there has been reported a high degree of placebo effect ([See previous article](#) MHCAIDD Volume 9 Issue 2, 2018). There is not the support for the use of casein-free diet or gluten-free or combination for individuals with ASD.⁴ There is a need for standardised definitions of adverse reactions to both food and medications. The term food allergy is sometimes applied where the reaction is non toxic but immunologically generated.

Gastro-oesophageal disorders are sometimes communicated especially in the non verbal developmentally delayed by challenging behaviours including agitation and aggression as well as sleep disturbance. So understanding the reason behind the challenging behaviour and treating can reduce the need for psychotropic medication.

Medication used to treat gastrointestinal disorders

Neutralising agents

These include preparation such as aluminium hydroxide gel and magnesium hydroxide gel (brand names such as Mylanta® and Maalox®) have largely been discontinued as they were used primarily for the neutralisation of acid in heartburn and gastritis. Mylanta® is now available in tablet form. For best results the tablets should be taken apart from other medication (at least 2 hours). There are also several drug interactions with these preparations so use should always be discussed with doctor and/or pharmacist. These preparations also sometimes contained simethicone which was added as it reduces the production of gas.

Anticholinergic agents

These are related to belladonna (atropine) and hyoscine preparations and by themselves can be helpful for abdominal discomfort as well as peptic ulcers, diarrhoea as well as nausea and vomiting but there is an additive effect with antipsychotic medications such as risperidone, olanzapine and quetiapine together with some antidepressants such as amitriptyline and mirtazapine as they also have anticholinergic effects. Additive anticholinergic effects include dryness of mouth leading to increased risk of dental caries, constipation, urinary retention and incontinence, agitation and disorientation.

Proton pump inhibitors

This group of medications has been available since 1980s but their use has become more widespread and availability increased with some being able to purchase over the counter. They work by blocking the gastric acid secretion of the parietal cells of the stomach

“understanding the reason behind the challenging behaviour can reduce the need for psychotropic medication...”

suppressing both the stimulated and basal acid secretion when taken before a meal. These medications include pantoprazole, omeprazole, esomeprazole and lansoprazole. They are primarily used to treat peptic ulcer disease, help in eradication of *Helicobacter pylori* infections, treatment and prevention of gastroduodenal ulcers caused by other medications including non-steroidal anti-inflammatories (NSAIDs such as ibuprofen), and gastrointestinal reflux disease (GERD). These medications are commonly prescribed on PBS and in 2018/9 esomeprazole was number 8 in the list of top 10 drugs by defined daily dose prescribed on PBS/RPBS.

H2 antagonists

The other class of medications used for GERD is the H2 antagonists such as cimetidine and ranitidine.

These work by inhibiting the gastric acid secretion by blocking the histamine 2 receptors on the basolateral plasma membrane of the parietal cells mainly during the night. Not quite as effective for post meal reflux but effective for gastroduodenal ulcers. **H2 antagonist's effect quickly rises after first dose but a tolerance can develop by gradually weakened acid suppression with repeated administration over 2 weeks.** In recent times there has been some issues with the manufacture of ranitidine, finding that it has been contaminated with N-nitrosodimethylamine (NDMA) and thus supply has not been able to be guaranteed. Cimetidine use has also decreased due to potential for drug drug interactions due to its ability to inhibit one of the drug metabolising enzymes CYP2C9 and thus affect the drug levels of several medications.

Some gastrointestinal conditions

Gastrointestinal reflux

Gastrointestinal reflux in very young may be associated with vomiting and regurgitation but improves by 12 months of age. Signs associated with gastro oesophageal reflux disease (GORD) include failure to thrive, oesophagitis, stricture, refusing to feed, recurrent pneumonia, anaemia, dental erosions, apnoea and life threatening events and these can be hard to describe



and should be fully investigated not just as GORD but also other conditions maybe contributing⁷.

Acid suppression

The stomach is only organ that secretes acid (pH 2). Such gastric secretion is important for the sterilisation of bacteria in ingested foods but also for digestion and absorption of nutritional factors such as proteins, iron, calcium and vitamin B12. These can lead to deficiencies.

Helicobacter infections

Helicobacter pylori is a bacterial infection causing gastritis and peptic ulceration is prevalent in up to 30% of adult Australians and primarily acquisition occurs during childhood⁵. Apart from the gastritis symptoms, there is also a degree of functional dyspepsia which when treated with *H. pylori* medication eases symptoms. It is diagnosed by a breath test or via scope. Successful eradication treatment includes two different antibiotics and a PPI (first line is esomeprazole) over a 7 day course.

According to Australian Therapeutic Guidelines Gastroenterology, empirical treatment should be avoided in **children, and the ‘test-and-treat’ strategy for upper gastrointestinal tract symptoms used for adults is not appropriate.** Children should only be tested for *H. pylori* in the rare situation where their symptoms are strongly suggestive of organic disease. Upper gastrointestinal endoscopy is recommended to confirm *H. pylori* infection in children.⁷

Constipation

This can be overlooked as well as managed by the general practitioner and can be medication related as well as other factors. These can include poor food including low fibre content or oral intake especially in those with swallowing difficulties. Poor mobility and severe intellectual disability also increase the incidence of constipation. Constipation may be expressed as intermittent pain and then in some circumstances lead to constipating medications being prescribed to fix a pain problem but also contributing to underlying constipation problem.

Constipation in children had three principles of management.⁶

- Adequately soften stools to eliminate fear of painful evacuation
- Empty rectum if impacted and keep it empty
- Encourage good toileting behaviour

Mild constipation is often treated with increased dietary fibre and toilet training and any use of laxatives continued until after training has occurred or regular bowel movements.

Chronic constipation will need laxatives used include macrogol 3350 (brand names include Movicol or Osmolax) powder which is dissolved in water or other fluids as per instructions and the consumed. Other preparations include lactulose as well as sorbitol. Liquid paraffin 50% (Parachoc®) can also be used but contains 50% chocolate flavouring. Daily dosing if preferable and needs to continue until stools are the correct consistency – wet cement or porridge.⁶

After 2-3 months treatment and not inducing regular stooling then stimulant laxatives can be started, these include either bisacodyl tablets or enemas, senna preparations or sodium picosulfate (Coloxyl Drops®). Colicky pain is often an adverse effect of these preparations.

For severe faecal impaction, adolescents can have up to 8 sachets of macrogol 3350 daily for 3 days under medical supervision. If this unsuccessful then admission to hospital maybe needed. Followed by the regimen for chronic constipation.

Long term effects of proton pump inhibitors

While most of these epidemiological studies have been in the older population there has been some interesting findings which has lead the PBAC (Pharmaceutical Benefits Advisory Council) to change the benefits available for the PPIs on the PBS (Pharmaceutical Benefits Scheme) in May 2019. In recent years it has become apparent that there is long term/chronic effects of proton pump inhibitor (PPI) use, these include hypocalcaemia, hypomagnesaemia, *Clostridium difficile* infections, changes in gut microbiome as well as small intestine bacterial overgrowth and pneumonia. The long term loss of calcium and magnesium can cause cardiac and bone density problems leading to fractures and osteoporosis. More epidemiological studies are needed. Infections such as community acquired pneumonia and *C. difficile* are possibly due to increase in the gastric acid pH due to chronic use of PPIs leading to inability to suppress the opportunistic enteric bacteria thus allowing colonisation.

“Poor mobility and severe intellectual disability also increase the incidence of constipation...”

PBS changes

These included changes in the classification of doses from highest, high and low to high, standard and low. Restrictions on highest dose esomeprazole has increased to needing a telephone authority. Standard doses of PPIs all now require telephone authority prescriptions and high dose treatment for GORD, have symptoms which are inadequately controlled using standard dose PPI. Standard dose treatment for GORD is streamlined authority and be long term maintenance in patients not adequately controlled using low dose PPI. These restrictions will be reviewed in 2 years.

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Further Reading:

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This article includes some non-pharmalogical treatment options.



Paying attention to the mental health of parents of children with a disability

Dr Elise Davis and Dr Kim-Michelle Gibson

<https://aifs.gov.au/cfca/2018/10/15/paying-attention-mental-health-parents-children-disability>

This short article explores opportunities to build workforce capacity to better support the mental health of parents of children with a disability.

Being a parent of a child with a disability can be challenging and stressful. Parents of children with a disability – particularly mothers – have been shown to report poorer physical and mental health than mothers of typically developing children (Gilson et al., 2018; Singer, 2006). There is a range of reasons why parents of children with a disability may experience poorer mental health, including the intensity of the day-to-day care requirements for the family, the struggle to find services for their child and family, social isolation, financial concerns and difficulty maintaining employment. Maternal mental health is not only important for mothers but is integral to child development (Bernard-Bonnin, 2004).

The role of practitioners in supporting parental mental health

Although it is well recognised that parents of children with a disability have poorer mental health than other parents, there are few services or programs in Australia that provide targeted support for parents of children with a disability. From a population-health perspective, there are many opportunities to improve the mental health of parents of children with a disability given they are often in regular contact with early intervention, disability and health services for their child. However, such opportunities are often hampered because professionals who work with children often lack the confidence, skills, resources or time to talk to parents about their own mental health. Even for adult-focused practitioners who may be more equipped to support the mental health of parents of children with a disability, it can be particularly challenging for these parents to prioritise their own health and wellbeing, and so interactions with adult practitioners may be minimal and insufficient.

Child practitioners are in a unique position to support the parents of children with a disability because they have such a **thorough understanding of how the child's needs and services may impact on the family, and often have an ongoing relationship** with the family. However, to effectively support parents, it is important that child practitioners feel confident talking about parental mental health, know the boundaries of their role and are knowledgeable about referral pathways.

Training and professional development in this area is essential for practitioners. To be most effective, the training needs to be complemented by a range of strategies across an organisation that support practitioners in their role. Researchers at the University of Melbourne are currently working to develop and evaluate new programs to build the capacity of early intervention services to better support the mental health of parents and the mental health of professionals. As part of this work, the Staff and Parent Wellbeing in Disability Services study is currently evaluating a program that aims to increase the **self-efficacy of key professionals to better support parents' mental health**. More information about the study is available on the [University of Melbourne](http://www.unimelb.edu.au) website.

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