

# An integrated approach to mental health care provision for students with Autism Spectrum Disorder and Intellectual Disability

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## Abstract

Autism Spectrum Disorder (ASD) is associated with high rates of psychiatric co-morbidity that seriously impair students' ability to learn. Conventional approaches to addressing these problems rely on consultation with office-based professionals. Services are often scarce, waiting times and travel can be lengthy and consultation times inadequate. Students with ASD can be very distressed by and intolerant of this process. The Giant Steps School in Sydney enrolls students with severe ASD and Intellectual Disability (ID) in the moderate or below range. It emphasises an integrated transdisciplinary approach to student development, with allied health staff including speech pathology, occupational and music therapy as well as psychology working alongside teaching staff. Despite optimal attention to individual programs and environmental factors many students remained agitated and distressed. An on-site mental health clinic was therefore established, named after the original Giant Steps Chairman of the Board, Rob Llewelyn-Jones. A developmental paediatrician and an adult psychiatrist visit three to five times a term. Students are seen in the classroom or playground followed by extensive discussion with parents and staff, culminating in treatment strategies to which all make a contribution. Carers are thereby

more invested in the consistent implementation of behavioural programs and data recording, and outcomes have been greatly improved. Feedback has been universally positive.

## Background

The psychiatry of Intellectual Disability is a challenging and under resourced sub-speciality. Rates of psychiatric disorder are at least double those seen in the neurotypical population. Assessment is compromised by poor communication abilities, making access to the patient's subjective state limited (Witwer & Lecavalier, 2010). Apart from small, isolated local initiatives there are few services devoted to this population in New South Wales. The only service in Australia that provides comprehensive assessment and continuing treatment is the ACT Mental Health-Intellectual Disability Service (Wurth & Brandon, 2014). There is a shortage of child psychiatrists and most children and adolescents are seen by paediatricians.

Autism Spectrum Disorders (ASD) are over-represented in individuals requiring psychiatric care, a result of high comorbid anxiety and other conditions. Private office-based practice in this area is challenging and unpopular. Clinic visits can be compromised by



high levels of noise and disruptive behaviour, the time constraints of private practice and the lack of opportunity to observe the patient in other than a highly artificial environment. The practice of psychiatry in this area is limited by the individual's severe communication difficulties leading to high levels of uncertainty about diagnosis and treatment response, rendering a systematic approach to intervention essential. This process is often hampered by problems of understanding and acceptance by support staff, when opportunities for direct contact between the clinician and such staff are few.

Public mental health initiatives in this area are scarce. The recent New South Wales Mental Health Care Plan made no allowance for this population, despite strong recommendations from the Mental Health Services Commissioner (NSW Mental Health Commission, 2014). Under-resourced public mental health services are struggling to provide limited service to patients with serious mental illnesses, and are unable or unwilling to assist in this specialist area. The need for the clinic arose from increasing awareness of the lack of suitable services for this population. The practice of transporting students off site for medical services was inefficient and disruptive and results were poor. Students were typically accompanied to office visits by parents and a senior member of allied health staff, and were often distressed, disruptive and impatient, which compromised the quality of assessment. The process was opaque to the majority of school staff and their cooperation in the rigorous collection of data and implementation of behavioural programs was limited.

### **Giant Steps School**

Giant Steps runs a school program for 84 children aged 3 to 18 and a College for 13 young adults over 18 years of age, all with Autism Spectrum Disorder. It is unique in that teachers and therapists work alongside each other for the majority of the day. This trans-disciplinary approach is fundamental to the education, health and welfare of the students. Giant Steps also provides parent training, siblings support groups, inter-agency training and consultation, vacation care and a specialist autism diagnostic and assessment clinic as well as a range of other outreach services.

Integration and inclusion are cornerstones of the program. As a result 69% of the Early Learning cohort aged 3 -6 years of age were able to leave Giant Steps in 2014 and enter regular or support classes in mainstream schools rather than continuing in such a specialised school setting. All programs are functionally relevant with learning occurring in authentic situations so that the capacity to participate in all areas of life is developed.

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Over the last decade there has been an increasing number of opportunities emerge for children with ASD in mainstream contexts over the three education sectors – Catholic, Independent and Public Schools (NSW Department of Education and Communities, 2012). As a consequence Giant Steps has had an increase in the proportion of students aged 8 years and above with more severe and complex needs. Only 3 out of 75 students have scores on the The Developmental Behaviour Checklist (DBC) (Enfield & Tonge, 2002) below the clinical cut off of 30. Nearly all students have an intellectual disability in the moderate to severe range. Epilepsy occurs in 27% of the students and 40% take psychotropic medication, with 81% of the latter taking more than one psychotropic medication.

Staff are trained extensively in order to maximise educational engagement and to optimise the management of challenging behaviour. All staff were trained in functional assessment of behaviour and in the systematic collection of quantitative behavioural data. Checklists were established to ensure that all pedagogical and autism-specific strategies - such as skills development, sensory supports and communication aides – were in place. The school developed the Student Engagement Support to structure implementation and monitor progress in these areas. Students were graded into three tiers according to their need for support, with those in Tier 3 being most in need of mental health services.

### **Structure of the Giant Steps Clinic**

The original intention of the Board was to engage both an adult and a child psychiatrist for the school clinic. The shortage of child psychiatrists resulted instead in the serendipitous appointment of a developmental paediatrician. The combination of these two specialities has been advantageous given the high rates of physical comorbidity in this population.

The Board of Giant Steps was able to secure substantial funding from a charitable foundation for a 2 year pilot program. Clinics began in February 2014 and have been held three to four times a term, enabling reviews at roughly monthly intervals, much more frequent than is often possible in private practice. The



service offers the rare opportunity for private practitioners to work as members of a multi-disciplinary team, with the core clinic team comprising the visiting medical professionals and two senior staff with backgrounds in psychology and occupational therapy as well as advanced behaviour support training.

Each appointment begins with the doctors visiting the student within the classroom. During this visit doctors will observe the student, perform limited physical examinations if necessary and discuss matters with the class team. The doctors then meet with the student's parents, clinic allied health staff, the class teacher, and others such as group home staff. Behavioural and other relevant data are presented and developments discussed. Longer and more frequent appointments are available for more complex cases. Students may see the doctors separately based on their age or as a conjoint appointment. Conjoint appointments have been found to be the most effective, and after the first year of operation have become the norm. This allows for a comprehensive team approach to complex scenarios, and for more varied discussion of possible care pathways. Patients twelve years and under are seen primarily by the paediatrician with psychiatrist input, with roles reversed for those over twelve years. Parents are charged a fee for service partially rebated by Medicare, Australia's publicly funded universal health insurance scheme.

### **Benefits of the School Clinic**

The culture of Giant Steps and the extensive training of staff in the two years prior to commencement of the clinic have married unusually well with the operation of the clinic. The regular presence of the doctors throughout the school and the process of consultation with staff from many disciplines, both in the classroom while visiting the student, and afterwards during case conferencing, have addressed a number of problems. Staff have been able to more fully understand the reason for requests for detailed feedback in both structured, quantitative form and narrative, qualitative form. Concern that recording evidence of problematic behaviour would be used to question their level of skill evaporated, as did the worry that data would not portray adequately the magnitude of challenges they face.

They see how their feedback assists clinical decisions, and understand the central importance of maintaining consistency of behavioural management and minimising environmental disruptions. Staff gain a much fuller understanding of every aspect of the treatment process and of the relevant medical problems that may be the student's presentation. They are thereby more understanding of the trial and error basis of much intervention.

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Central to an evidence-based approach to treatment in any field of medicine is the ability to accurately and validly monitor outcomes. Self-report, widely used in general psychiatry, and of problematic validity, is unavailable in this population. Psychiatry is a specialty without the benefit of objective data such as numerical test results. Narrative information from observers is inevitably subject to a number of biases and rarely quantifiable. Challenging behaviour in this high needs population is often severe and frequent, and the achievement of substantial improvement can easily be overlooked or forgotten when the absolute level of residual behaviour remains high. In medicine a 50% reduction of a target symptom or abnormality is held to be evidence of treatment efficacy, a very severe behavioural problem can be reduced by 50% and still leave a significant burden of distress and disruption. The school established a rigorous data collection method that captures interval based recording of episodic severity data across the day for high frequency behaviour. Further refinement in the way that this data was presented, including colour coding, aided in the quick and efficient decision making needed within the clinic setting. This quantified behaviour data has minimised the problem of false negatives through observer habituation leading to underreporting of high frequency behaviour, is user friendly and low effort, and highlights changes in frequency and severity that provide the feedback necessary for rational management. Some families adopt this scheme or simplified formats for use at home. The behaviour support team ensure that support systems are in place and monitor and organise data collection. Feedback from direct care staff is summarised.

### **Outcomes**

The DBC was used to track changes in problem behaviour. Changes over time were tracked between 2014 and 2015, with the difference in scores displayed below. The average across 19 students was a reduction of 6.7 on their Total Problem Behaviour Score, the range being a gain of 35 and a loss of 43. These results demonstrate that while most patients at the clinic are making gains others require ongoing treatment and support.



**Graph 1**

DBC Total Problem Behaviour Score changes over time for each student who accesses the clinic

### Case Histories

1. This is an 8 year boy with a history of severe self-injurious behaviour from the age of two. Regular attempts at review by paediatricians and psychiatrists had made little difference. Physical aggression towards others was frequent. A major barrier to effective treatment was his intolerance of unfamiliar environments. He would insist on leaving consultations immediately upon entering the office. High levels of agitation and aggression put himself and others at risk. Opportunities for history taking and examination had been limited. His attendance at the clinic enabled observation in the classroom and thorough assessment for the first time. His parents were available for more extensive discussion than had been the case in previous office-based consultations. More informed and systematic use of psychotropic medication lowered his arousal and permitted his greater engagement in classroom activities and behaviour management strategies. These processes produced a substantial reduction in self-injurious and aggressive behaviour.

Scale	Score SEP 2013	Score DEC 2014
Total Problem Behaviour Score (TPBS)	88	60
Disruptive / Antisocial	26	16
Self-Absorbed	38	29
Communication Disturbance	9	8
Anxiety	12	4
Social Relating	2	2

**Table 1**

DBC score changes between September 2013 and December 2014

2. This is a 12 year old boy with a long history of rigid behaviour that had increasingly limited his education and impaired his health. Over the preceding six months his world had contracted. He could not leave his bed without engaging in extensive rituals. He could take up to two hours to cover 100 metres at home and school. He refused to swallow, even his own saliva, leading to weight loss, dehydration and eventual hospitalisation. Visits to his office-based paediatrician and psychiatrist became increasingly difficult. Behavioural intervention was ineffective.

Crucial to success was the engagement of all school staff in the process of his psychiatric management by their inclusion in the clinic process. This resulted in much more rigorous attention to detailed recording of behaviour and thorough implementation of behavioural strategies than had previously occurred. As a result subtle improvements in his clinical state were more clearly apparent and able to thereby be preserved, whereas previously such modest gains had been overlooked. These gains were then built upon with succes-

sive alterations to medication that were ultimately more effective. His mood improved, anxiety and rituals lessened, and he became much more responsive to behavioural measures. Within a few months he was moving between locations freely and eating, drinking and taking medication readily.

Scale	Score FEB 2014	Score DEC 2014
TPBS	92	61
Disruptive / Antisocial	27	15
Self-Absorbed	33	18
Communication Disturbance	13	15
Anxiety	9	5
Social Relating	14	8

**Table 2**  
DBC score changes between February 2014 and December 2014

- This is an eleven year old girl with a moderate ID and little speech. She is very ritualistic and constantly seeks sensory stimulation. She settled considerably with the addition of risperidone at the expense of substantial weight gain. She had a history of reflux and severe constipation. She had become very distressed and screamed every morning. Higher doses of risperidone and more vigorous efforts to treat reflux and constipation had not helped. Multiple changes of psychotropic medication at another clinic led to severe worsening of her distress and self-injury.

A presumptive diagnosis of recurrence of severe constipation combined with adverse effects of the new psychotropic medications was made. Psychotropic medication was substantially reduced and a bowel cleanout using very large doses of aperients was prescribed. Classroom staff made significant complementary adjustments to her daily routine; she was given multiple small meals, fluid intake was increased and movement was encouraged. A visual schedule incorporating these changes was developed, and maintenance of independent toileting was supported. The capacity of Giant Steps to differentially allocate resources according to need, as well as the combined efforts of clinic and classroom staff, was instrumental to this outcome.

Scale	Score Feb 2015	Score April 2016
TPBS	90	77
Disruptive / Antisocial	29	23
Self-Absorbed	43	40
Communication Disturbance	9	9
Anxiety	5	2
Social Relating	7	5

**Table 3**  
DBC score changes between February 2015 and April 2016

The opportunity to review patients in a multidisciplinary case conference and the availability of sufficient time for discussion are routine in this clinic but rare in private practice. The contributions made by parents and by staff from so many disciplines – psychiatry, paediatrics, psychology, occupational therapy, speech pathology and teaching – plus the ability to observe the patient uninterrupted from their normal environment and routines allow far more valid assessment, diagnosis and monitoring of the impact of treatment. Decision making is transparent to all parties. The network of personal relationships that has developed has resulted in the doctors being seen more as belonging to staff than as outside consultants. Staff and parents are confident that their perspec-



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tive is acknowledged and actively contribute to decisions being made. This helps everyone persevere in the face of the occasional but inevitable negative effect of interventions, and creates greater understanding of the possibilities and limitations of medical treatment.

The clinic provides opportunities for trainee medical specialists and research. A number of advanced trainees in developmental paediatrics and intellectual disability psychiatry have attended. The possibility of creating a computer app for the behaviour monitoring tool is currently being investigated. Conjoint assessment and treatment by a paediatrician and a psychiatrist is rare outside specialised developmental clinics within teaching hospitals. The psychiatrist has had the opportunity to work extensively with children for the first time, and to thereby better understand developmental trajectories in autism. The educational process has been bidirectional between clinic and classroom staff. Feedback from parents and staff has been consistently positive. Preliminary data show a trend towards a reduction in workers compensation claims for staff injury by students, with the majority of recent events involving students not yet seen in the clinic.

While this is not the first mental health clinic established within a school, it is unique in Australia in its level of integration across all parties. It represents an extension and a completion of the model of the transdisciplinary approach fundamental to Giant Steps. Although this clinic is unusually well resourced, this standard should be commonplace given the complexity of this psychiatric sub-specialty.

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