

# 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 Statewide Behaviour Intervention Service team of The Benevolent Society, 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](http://www.schoollink.chw.edu.au)**

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

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

# Editorial

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Welcome to the last edition of the journal for 2017. It has been a big year for us here at CHW School-Link, with Kim Eisler joining our team, wearing two School-Link hats from with her other part-time role at Sydney Local Health District, and welcoming back Hebah from maternity leave last month. I have also finished my masters degree in social work, after more than four years of part-time study!

In 2017, our partners at Ageing Disability and Home Care, Department of Family and Community Services have begun their transition to the NGO sector, with our colleagues from the Statewide Behaviour Intervention Service having already completed their move to The Benevolent Society. Our education partners have been busy recruiting to additional school counselling positions across NSW.

In August 2017, the NSW Ombudsman released a report and reform proposals after their *Inquiry into Behaviour Management in Schools*. This document outlines the importance of: the Positive Behaviour for

Learning (PBL) framework in schools; the leadership and culture within a school; access to specialist behaviour management skills; safeguarding against restrictive practices, part day attendance, distance education, suspensions and expulsions; support for children in residential out of home care; improving engagement and outcomes for Aboriginal children and young people in school; strong interagency practice and partnership with students and their families; and a strong complaints resolution process and governance.

As 2017 draws to a close, we would like to reflect on and improve our School-Link services for 2018. We have developed a survey as we would value your feedback on how CHW School-Link can better support you in meeting the mental health needs of children with an intellectual or developmental disability. We are also asking your thoughts about this journal. The brief survey (only 12 questions, most multiple choice) will be open until 28th February 2018 and can be accessed [here](#).

Have a safe and happy holiday season and we look forward to hearing from you in 2018. Enjoy reading this edition of the journal and please send any feedback or your own contributions to [schoollink@chw.edu.au](mailto:schoollink@chw.edu.au)

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# Ewan's Story: Psychosis in Intellectual Disability and Autism

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## Introduction

**Ewan's Parents provide a personal account of the challenges that mental illness present in a young person with intellectual disability.** It emphasises the hardship and anguish that Ewan and his parents faced; the essential importance of good quality mental health services for young people with intellectual disabilities; and the importance of cross specialty and agency collaboration.

## Parent Experience

### Ewan's Story

Our 15-year-old son Ewan has a chromosome 18p deletion which was diagnosed just before his 3<sup>rd</sup> birthday. He has a significant intellectual disability, hypotonia, sensory issues, a divergence in his left eye, and required grommets/t-tubes from 8 months to 13 years. He had no other health issues until March 2015 when he started high school at age 13 years.

Ewan attended a mainstream Catholic Primary School with learning support. He loved school and couldn't wait to get there in the morning. He would be disappointed on the weekends when he couldn't go. He be-

haved extremely well while there, always completing his work and was respectful to his teachers. While he was shy and would tend to stay on the outer of activities, he was well liked by his peers and teachers. His best friend was a girl with Down syndrome and the pair were always together being cheeky and happy. Towards the end of primary school Ewan hit puberty with seemingly little affect.

Towards the end of 2014, Ewan completed a transitional program at our local Catholic High School, where he was due to start in February 2015. There were a few teething problems due to the level of care which Ewan required, within a week these were addressed and Ewan was deemed to be doing well. His case manager even commented that he was star pupil material!

At the start of high school, there were a few teething problems with the level of care Ewan required but these were addressed promptly. In March 2015, Ewan began displaying some strange behaviours, he would **watch the neighbour's trees from the upstairs windows** saying there were things in them wanting to kill him. He would slam shut all our window shutters and he kept going on about a girl trying to get him. When



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“Back at home things continued to deteriorate, Ewan was changing from a happy boy to a violent child...”

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asked where she lived he replied “in the trees”. He began removing all his toys from his bedroom because **‘the girl was touching them’**. While in the shower he would scream at something he believed was sitting on the toilet and would make us sit there while he watched muttering away to himself. He took to screaming at the television whether it was on or off. He would scream at our ceiling fans which I eventually covered with pillow cases. It appeared to be reflective surfaces which upset him. When we were in the car he would scream at the windows and try to get out of the car. We had to put the child safety locks back on the doors and the windows. It was around this time that **Ewan’s best friend went away for 3 months without warning**. We had been unable to prepare him and when she did return Ewan would have nothing to do with her.

In April, the family went on holiday to the beach, while we were there I was on my own with Ewan when he had a major episode in the car, physically assaulting me, screaming and trying to wrench the dash board off. I pulled over and got him into the back seat, he continued to kick and punch for about 10 minutes, this continued for sometime and at one point he appeared to be having a seizure when in fact he was shaking with sheer rage.

I had previously tried to see Ewan’s long term paediatrician, but had to wait 8 weeks for an appointment. Several services I was asked to contact kept directing us to other services.

Back at home things continued to deteriorate, Ewan was changing from a young boy who was happy, lively full of energy, who loved to play electronic games, ride his scooter, swim, go to acrobatics and watch TV to a very angry, tormented, withdrawn and violent child. He lost interest in everything and would pace the house for hours. He never had a problem going to bed and to sleep at night. All of a sudden he would be up till all hours, completely manic, chasing the cat laughing, or smashing up the house in anger. He started hurting our cat, something he had never done before.

By late April 2015 we had an appointment with the local youth mental health service. Over the next few

months we met with a multidisciplinary team consisting of a psychiatrist, community nurses and an OT. Ewan was diagnosed with psychosis and commenced on risperidone. The team supported him with frequent home and school visits, however we were often told by **some members of staff that this was ‘not their area of expertise’**.

Over the following months, Ewan developed dystonia to the point where his head was permanently turned toward his shoulder. He began constantly putting his fingers in his mouth, he started talking to his hand and would squeeze it quite viciously when angry. He would also pull his hair, hit his head and frequently cry stating **“I can’t take it anymore”**. A brain MRI showed no abnormalities but his cognitive abilities deteriorated. He had difficulty processing even the simplest things, his speech previously was very limited became increasingly more difficult to understand, which often led to meltdowns. He also lost all interest in events that he used to find exciting.

Things were deteriorating at school, Ewan was no longer able to attend many of his classes. Following meetings with counsellors from the Department of Education, it was decided that Ewan should attend a government school for specific purposes in 2016.

In January 2016, Ewan was admitted to an adolescent psychiatric inpatient unit for 6 weeks. His risperidone was replaced with a low dose of quetiapine, which had little effect. This led the doctors to conclude that Ewan was not suffering a psychiatric illness but rather a deterioration in his disability. Information from the Chromosome 18 registry in San Antonio, Texas did not help clarify the situation except to confirm **that Ewan’s condition was not common for Chromosome 18p**. We regularly visited Ewan in hospital, where he would ask to go home, and when told no, would become angry and violent. Towards the end of his stay his quetiapine was stopped and sodium valproate was commenced at a low dose but overall we felt the inpatient stay was of little benefit.

Once home, Ewan commenced at a school for specific purposes for intellectual disability. He would refuse to put on his uniform or get on the school transport.

We pursued an appointment with a Neurologist at the **children’s hospital who referred us to a Child Psychiatrist** with a special interest in intellectual disability with whom we had our first appointment in March 2016. He agreed that Ewan was suffering psychosis, and was optimistic about treatment but stated it would take some time. Over the next year we saw him monthly and trialed different drug combinations, including



“In November, we started having Ewan home for short visits with a carer. Over the next 6 weeks these visits gradually increased...”

Clonidine, Fluoxetine, Melatonin, Propranolol, Epilim, and Quetiapine.

During this time, the level of violence was increasing. Ewan would kick windows, doors and assault his family members. We had to install Perspex on Ewan's bedroom windows and a lock on his bedroom door. For safety reasons, Ewan was spending more and more time locked in his bedroom which resulted in more screaming and property damage. We needed help and were advised to call the police, however by the time the police arrived Ewan had exhausted himself and was asleep. The Police were sympathetic but unsure of how they could help, except reporting an incidence of domestic violence. In July, Ewan had an extremely violent outburst; I called the police and told them that I could no longer have Ewan in the house. The police called an ambulance to take him to hospital, which Ewan refused to get inside, and so I ended up driving him myself with a paramedic in the car.

At the local hospital, he was agitated and violent towards me. The Emergency Department consultant contacted the children's hospital psychiatry team who recommended paliperidone intramuscularly and an increase in his quetiapine. He was transferred to the local children's ward where the pharmacist opted to disregard the paliperidone for a much lower oral dose of quetiapine.

Over the next week I had meetings with paediatricians, the government disability service, and a hospital social worker, who concluded he was not suffering psychosis but “a deterioration of his disability”. They recommended I take him home; I refused. After a phone call with a senior manager, it was agreed they would support us. We did not want to give our son up, but the level of violence gave us no choice and we had to protect our other child. Ewan stayed at an NGO disability respite home, a service we were familiar with but after 3 nights they had to call the police. He was taken back to the local hospital and was given intramuscular droperidol.

The children's hospital psychiatry team was contacted and recommended the intramuscular paliperidone again. He was then transferred to the local paediatric inpatient service, where they refused to diagnose a psychiatric illness. After nine nights, Ewan was discharged back to the NGO disability respite service. The NGO's prn administration policy meant that Ewan didn't always receive prn medication when needed.

A month later after another escalation, police call and hospital visit, Ewan was taken to the government disability service run respite facility until a more permanent placement could be found. Ewan enjoyed the new facility which was better suited for his needs. We were still seeing the children's hospital psychiatrist and still trialing Ewan's medications.

In September, Ewan moved into a two-bedroom house with carers from an NGO who were experienced in aged care. The new environment did not suit him and after, numerous escalations and violent episodes, the police were again called. After a brief stay at the paediatric emergency service, Ewan was transferred to the child and adolescent inpatient unit at the tertiary children's hospital for an observation period. During his stay, his only aggressive outburst was when he was fasted for too long during a repeat MRI.

Ewan was discharged back to the two-bedroom home with a new team of carers who were trained to deal



with children with severe behavioural issues. Around this time, we began to see a difference in Ewan; he **was less violent, he didn't appear to be suffering from hallucinations**, he was enjoying going to school, and sleeping better. He was becoming cheeky again. The staffing ratios were reduced; and staff reported that they all enjoyed working with Ewan.

In November, we started having Ewan home for short visits with a carer. Over the next six weeks these visits gradually increased, until December when he finally came home.

The last 10 months have been difficult. We have had regular meltdowns but are usually able to find a reason for them. Ewan is very much a toddler in a teen **body and will have tantrums if he doesn't get his own way**. This is challenging considering he is 60kgs and over five foot. He is very food driven and as his hunger **can lead to a meltdown, I've learnt to always have food available**. His speech remains an issue but slowly he is working out ways to make himself understood.

Ewan has received an excellent NDIS package which has enabled him to access speech, occupational and behavioural therapy. He attends regular respite which he adores. He has grown to love school again, where his teacher is amazed at the progress he has made. He is beginning to enjoy activities that he has not looked at for almost two years such as playing the Wii, swimming and acrobatics. He enjoys colouring in, cutting out his pictures and gluing them in a scrapbook. If we go out somewhere he is extremely sociable saying **"hello" to everyone. He sleeps well and will go for a nap if he's tired. He laughs and plays little pranks on us**. The other day I asked him if he was happy and he **replied "yes"!** Ewan is not the little boy he was two years ago, but with the right combination of drug therapy he's no longer a tormented angry violent child.

## Psychosis in Intellectual Disability and Autism

By David Dossetor

Ewan was 14 when he presented for a psychiatric second opinion. The referring neurologist described him as suffering from a paranoid psychosis associated with becoming aggressive, destructive and violent. He also had a deletion of the short or p arm of chromosome 18. Quoting a review of the behavioural phenotype literature, his parents reported that since he had 18p deletion he should be suffering anxiety, whereas it is 18q (long arm) deletions that have the psychotic, manic and depressive disorders. In the last few years, with the rate of the genetic revolution, every month I meet

a new patient with an unfamiliar or newly described genetic abnormality. However, it was novel for a family to challenge the psychiatric diagnosis in their boy with severe intellectual disability based on the genotype!

Their concerns included loss of skills starting a year previously on transition to high school. He became violent and tormented, pacing the house, walking up and down stairs and around the garden. In mainstream primary school, he was able to complete most of his classes. At high school he needed significant support, he withdrew from all his friends, including his girlfriend who had Down syndrome. He was getting lost and **wouldn't know where to go in the classroom**.

At home he lost interest in his preferred activities and his self-care skills declined. He appeared unhappy and angry. He cried frequently. There was a change in his sleep pattern, waking in the night and often staying up. He lost concentration down to 10 seconds. He became intolerant of going out and noise. He now also hit, kicked and bit his mother several times a day. He punched himself, whacked his head on the floor, pulled his hair and threw furniture. His speech changed so that he would only speak in the present **tense. He didn't like touching or cuddling, when he used to always give a kiss**. In interview, he showed a habit of talking to his little finger in indistinct language.

He seemed to have depression with psychotic features and developmental regression. He also had an autistic pattern of development and behaviour. He was started on fluoxetine 10 mg.

The introduction also highlights how thoughtful, informed and caring his professional family are. They also showed great determination and communication skills in negotiating his care needs, when it became too dangerous to care for him at home. The treatment process was a joint exploration of his symptomatology and impairment, as it relied so much on their observation than on his communicative capacity of his mental state.

At initial follow up he was agitated, hyperactive, stimulating and giggly but his parents felt he was 10-15% better with improved mood. However, he continued to have meltdowns daily for 10-30 minutes. He remained anxious. It was difficult to distinguish between possible behavioural activation from fluoxetine and partial treatment of his depression and hypomania. We increased his fluoxetine to 20mg, increased his valproate to 100mg am and 200mg pm. The increase in fluoxetine had no benefit. A trial of propranolol for anxiety had no effect. We added quetiapine XR 50mg morning and afternoon and 50mg IR at night.

Over the next month there was an increase in non-contingent violence, requiring help from the mental health emergency services and child protection services. At representation at his local hospital for violence, he was deemed 'not psychiatric' and was discharged into the care of Family and Community Services (FACs), as he was unsafe to be at home. Following a further attendance to the hospital for violence, we provided telephone advice to start him on depot paliperidone 100mg/4 weeks. At outpatient follow up, due to the continuing level of violence his quetiapine was increased to 100mg XR bd and 100mg nocte. The differential diagnosis of bipolar disorder versus a paranoid psychosis was considered.

There was no doubt that skilled violence minimisation skills were needed in his residential setting. The specialised government funded disability respite home was both better trained and a more suitable environment to keep him safe and protect staff from injury. He was also better managed at his school.

With on-going diagnostic concerns, he had a planned two-week admission to our in-patient service. There were no incidences of violence while an inpatient with episodes of increased agitation being managed with additional quetiapine and distraction. Ewan displayed high levels of engagement in activities and some capacity for engaging with other teenagers and staff. It was also observed that he talked to his right hand when he was in a good mood and his left hand when he was in a bad mood. His behavior was seen as characteristically autistic, and the self-talk did not convince staff that he still had an active psychotic process, even though it was felt that he had had a psychotic illness from which he was starting to recover. Two months later, with steady continued improvement he returned to live with his family, although there remained high levels of anxiety about his potential for explosiveness. He did have some hour-long meltdowns requiring additional quetiapine. He was still very demanding, but with his steady improvement in mood and energy, and improvement in his language, he started to be able to **accept negotiation of what he could or couldn't do**, and back down and wait, rather than explode. He has even started singing again and enjoying occasional visitors.

Two years after onset and one year after presenting to me, he was doing well and presented very differently. His parents described him as a different child, happy, seeking an interest in things, talking more, eating well, sleeping okay. He was happy to go to school. His skills were progressively returning. He was playing with another child. In the six months they had had him

home, he had had seven episodes of violence. However, they were always able to work out afterwards what provoked it. For example, he would become angry when he was hungry. After school, he was often a bit agitated but with a snack he was happy again by the time they were home. He reverted to his 'toddler behaviour' of wanting attention all the time. He was smarter. For example, if Mum said 'no' he would go to Dad to see if he would give him what he wants.

His teacher reported that he had made the most progress that he had ever seen in a child. The majority of his self-care skills returned. He still self-talked but not to his hand. Although they had a good National Disability Insurance Scheme (NDIS) plan, they didn't use much of it as they were now able to care for him again as a family. Community-based respite required one-to-one support. Overall, they felt he was 75% back to his normal personality. They see glimmers of the old cheeky lively socially engaging boy they had.

#### *Current Medications*

He is still taking Seroquel 200 mg XR at 7 AM and 2:30 PM and 200 IR at 7 PM and PRN, valproate 200 mg at 7 AM and 7 PM and depot paliperidone 100 mg four weekly IM. He is on benztropine 0.5 mg at 7 AM and 7 PM as his face was parkinsonian and expressionless. It is likely that he will need treatment for at least a year to come.

#### **Reflection on Ewan's case study**

In patients with severe intellectual disability, attention to a detailed history is critical, and given the clear description provided by his parents above, it is unlikely that any psychiatrist would dispute a diagnosis of a psychotic illness, but this is often more difficult in the context of a presentation to an emergency department. In retrospect, one can see that he had a progressive intellectual decline over a period of a year, but in those with limited skills this is often difficult to define. It seems clear that he has had a psychosis with significant depressive content but he did not respond to antidepressants nor did he respond to low levels of antipsychotics. In adolescence, it is often difficult to distinguish between Depressive Psychosis and a Schizoaffective Disorder. His social skills remain at a two-year-old social and developmental age with an inability for turn taking except when supported by an adult.

At the most distressing and disturbed stage of this illness, health services responded with diagnostic overshadowing: the family was told by a paediatrician that his developmental decline was part of his intellectual disability and psychiatrists saying there was no psychiatric disorder to explain his violence. Yet it was also





“In patients with severe intellectual disability, attention to a detailed history is critical...”

skilled in minimisation of aggressive behaviours for those with intellectual disability, I fear that there will be a lack of a service setting to manage such clients.

### The links between ASD, psychosis and genetics: review of the literature

This family provided me with an unusual if not unique challenge, arguing for a psychiatric diagnosis in their boy with severe intellectual disability based on his genotype! There are a number of well-known genetic conditions that have a marked increase of a psychotic diagnosis from the genetic abnormality, notably 22q11.2, velo-cardio-facial syndrome, which has 25% risk of psychosis, the same risk as that of an identical twin of someone with schizophrenia. In 22q11.2 this risk of psychosis is unrelated to the premorbid presence of ASD, but does seem to be related to cognitive decline in adolescence. Prader-Willi syndrome, 15q11-13, also has an elevated risk, especially those with uniparental disomy in whom 62% were found to have psychosis versus 17% of those with deletion (Soni et al, 2007). The latter remains a high risk.

striking that even significant doses of a major tranquiliser (quetiapine) did not halt his decline. It was the addition of a second major tranquilliser (depot paliperidone) which coincided with the change in the course of his illness. The increased and extreme violence was associated with a psychotic illness and there was a failure to appreciate the severity of his mental illness. As the literature describes, the decline in skills and ability is the most evident feature of psychotic change, although difficult to measure, and, due to his disability and limited communication, it was easy to minimise the severity of his mental health symptoms. In my experience, psychosis in those with intellectual disability is often slower to recover, but then the length of the illness may also be affected by any delay in diagnosis and treatment. Arguably the service collaboration between Mental Health, the government disability service and FACS was the optimal approach to manage him in a community setting. The current service structure has no specialist mental health services for those with intellectual disability. In the future and with the transfer of state funded services to the NGO sector and their specialist respite services, staffed by people

Autism (although not associated with a specific genetic disorder) is reported by some as having a marked increased rate of psychosis, as high as 28% in one study. However, Selden and colleagues (2015) in a population-based study found an increased odds rate of 5.7. Howlin (2000) in her longitudinal follow up study of high functioning ASD suggested a prevalence of schizophreniform disorder in 10% and another 3% meeting criteria for schizoid disorder. Lai and Baron-Cohen (2015) identified the problems of diagnosing ASD in adulthood often including: a lack of developmental history, the acquisition of camouflaging strategies, the high frequency of co-occurring disorders, and problems with differential diagnoses, particularly anxiety, depression, OCD personality disorders psychosis and other neurodevelopmental disorders.

King and Lord (2010) emphasise the overlap between schizophrenia and autism spectrum, particularly in their broader phenotype. Studies reveal theory of mind deficits in both disorders, mirror neuron deficits, similar under-connectivity deficits in functional imaging



studies, also found in hallucinations and delusions. They share several genetic signals for example parental schizophrenia is a significant risk factor for ASD and copy number variants and Shank3 gene deletions are significant risk factors for both. Both have been described as spectrum disorders.

ASD was originally called childhood schizophrenia and Bleuler, in the 19th century, reported autism was a cardinal descriptor of schizophrenia. Although age of onset traditionally indicated a separateness, these neuro-scientific features suggest significant overlap. King and Lord also suggest some commonality from the benefit from antipsychotics for both conditions, with possible improvements in social cognition and current interests in the glutaminergic system.

Further, Sullivan and colleagues (2013) in the Avon longitudinal cohort study, of over 5000 children assessed at 12 years, showed an increased risk of psychotic experiences in ASD suggesting a shared neuro-developmental origin. They also point out the commonality of environmental risk factors for both disorders: advanced paternal age, winter season of birth, obstetric complications and maternal infections. In a similar vein, Khandaker and colleagues using the Avon population-based longitudinal study (2014) showed that of the 5.9% that had any neurodevelopmental disorder (ASD, dyslexia, dyspraxia, dysgraphia, dysorthographia, or dyscalculia) had increased risk of psychotic experiences by the age of 9 years. Although all neurodevelopmental disorders were associated with reduced IQ, **this didn't account for the increased psychotic experiences** (apart from an association with working memory).

Craddock and colleagues (2005) suggest that genetics undermine the longstanding distinction between schizophrenia and bipolar disorder with a number of genes predisposing to both (DAOA (G72), DTNBP1 (dysbindin), COMT, BDNF, DISC1, and NRG1). These observations support the hypothesis that they both lie on the spectrum of social disability and have a common neurodevelopmental aetiology.

Nonetheless the high rates of association of psychosis with genetic deletions generates enthusiasm about the genetic causality of psychosis from a wider research community than those who work with people with intellectual disability.

### Diagnosing psychosis from a genetic diagnosis, especially a deletion of chromosome 18.

In the review of literature on chromosome 18 deletions and associated psychiatric disorder, the findings **may be a little more ambiguous than '18p deletions leads to anxiety disorder and 18q leads to psychotic disorder'**. Firstly, there is one case report of a 42-year-old man with 18p deletion and paranoid schizophrenia. The above account represents a case 18p deletion with depressive, or schizoaffective psychosis.

Zavala and colleagues reported on the largest study of chromosome 18 behavioural phenotype (2009) and found the following:

Deletions or abnormalities of 18q (the long of chromosome 18) had significant risk of: depression (58%), anxiety (58%), manic symptoms (25%), and psychotic symptoms (23%); however, they also had ADHD (42%), stereotypic movement disorder (15%), learning disorders (41%) and communication disorders (33%).

Of those with 18p (the short arm) abnormalities: 66% had anxiety, but none had depressive, manic or psychotic symptoms, but they also showed ADHD (67%), stereotypic movement disorders (33%) and communication disorders (33%).

They also reported on those with 18p tetrasomy (a **supernumerary 18p chromosome or 'isochromosome'**) who had anxiety (50%), psychotic symptoms (12.5%), and mood disorders (12.5%).

Accordingly, all three chromosomal disorders were associated with high rates of different anxiety disorders, ADHD, ASD, violence and aggression and other developmental disorders (Zavala et al, 2009). A strength of this study is psychiatric diagnosis was made by psychiatrists with the aid of standardised interviews, blinded to the genetic status.

Chromosome 18 deletions are rare at 1/40,000 births and result in a wide range of physical and develop-



mental abnormalities, including short stature, deafness, epilepsy, intellectual disability, delayed speech, articulation problems and mutism. These are to be distinguished from Edwards Syndrome which an 18 trisomy with such severe developmental problems that they seldom live beyond one year. All reports of chromosome 18 deletions are of small samples, and in this study, there were 13 young people with 18q deletions, 9 with 18p tetrasomy *but* only 3 with 18p deletions, with unmatched and disparate ages from 3 to 32 years.

In the search for a gene for psychosis or bipolar disorder, there may be a distorted motive for the study to focus on the rates of psychosis. Yet the authors are suggesting 25% rates of mania, depression and psychosis on the same 3 cases, although an additional 2 also had depression. What they do not emphasise is that 18q cases also had ADHD (42%), stereotypic movement disorder (15%), learning disorders (41%) and communication disorders (33%); 18p cases also showed ADHD (67%), stereotypic movement disorders (33%) and communication disorders (33%) and 18p tetrasomy also had ADHD (62%), anxiety 37%, mood disorders at 12.5%, stereotypic movement.

### How easy is it to diagnose psychosis in ASD and or intellectual disability?

This problem was recently looked at by a study by Laron and colleagues (2016). In the introduction, they report that the relationship between psychosis and ASD is complex with substantial overlap but age of onset is a distinguishing feature. People with ASD are at greater risk of psychosis, approximately 10% compared with 2-3% of those with intellectual disability. But these previous findings are from small cohorts and there was a lack of systematic study on how psychotic illness presents in ASD. This study considers the hy-

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“there was little confusion between ASD and psychosis which was always associated with a change from previous functioning...”

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pothesis that maybe psychosis occurs in a genetic subtype of ASD, such as copy number variants rather than single nucleotide polymorphisms and possibly with different characteristics? Alternatively, are features of ASD misdiagnosed as psychotic symptoms, e.g. **difficulty in reading other's minds is interpreted as paranoia**, communication difficulties as thought disorder, or meltdowns as resembling catatonia? Thirdly there may be a group of symptoms which fit in with both ASD and psychosis, being distinct from each on their own?

They report a cross-sectional study of people with ASD and psychosis (ASD-P). These were compared with a group with ASD with no psychosis (ASD-NP) and compared with a psychosis only group (PO) (substance induce psychosis was excluded). The ASD-P cohort was referred from across UK in 2010-13, were over 16 years and able to give consent for themselves. ASD-P group was 116 (M: F 89:27). They feel assured that they have a typical ASD-P group, as they were referred by experienced clinicians, yet this could also be a selection bias, avoiding referring ambiguous cases or those more impaired e.g. in IQ or negative symptoms. ASD was confirmed with ADOS and ADI-R and psychosis on Diagnostic Interview for psychosis or Mini PAS-ADD and ICD10, DSM-IV-TR, and Research Diagnostic Criteria were used to confirm diagnosis. In practice, there was little confusion between ASD and psychosis which was always associated with a change from previ-





“Neuroscience research is likely to uncover important commonalities in the underlying brain processes that predispose to mental illness...”

ous functioning and rarely involved a person’s special interests or repetitive behaviors.

The results from this study showed: ASD-P had varied age of onset, including some in early childhood (6 were <12 yrs), others in middle age (2 were >45yrs). Onset was variable with 42% with insidious onset (>6months). 71% reported severe impairment for at least 2-3 days and needing admission; 53% had more than one episode lasting more than 2 years. In assessment of lifetime experience: 89% had core affective features; 64% reported affective symptoms occurring concurrently with psychotic symptoms. 85% had delusions, and 82% hallucinations, 30% thought disorder and 50% mania. More than half had a persecutory delusion with or without other psychopathology. Different diagnostic systems agreed in 79%, for Psychosis-NOS 32% & schizophrenia 21%. Compared with PO affective psychosis was similar frequency but schizophrenia was less in ASD-P, which seemed to relate to a larger group of Psychosis-NOS in ASD-P (52%). Only 4 were not taking psychotropic medication, 77% were taking at least 1 antipsychotic, including 8% on clozapine; 50% were on one psychotropic medication, 35% two and 11% three although the most common second medication was an antidepressant/mood stabiliser. Three took a benzodiazepine, two procyclidine (antiparkinsonian agent). Three reported drug reactions or sensitivity to antipsychotics. Comparing with ASD-NP, ASD-P had fewer women, had lower verbal IQ, were older and scored less on repetitive and stereotypic behaviour.

They concluded that people presenting with ASD with psychosis have fewer stereotypic behaviours, less schizophrenia and more Psychosis-NOS (ie more affective features) than those with intellectual disability. They speculate that higher rates of affective features may be related to shared genetics or long-term stress as shown by the high rates of a bipolar in relatives of those with ASD, and also higher rates of anxiety and depression in this population. The variability of presentation argues against a unique or different form of psychosis in ASD-P. They argue for a stress-neurodevelopmental vulnerability model in which the genetic components are poorly understood, but it could relate to the risk factors for social-

communication difficulties and genetic risk for psychosis (such as FOXP2 found in schizophrenia associated with language impairment). ASD-P evidently have differences to psychosis only and diagnosis can vary between different diagnostic manuals. This suggests caution and consideration of more than one diagnostic system. This is a large but retrospective controlled study and clarifying some of these issues would require a large scale and costly epidemiological study.

As is often the case this study excludes those with severe intellectual disability and those with additional impairments, as informed consent was required to participate. **For example, they don’t comment on Catatonia.** Their study confirms that it is important to look for first rank symptoms of hallucinations and delusions **(although most of my patients don’t have the communicative skills to define this)**, but also include affective features. Nonetheless it provides limited guidance in those cases that present with deterioration of independence and cognitive skills and who are functionally non-verbal as in the case presented.

### Conclusions

The paper by Larcon and colleagues (2016) indicates that psychosis in those with mild intellectual disability should be readily diagnosed and treated in mainstream psychiatry services. This case report shows that diagnosis in those more severely disabled remains a challenge, with little literature to support diagnostic reliability. Indeed, the literature suggests there is inconsistency due to the difficulties of eliciting subjective mental phenomena but this may be made worse by differing diagnostic national and cultural biases between DSM and ICD in those with intellectual disability (Dossetor, 2014). In those with severe intellectual disability this process is often driven by hypothesis testing with treatment, rather than clear diagnostic criteria.

The review of psychiatric diagnosis in chromosome 18 deletions suggests that these deletions are a risk factor for a range of psychiatric disorders as found in other genetic syndromes. The case study confirms that psychosis is a severe mental illness, regardless of genetics or intellectual disability. Although some academics wish to supersede psychiatric diagnosis with genetic and other biomarkers, the wisdom and therapeutics that has arisen from psychiatric classification still needs to be respected as a critical part of medicine.

Genetic risk factors so often predispose to different psychiatric disorders at different developmental stages of life, and the notion of a single genetic or molecular cause for psychosis does not seem any nearer. We



have such limited understanding of the normal development of the mind and what genetic, epigenetic and environmental factors modulate these processes.

Psychiatric diagnosis is a structured process to assess the severity and subtyping of the loss of social reciprocity and adaptability. All psychiatric diagnoses can be seen as classification of different patterns of loss of social integration and attunement. After all, both ASD and psychosis are severe disorders of social reciprocity, and conversely, many contend that major mental illnesses are developmental disorders. Genetic vulnerability supports the linkage between a range of neurodevelopmental disorders and a range of psychiatric disorders. Indeed, we find developmental continuities: neurodevelopmental disorders of attention, communication, intellect and social interaction of infancy predispose to anxiety disorder and ADHD in childhood which predispose to depression and psychotic illness in youth. Neuroscience research is likely to uncover important commonalities in the underlying brain processes that predispose to mental illness.

Finally, the last 70 years history of mental illness and of intellectual disability has been one of progressive deinstitutionalisation with the advance of psychiatric therapeutics and community models of care. If the new NDIS funded disability services exclude those with

complex mental disorder and intellectual disability, where will they go: into the care of family and community services, the long stay psychiatric wards, the justice system or homelessness on the streets? With the devolvement of complex disability from a government agency to an insurance scheme, does our community have the will to care for such doubly disabled people?

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# 3DN Improving Mental Health and Well-being of People with Intellectual Disability:

## A Research to Action Day for Professionals and Carers

*Reviewed by Kim Eisler from the 3dn website <https://3dn.unsw.edu.au>*

On 25 July 2017, 3DN launched a series of new must-have practical tools and resources designed to enhance the skills of professionals and carers who support people with an intellectual disability. The Department of Developmental Disability and Neuropsychiatry, also known as 3DN, was set up by the Chair of Intellectual Disability Mental Health to improve mental health policy and practice for people with intellectual or developmental disability (IDD). The following article is drawn from the information available on the 3DN website <https://3dn.unsw.edu.au>.

The new resources were officially launched by the Hon. Tanya Davies, Minister for Mental Health at a *Research to Action Day* which was kindly sponsored by NSW Health, and Ageing, Disability & Home Care, Family and Community Services. The day included presentations by carers, advocates, and health and disability professionals, some of whom were involved in the development of the resources. Workshop activities helped attendees become familiar with the resources and how they could be implemented. The day was well attended by health, mental health and disability professionals, carers and advocates, along with academics and those involved in policy development.

The resources that were launched include:

- The Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals
- New e-Learning modules for disability professionals, carers and mental health professionals
- Podcasts on responsible prescribing to people with an intellectual disability for health and mental health professionals
- A new Positive Cardio-metabolic Health for People with Intellectual Disability e-Learning module aimed at health professionals.

The importance of these resources and the need to provide such tools is well recognised by people with an ID and their advocates. Compared to the general population they are 2-3 times more likely to experience

common mental health disorders and are more likely to be exposed to risk factors associated with poor mental health (e.g. poor physical health, trauma, stress). Additionally people with an ID are less likely to access mental health care.

### Resource 1: [The Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals](#)

The Intellectual Disability Mental Health Core Competency Framework: A Practical Toolkit for Mental Health Professionals has been developed to accompany the previously released Manual. The Toolkit is a guide about *how* mental health professionals in mainstream services can develop the core competencies outlined in the Framework Manual.

It provides practical information, assessment tools and links to resources to assist in the development of the core attributes described in the Framework Manual. The mental health workforce can use the resources to continue to support their professional development in the area of intellectual disability mental health. A section also outlines how service managers can help to implement the Framework and Toolkit in their mainstream mental health services.

### Contents

The main section of the Toolkit covers considerations for each stage of the treatment pathway – i) Intake, ii) Engagement, iii) Assessment, iv) Treatment, and v) Transition. It also contains assessment tools that are suitable to use when assessing people with an intellectual disability (e.g. psychopathology, behaviour and

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“It provides practical information, assessment tools and links to resources...”

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emotion, and support needs); links to resources including training and education opportunities, guides, reports and discussion papers, relevant policy documents, and resources that can be provided to people with an intellectual disability, their family and support networks.

You can also find the launch article of this framework in Volume 7 Issue 2 of our Journal.



#### Where to find it:

<https://3dn.unsw.edu.au/idmh-core-competency-framework>

#### Resource 2: [New e-Learning modules for disability professionals, carers and mental health professionals](#)

These learning portals provide excellent information, helpful explanations, comprehensive reference lists and a range of practical tools and resources. Most

modules can be completed within 30 -90 minutes. Mental health professional modules assume that the practitioner has some familiarity with the health service systems and health service delivery whilst the modules for disability professionals and carers require no previous knowledge of the health system. In each section there are links to websites and documents to facilitate the learners understanding and provide resources to assist in their practice.

The two key messages to come from the module *Introduction to Intellectual Disability* include that:

1. Intellectual disability involves more than just below average IQ. Intellectual disability means a person also experiences difficulties in various domains of functioning, and has begun to experience these characteristics before the age of 18.
2. Intellectual disability is a complex disability that can affect a person in many different ways, and specific patterns of ability and disability vary widely between people with an intellectual disability.

One of the modules that professionals are likely to find **extremely helpful is Module 7 “Consent, decision-making and privacy – a guide for clinicians”**. For those not working in the disability field this is frequently a very difficult area to navigate and a cause of considerable concern. It is a complex situation requiring a **clinician to determine such things as a client’s capacity to understand and process information, balancing individual rights against the concerns of families and carers and ensuring client’s wishes are respected**. A multifaceted perspective is needed to guarantee the right of a person to freely make decisions about their own **health care while meeting one’s Duty of Care and legal**



## Intellectual disability mental health e-Learning

3DN provides free eLearning about intellectual disability to professionals, carers, and consumers. Our goal is to improve your knowledge, skills and confidence, leading to better mental health and wellbeing for people with an intellectual disability.

LEARN MORE

### Professionals

This section of the site contains e-learning developed specifically for health/mental health professionals and disability professionals. It may be of interest to other professionals.

[Register](#) [Learn More](#)

### Carers

This section of the site contains eLearning developed specifically for families and people caring for someone with an intellectual disability.

[Register](#) [Learn More](#)

### Consumers

COMING SOON: This section will have learning for people with an intellectual disability. You can register now and we will let you know when it is ready.

[Learn More](#)



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responsibilities.

Packed full of useful information and making clear reference to the current legislation this module can be completed in about 90 minutes. It includes specific reference to the legislation and guidelines in each state of Australia so practitioners from across the country can refer to the documents relevant to them.

This module covers the following:

- Informed Consent;
- Capacity to make decisions;
- Assessing decision-making capacity;
- Supporting decision-making; Authorised substitute decision-makers;
- Principles of substitute decision-making;
- Right to privacy

For instance in the section on capacity they include a Checklist from the Office of the Public Guardian in NSW [http://www.publicguardian.justice.nsw.gov.au/Documents/capacity\\_toolkit0609.pdf](http://www.publicguardian.justice.nsw.gov.au/Documents/capacity_toolkit0609.pdf)

Below is an overview of the modules for the three various audiences of mental health professionals, disability professionals and carers which is available at <http://www.idhealtheducation.edu.au/>

### *e-Learning for Mental Health Professionals*

#### Contents

##### About Intellectual Disability

- Module 1 – Introduction to Intellectual Disability
- Module 2 – Living with an Intellectual Disability
- Module 3 – Intellectual Disability – Changing Perspectives

##### Fundamental Skills in IDMH

- Module 4 – Communication: the Basics
- Module 5 – Improving your Communication
- Module 6 – Equality in Mental Health Care – A Guide for Clinicians
- Module 7 – Consent, Decision-making & Privacy – A Guide for Clinicians

##### Clinical Foundations in IDMH

- Module 8 – Mental Disorders in Intellectual Disability
- Module 9 – Assessment of Mental Disorders in Intellectual Disability
- Module 10 – Management of Mental Disorders in Intellectual Disability

##### Specialist Topics in IDMH

- Module 11 – Challenging Behaviour I – Introduc-

tion

- Module 12 – Challenging Behaviour II – Assessment
- Module 13 – Challenging Behaviour III – Management
- Module 14 – Emergency Mental Health Care 1: Understanding Intellectual Disability in the Emergency Department
- Module 15 – Emergency Mental Health Care 2: Journey Through the Emergency Department

### *e-Learning for Disability Professionals*

#### Contents

##### IDMH Introduction

- Module 1 – Why is it Important to know about Mental Health?
- Module 2 – Introduction to Mental Health
- Module 3 – Mental Illness in Intellectual Disability

##### IDMH Practical Skills

- Module 4 – A Person-Centred Approach
- Module 5 – Recognising Common Mental Illness
- Module 6 – How to Support a Person with a Possible Mental Illness and Intellectual Disability
- Module 7 – Supporting Behaviours of Concern

##### IDMH Advanced Topics

- Module 8 – Enhancing Interagency Working with Health Professionals
- Module 9 – Treatments and Supports for Mental Illness
- Module 10 – How to Support a Person in a Mental Health Crisis
- Module 11 – Supporting Carers, Colleagues and Self-Care

### *e-Learning for Carers*

#### Contents

##### Foundations

- Module 1 – About Intellectual Disability
- Module 2 – About Mental Health

##### Mental Health and Illness

- Module 3 – Mental Health and Intellectual Disability
- Module 4 – Detecting changes in Mental Health and Wellbeing

##### Specific Mental Illnesses

- Module 5 – Signs and Symptoms of Mood Disor-

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“A downloadable ‘wellbeing record’ is available separate to the carer module...”

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ders

- Module 6 – Signs and Symptoms of Anxiety Disorders
- Module 7 – Signs and Symptoms of Schizophrenia and Other Psychotic Disorders
- Module 8 – Signs and Symptoms of Dementia

**A downloadable ‘wellbeing record’ is available separate to the carer module.** This document will support **carers to keep a record of the person’s wellbeing.** It is available here: <https://3dn.unsw.edu.au/wellbeing-record>

**Resource 3:** [Podcasts on responsible prescribing to people with an intellectual disability for health and mental health professionals](#)

#### Who is it for?

Medical and mental health professionals.

#### Aims

To educate professionals on safe and effective prescribing practices for the treatment of mental health disorders in people with an intellectual disability.

#### Contents

- Podcast Series 1. Responsible psychotropic prescribing to adults with an intellectual disability
- Podcast Series 2. Responsible psychotropic prescribing to children and adolescents with an intellectual disability.

#### Where to find it:

<https://3dn.unsw.edu.au/content/responsible-psychotropic-prescribing-people-intellectual-disability-podcasts>

**Resource 4:** [A new Positive Cardio-metabolic Health for People with Intellectual Disability e-Learning module aimed at health professionals.](#)

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney has launched two new



e-Learning modules:

- Cardiometabolic health for people with intellectual disability – understanding risk
- Cardiometabolic health for people with intellectual disability – screening and intervention strategies

By completing these courses, health professionals will develop an understanding of the specific cardiometabolic risk factors that affect people with intellectual disability. The modules build on general clinical assessment and intervention skills, and examine ways to adapt these skills to support cardiometabolic health in people with intellectual disability.

The modules belong to a wider suite of resources on Positive Cardiometabolic Health for People with Intellectual Disability, including an early intervention framework; online resources for clinicians, carers and people with intellectual disability; and new podcasts for health professionals on responsible psychotropic prescribing to people with intellectual disability. All resources can be accessed from the 3DN website at: <https://3dn.unsw.edu.au/positive-cardiometabolic-health-ID>

#### Where to find it:

The modules can be freely accessed at [www.idhealtheducation.edu.au](http://www.idhealtheducation.edu.au)

#### Conclusion

Over 400,000 Australians have an intellectual disability and compared to the general population, they experience poorer health outcomes, including higher rates

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“A range of barriers prevent people with an intellectual disability from accessing healthcare...”

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of physical and mental health conditions, and premature death from preventable causes. Conditions are frequently undiagnosed, undermanaged or inappropriately treated. A range of barriers prevent people with an intellectual disability from accessing healthcare. For example, stigma and exclusion, the person or their family and carer(s) not being aware of symptoms, and a lack of adequate training for health professionals. The shortage of education opportunities and guidelines in this area contribute to the lack of skills, knowledge and confidence reported by the health and disability workforce when working with people with intellectual disability. As such there is no doubt that these educational programs and resources are urgently needed and provide a valuable professional learning opportunity for health workers or other professionals in this area.

More information about intellectual disability resources can be found at their website: <https://3dn.unsw.edu.au/content/education-resources>



# The Westmead Feelings Program 1 is Launched at APAC 17



*The Bandaged Bear celebrating the launch of Westmead Feelings Program 1 at APAC 17.*

The Westmead Feelings Program 1 has been launched, making this evidence-based program for children with Autism available to every child with Autism worldwide. Westmead Feelings Program 1: emotion-based learning for children with autism spectrum disorder and mild intellectual disability (WFP 1) was launched at the Asia Pacific Autism Conference 2017 (apac 17) held in September in Sydney. WFP 1 is a therapy program delivered by educators and allied health professionals that promotes emotions competence skills for children with autism and develops parent and teacher emotion coaching skills. WFP 1 was formerly known as Emotion-based Social Skills Training for Children with Autism (EBSST). Based on ten years of research and development, WFP is an evidence-based program that has been shown to improve children's emotions competence in treatment versus control trials of over 330 children on the autism spectrum, with and without intellectual disability (Ratcliffe, Wong, Dossetor & Hayes, 2014; Ratcliffe, Wong, Dossetor & Hayes, under review).

The publication of WFP 1 is in partnership between The Australian Council for Educational Research and the Children's Hospital at Westmead. Accompanying WFP 1 kits and manuals is WFP 1 Online Professional

Learning which develops skills, knowledge and competence in how to deliver WFP 1 and a pathway to becoming an accredited WFP 1 Facilitator. WFP 1 face-to-face Facilitator workshops are also available through the Children's Hospital at Westmead.

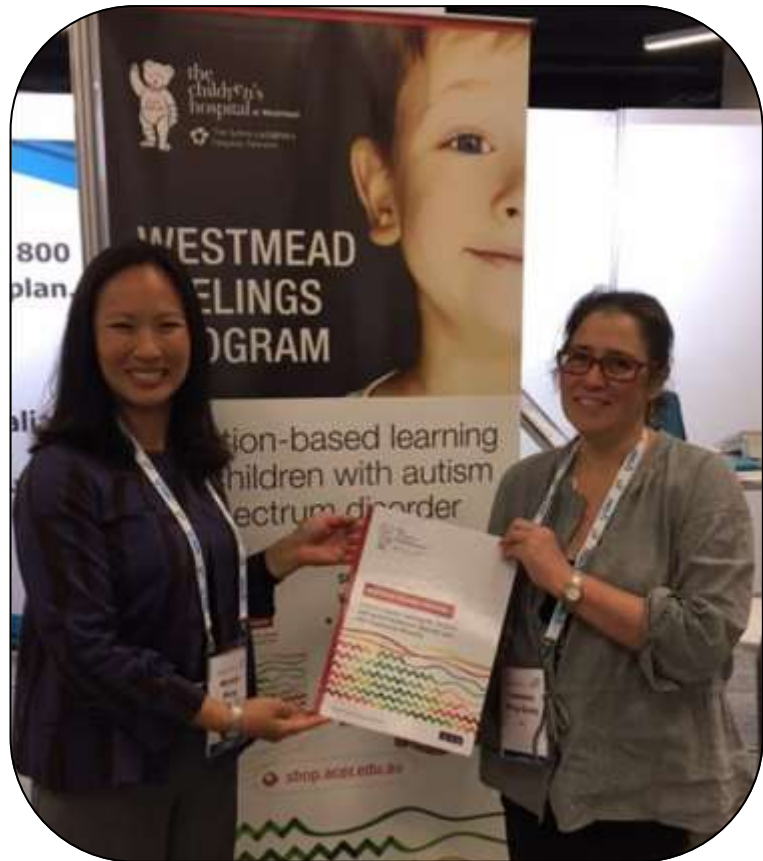
More information about WFP 1 can be found here: <https://www.acer.org/westmead-feelings-program>

Westmead Feelings Program 2: Emotion-based learning for children with autism without intellectual disability will be launched in September 2018.

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*Vanessa the Psychologist from Bendigo, Victoria is the first to take the Westmead Feelings Program 1 to her clinic.*





# The Medicine Cabinet: Medicinal Cannabis – why the fuss?

*Judy Longworth*  
*Clinical Pharmacist*  
*Department of Psychological Medicine*  
*The Children's Hospital at Westmead*

Medicinal cannabis became a controlled substance in the Poisons Standard on 1<sup>st</sup> November 2016 and thus is a Schedule 8 controlled medication but cannabidiol is schedule 4 (prescription medication). Prescribing medicinal cannabis requires state legislation and at present the only licensed product is Sativex® which is an oromucosal spray but currently there is no local sponsor and as such the product needs to be imported on a personal use and TGA Special Access Scheme (SAS) category B authorisation.

Each cannabis or marijuana plant (*cannabis sativa* or *indica* or *ruderalis*) contains up to 104 different chemical compounds called cannabinoids, terpenes and phenolic compounds (Patel, Williams & Wallace 2017; Andre, Hausman & Gueriero 2016). Cannabinoids are a diverse group of phytochemicals which have a wide range of pharmaceutical effects due to their action on the cannabinoid receptors that alter the neurotransmitter release in the brain. Science is still learning the effect of each of these chemicals. The most notable of the cannabinoids is tetrahydrocannabinol (THC) which

is the primary psychoactive compound in cannabis and also shown in animal studies to have both anticonvulsant and proconvulsant properties. This means that under some circumstances it can increase seizure rates and sometimes reduce seizure rates. Cannabidiol (CBD) is another major constituent of cannabis which tends to have more medicinal benefit in terms of our current understanding and less side effects, especially in terms of psychiatric symptoms. There are multiple strains of cannabis and there are multiple cannabinoids within each strain. The correct treatment requires the right drug for the right symptom for the right person, which is difficult when so many different





chemicals are in the one plant, many working in different ways and different doses for different conditions.

Currently, there is no approved manufacturer of medicinal cannabis in Australia and worldwide there is scarce supply with Israel being one of the most advanced groups in the production of specific strains. Legislation that passed on 30<sup>th</sup> October 2016 was needed to allow Australian cultivators to begin to produce medicinal cannabis for clinical trials and research. Shipments of medicinal cannabis have been allowed into Australia as an interim measure while the domestic medicinal cannabis industry continues to develop. The cultivation and manufacture of medicinal cannabis will be controlled by the Office of Drug Control (ODC) similar to that for locally grown Opium poppies (*Papaver somniferum*).

### Why can't we use the home grown variety? (TGA Medicinal cannabis factsheet)

The (Therapeutic Goods Administration) TGA outline that for cannabis to be used in clinical trials and for it to be registered as a pharmaceutical there are several steps that need to occur.

1. The product needs to be uniform, i.e. each time the dose is given the same active ingredients need to be present
2. The active ingredients have to be safe and not contaminated
3. Manufacture needs to adhere to strict principles of quality control.

Access to medicinal cannabis is available through:

1. Selected clinical trials and
2. Personal import through SAS (Special Access Scheme) and authorised prescribers schemes administered by the TGA .

This will ensure that the same safeguards and legislation will apply to medicinal cannabis as to other experimental or emerging medications. The Australian government aims to maintain high standards of safety for patients who want to access medicinal cannabis and **it's use under suitably qualified clinicians and /or** through appropriate clinical trials.

### Current literature

#### 1. Cannabidiol in treatment resistant epilepsy

Devinsky et al (2016) led an open-label interventional trial on patients aged 1-30 years with severe intractable childhood-onset, treatment resistant epilepsy from 11 centres across the USA. The research was sponsored by a pharmaceutical company. The researchers conducted a safety study to test whether cannabidiol (CBD) as an add-on treatment to conventional antiepi-

leptic drugs would be safe, tolerated and efficacious in children and young adults with highly treatment resistant epilepsy.

The product tested was 99% pure oil-based cannabidiol extract of constant composition. 100mg/ml. doses were titrated to a maximum dose of 50mg per kg per day in 30% of patients during the 12 week observation period. Adverse effects were reported in 79% of patients with the most common being somnolence, decreased appetite, diarrhoea, fatigue, convulsions, appetite changes, status epilepticus, lethargy, changes in concentrations of concomitant antiepileptic drugs, gait disturbance and sedation. On further analysis diarrhoea and weight loss occurred more frequently in patients taking more than 15mg/kg/d.

Patients with Dravet and Lennox-Gastaut syndromes were the largest cohort of patients. Post hoc analysis revealed 50% of the patients with Dravet syndrome had 50% or greater reduction in motor seizures, with one patient who became seizure free during treatment. In patients with Lennox-Gastaut syndrome there was a median reduction in motor seizures of 36.8%.

#### 2. Cannabidiol in Dravet syndrome

Devinsky et al (2017) led multinational double blinded placebo control trial where 120 children were randomly assigned to cannabidiol solution at dose of 20mg/kg/day in addition to their standard antiepileptic treatment over a 14 week treatment period. This was a pharmaceutical company sponsored study. There were 177 patients screened and 120 underwent randomisation with the mean age of 9.7 years and 90% completed the treatment period. The primary end point was reduction in number of seizures with 108 patient included for protocol analysis.

The convulsive-seizure frequency decreased from a median of 12.4 seizures per month at baseline to 5.9 over the entire treatment period. In the placebo group there was also a reduction decreasing from 14.9 to 14.1 seizures. 8 patients withdrew from the cannabidiol arm due to adverse effects which included vomiting, fatigue, pyrexia, upper respiratory tract infections, decreased appetite, convulsion, lethargy, somnolence, and diarrhoea.

#### 3. Oral cannabis extract duration of use

Oral cannabis extract is increasingly being used in USA for the treatment of epilepsy. A study by Treat et al (2017) looked at the perceived benefit in a cohort of patients with paediatric epilepsy through a retrospective chart review. In this study, 119 patients were reviewed between December 2013 and July 2015, with 71% terminating their treatment during the study peri-



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**“The Australian government aims to maintain high standards of safety for patients who want to access medicinal cannabis...”**

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the study there was a low response rate similar to placebo rates for antiepileptic trials. Those patients whose families perceived there to be benefit, even with adverse events, continued on treatment the longest.

**4. Cannabidiol and commonly used antiepileptics**  
Gaston et al (2017) have recently researched the interactions between cannabidiol and other commonly used antiepileptic drugs. Significantly changed serum levels of clobazam, rufinamide, topiramate, zonisamide and eslicarbazepine were recorded in clinical trials with cannabidiol (CBD) which may account for some of the adverse effects reported from the Treat et al (2017) trial. CBD modulates several cytochrome P450 enzymes (CYP) and thus the potential for drug interactions. CBD is a potent inhibitor of CYP 2C19, CYP2D6 and CYP2C9 and a potential inhibitor of CYP3 family.

Baseline AED levels were done and again at each visit where CBD dosing was adjusted. Clinically significant interactions were found with clobazam and eslicarbazepine but not with topiramate and rufinamide when adult and child arms of the study were combined. Serum levels of N-desmethyclobazam, topiramate, eslicarbazepine, zonisamide and rufinamide increased after CBD was initiated. The interaction between CBD and N-desmethyclobazam appears much more **profound and is likely due to CBD’s potent inhibition of CYP2C19** which is responsible for metabolism of N-desmethyclobazam. This resulted in prolongation of the half-life and accumulation, thus leading to sedation.

Also of note was the interaction between valproate and CBD leading to abnormally high AST and/or ALT levels after CBD treatment; on rechallenge without CBD there was no recurrence of the abnormalities.

Note: eslicarbazepine is not available in Australia

**So where do I get it?**  
Currently the only authorised prescribers of medicinal cannabis in Australia include clinical trial investigators **and prescribers under the TGA’s Special Access Scheme**. There are 3 clinical trials under way in NSW: one for severe epilepsy in children; a second for adults

od. This study is looking at Colorado Medical Marijuana Registry program with a retrospective chart review.

The average age of patients were 7.5 years and the mean duration of treatment was 11.7 months (range 0.3-57). 49% of parents reported at least some improvement in seizures. The highest proportion of responders was for Lennox-Gastaut syndrome. The exact nature of the product used was not always recorded so this could not be analysed. The most common adverse events noted were worsening of seizures, somnolence, and gastrointestinal symptoms but greater than 40% of patients who had experienced adverse events continued with oral cannabis extract. Among the cohort in





in palliative care; and a third for chemotherapy related nausea and vomiting.

The epilepsy trial is using the overseas manufactured product Epidiolex® and there is also a compassionate use scheme for severe non responsive epilepsy. See <https://www.medicinalcannabis.nsw.gov.au/clinical-trials/paediatric-epilepsy-trial>

The research thus far has been limited by access to medicinal cannabis and also the complex nature of the make-up of cannabis and its many chemical compounds. Further research is needed across health areas for a better understanding of cannabis potential.

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

Dr Peter Wurth, Dr Patrick Concannon, Helen Appleton, Andrew Frakes and Kerrie Nelson  
*Giant Steps*

## 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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“The practice of transporting students off site for medical services was inefficient and disruptive...”

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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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## “They see how their feedback assists clinical decisions and the importance of consistency...”

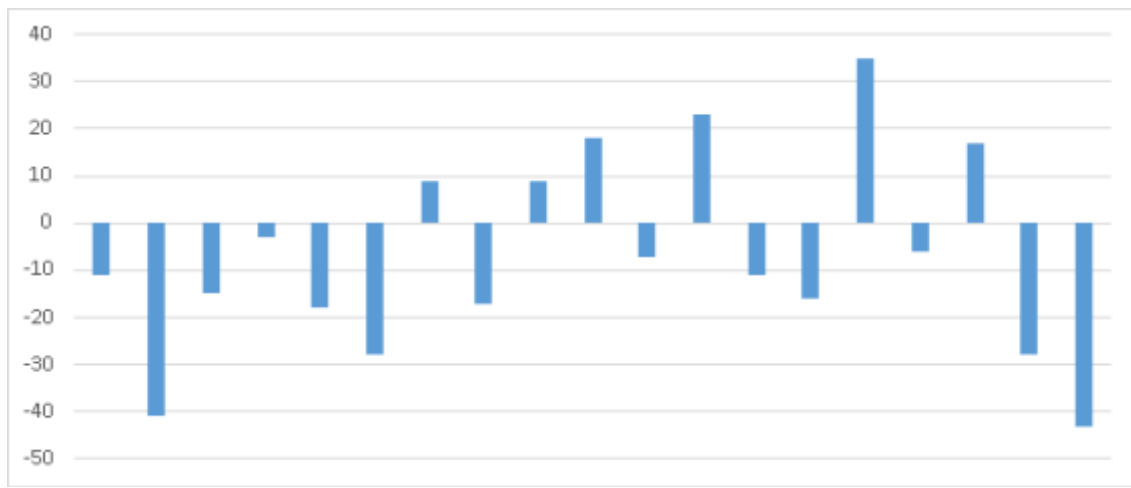
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Central to an evidence-based approach to treatment in any field of medicine is the ability to accurately and validly monitor outcomes. Self-report, widely used in general psychiatry, and of problematic validity, is unavailable in this population. Psychiatry 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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# “The educational process has been bidirectional between clinic and classroom staff...”

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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.

*This clinic would not have been possible without the generous and ongoing support of the Lorenzo and Pamela Galli Charitable Trust.*

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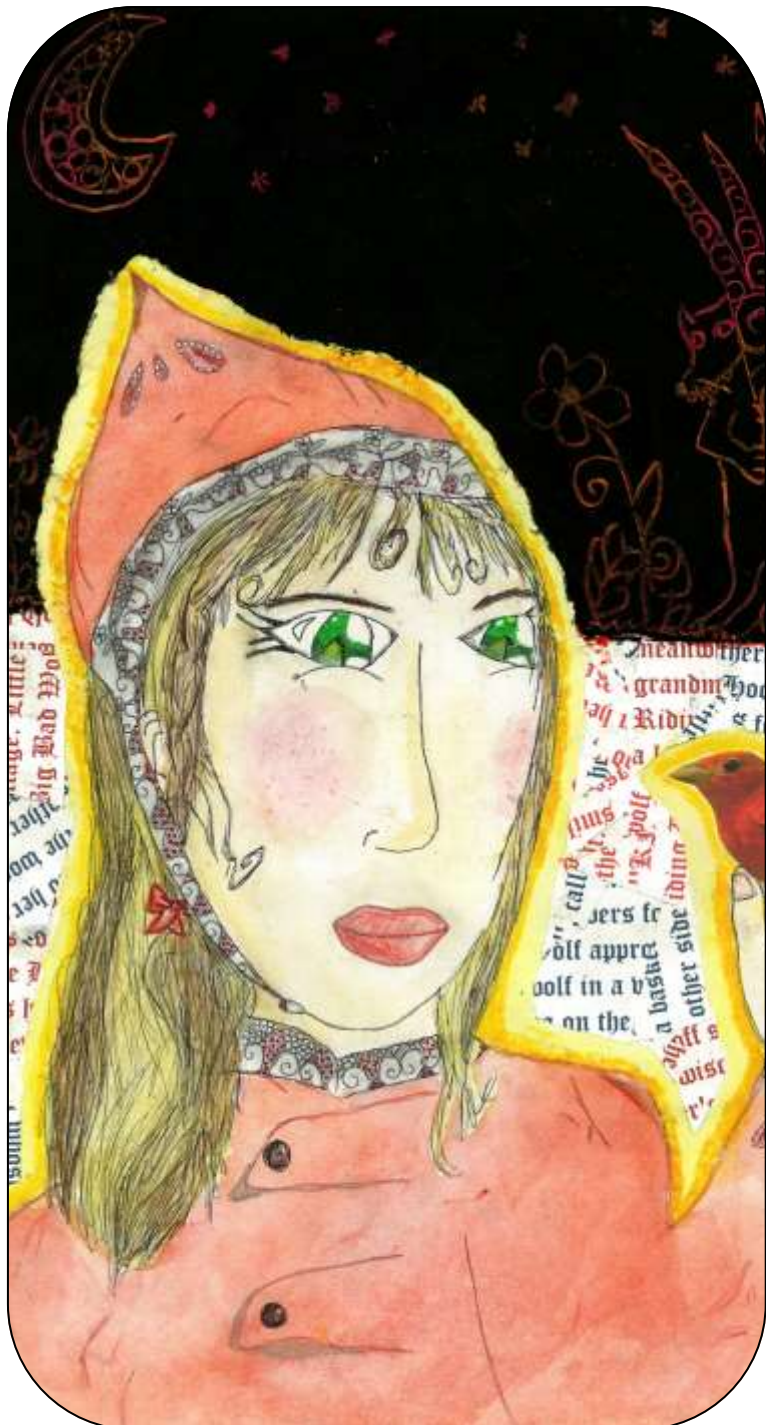
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# The Knotted Cord: Transgenerational Alcohol Related Neurodevelopmental Disorder (ARND) by Kieran O'Malley. 2016, Nova Science Publishers: A Book Review

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“The Knotted cord” is a review of Fetal Alcohol Syndrome (FAS) and non dysmorphic Alcohol –Related Neurodevelopmental Disorder (ARND) collectively called Fetal Alcohol Spectrum Disorders (FASDs). The book was written by O'Malley (2016) who is a child psychiatrist with 25 years of experience in clinical practice and research.

O'Malley (2016) stressed that FASDs were not well recognised and remain a hidden cause of disability. Both dysmorphic (FAS) and non dysmorphic ARND are caused by alcohol use in pregnancy and they lead to a huge mental health burden and cost to the community. O'Malley emphasised that there was a need for a multidisciplinary approach by medical and allied health teams for addressing the needs of this clinical cohort. In his book, O'Malley reviewed current diagnostic and management approaches, interwoven with case examples from his experience of managing patients in USA, Canada, UK and Ireland. The title of the book is a metaphor for the transplacental alcohol that impacts on a newborn; that is both caused by and causes complex dynamics within families and social/community contexts. The contributors to this predicament remain ambivalent to the significant problems. The book is an easy read with a directness of approach. It considers some of the ethical dilemmas of diagnosis, such as distressing the drinking mother, and the lack of openness to recognition and reporting, particularly within

Ireland that has the highest rates of female alcohol consumption but the lowest rates of recognition of FASDs.

In spite of progressively improved knowledge of the anatomical, diagnostic, biochemical, neurophysiological and psychological deficits which O'Malley summarised, there is dearth of literature on the management strategies for these conditions. We have to understand that this is a vulnerable group, which ends up with conduct disorders with aggressive violent outbursts, whose problems are blamed on placement and family dynamics, while completely underestimating brain and neurochemical dysfunction due to maternal prenatal alcohol exposure.

The author stressed that a transgenerational management approach was the only viable approach for managing these child and adolescent mental health patients often due to the impact of intergenerational and historical trauma, such as ‘the troubles’ in Ireland, contributing to excessive drinking habits. With the lack of clinical recognition, the onus for detecting these ‘subclinical’ cases of prenatal alcohol exposure was largely placed on schools and criminal justice systems. Additionally, the suggestion that FASDs are limited to Indigenous groups is significantly misrepresented. The common co-occurrence of complex conditions of Attachment Disorder, Trauma related disorders, ADHD, ASD, Aspergers, Mood disorders, Conduct disorders, Depression, and Self harm tendencies, are often a reflection of disabilities that track back to prenatal alcohol exposure although it is often difficult to prove this link.

O'Malley recommended a 6 dimensions approach to understanding clinical presentation. The dimensions included:

1. Motor and Sensory Disorder, including developmental coordination and sensory integration problems, (often the earliest presentation described in the Diagnostic Classification for 0-3 years, under ‘regulatory disorders of sensory processing’ with

subtypes of Hypersensitive fearful or defiant, Hypo-sensitive/under responsive, and Sensory Stimulation Seeking/impulsive) (O'Malley & Streissguth, 2006);

2. Disruptive Mood Dysregulation Disorder, with impulsive suicidal risk;
3. Language Disorder with impairment of social cognition and communication;
4. Cognitive Disorder especially executive function and working memory;
5. Facial Dysmorphology Disorder; and
6. Growth Delay Disorder.

In the book, O'Malley (2016) left no doubt about how comprehensive assessment and intervention needs to be, with multi-agency, multidisciplinary and multimodal approaches required to give these complex young people a chance to integrate problems of development and disturbance. Accordingly, his accounts provided useful guidance to clinicians faced with apparently impossible clinical predicaments. For example, PET scans were provided that illustrated the brain functional disconnects. With the dominance of genetic research, there is renewed interest in the epigenetic impacts of neurotoxic alcohol on prenatal brain development, including long term effects of alcohol craving as adults as one mechanism contributing to the transgenerational process.

The book provided a developmental framework not only for recognising the unique features of alcohol related disorders, but also expanded on the stigma and ethical dilemmas in patient management. O'Malley provided interesting clinical scenarios encompassing different ages from infancy to adulthood, throwing light on the presentations and their complex interactive mechanisms. These scenarios emphasised the need for ownership of patients by mainstream developmental neuropsychiatry and addiction medicine. The skills to care and support these children needs to be integrated into families and communities in order to **strengthen the 'cord knotted' that was harmed by alcohol** but not irreparably broken.

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**“This book expanded on the stigma and ethical dilemmas in patient management...”**

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The book was divided into 13 chapters, including prologue, post script and epilogue, and it was well referenced including recent studies. The chapters addressed diagnosis and management approaches, and emphasised the need for diagnostic formulation, as this leads to greater clarity of management. The book also provided an addendum of practical strategies for managing children/adolescents with neurodevelopmental disorders (including FAS/ARND) that were divided into issues such as attention, transition, organisations etc. O'Malley's advice on strategies benefitted from practical personal experiences that were mixed with case examples and quotes of poems. In the complexity of a systems-of-care approach, it is difficult to be clear as to the critical variables that should be targeted for the best outcomes. The role of paediatricians as part of multidisciplinary model is not well defined, although this may differ in different national service systems. In a nutshell this is an extremely useful book which provided an overview of diagnosis, but it also expanded our understanding and manage-





ment, particularly of the complex, lifelong and inter-generational co-morbid mental health issues of patients with FASDs.

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# Connecting Animals with People: implications for well-being and therapeutic applications.

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**Australians' love of pets is reflected in our rates of pet ownership and the money we are prepared to spend on them.** In a national study Animal Medicines Australia (AMA, 2016) found that 5.7 million households had at least one pet and it is estimated we spend more than \$12.2 billion on pet products and services each year (AVA: 10). With 62% of Australians owning a pet we have a slightly higher rate of ownership than the international average of 57% (AMA: 16); 38% of households have a least one dog and 29% have a cat (AMA: 10). Companionship was cited as the number one reason for owning a pet with the majority of pet owners considering them a part of the family (65% of households with dogs and 66% of households with cats) (AMA: 49). **The term 'fur baby' is now part of our lexicon.**

Researchers from the University of Western Australia have reported that pet ownership leads to stronger ties between neighbours and increases social connectedness within local communities – and it doesn't matter where you live or what kind of pet you own. The study focused on over 2,600 pet owners in Perth and in the US cities of San Diego, Portland and Nashville. It found that pet owners are perceived as being more trustworthy and an increase in social capital, which helps build stronger community ties. Pet owners led to more connected communities with pets enhancing contact between neighbours. (Woods et al; 446)

Pets can encourage us to lead healthier lifestyles and pet ownership has been found to be significantly correlated with a number of health benefits such as fewer doctor visits, lowered stress and increased social support for individuals. Additionally, pets have been found

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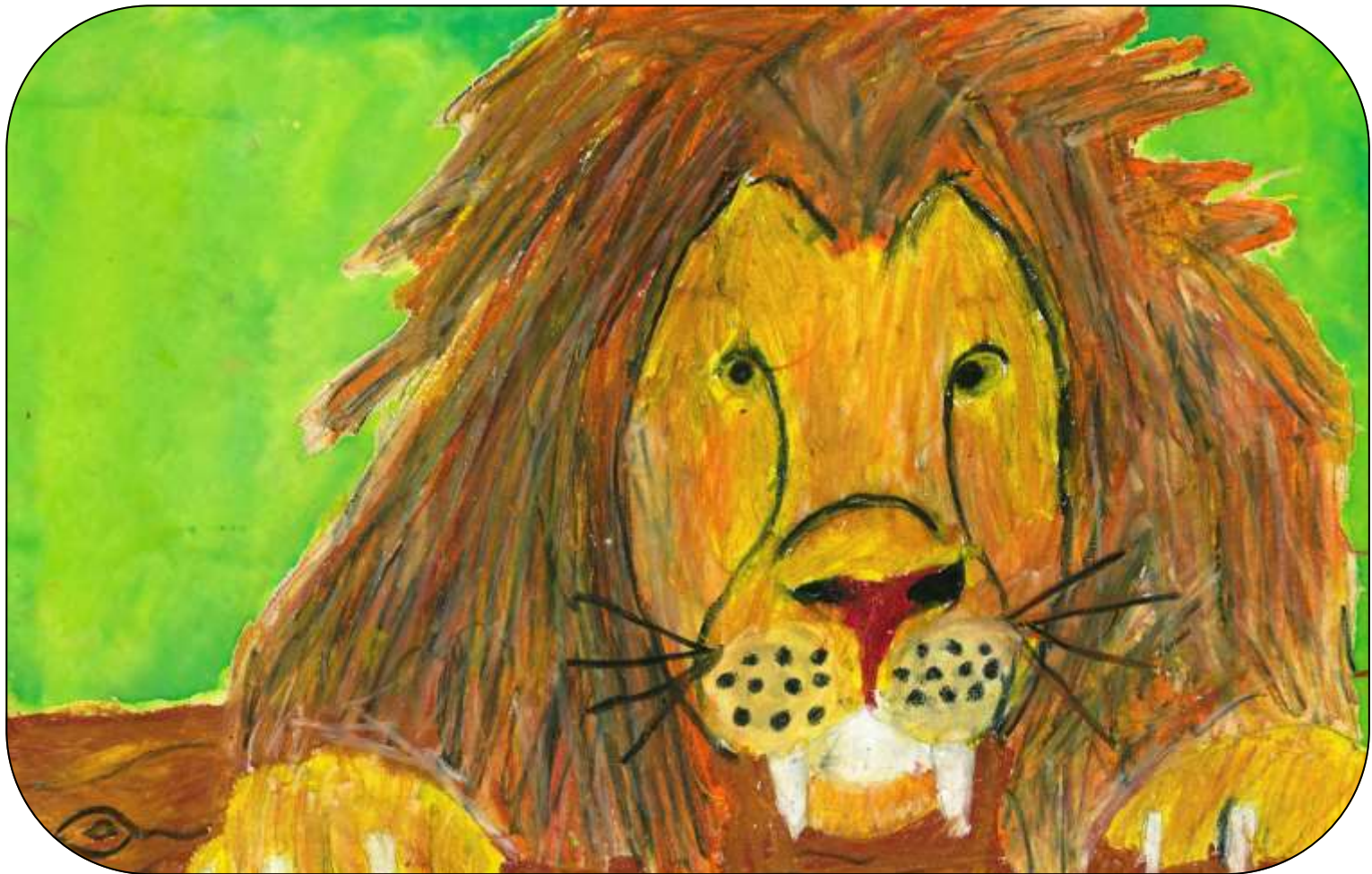
**“Pet ownership has been found to be significantly correlated with a number of health benefits...”**

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to help people cope with diseases such as heart disease, dementia, AIDs and cancer (Morrison, 2007). A correlation between the presence of companion animals and the alleviation of depression, loneliness and low morale whilst dealing with the treatment of chronic illness has also been reported. (AMA: 54)

While owning a pet can have various positive outcomes for their owners they are not necessarily considered to be providing an Animal Assisted Intervention (AAI) per se. The American Veterinary Medical Association (AVMA) classifies AAI into three categories: (i) animal-assisted activities (AAA) that utilise companion animals in spontaneous, unspecified manners (ii) animal assisted-therapy (AAT) that utilises therapy animals, and (iii) service animal programs (SAP) that utilise service animal. (Kamioka et al, 2014).

**Krskova (2010) defines AAT as “..a goal-directed intervention in which an animal that meets specific criteria is an integral part of the treatment process. AAT is practiced with human professionals. Key features include: specified goals and objectives for each individual and measured progress. AAT is designed to promote an improvement in human physical, social, emotional, and cognitive function” (Krskova, 2010: 140). While Maber-Aleksandrowicz (2016) state “Animal-assisted therapy includes deliberately planned pedagogic, psychological and socially integrative interventions with animals for children, youths, adults and senior citizens with cognitive, social-emotional and motoric disabilities, and behavioural problems, and for focused support. It also includes health-promoting, preventive and rehabilitative measures. Animal-assisted therapy takes place individually and within a group setting. Animal assisted therapy is based on the relationship and process structure within a triangular relationship between the client, animal and therapist. Animal-assisted therapy involves methods by which clients interact with animals, communicate via animals or are active for animals.” (Maber-Aleksandrowicz 2016: 334)**



The most common AAT animal is the dog, which is probably not surprising when you consider that archaeologists have found evidence of our shared evolutionary past reaching back over 140,000 years (Solomon, 2012: 145). Through their continued connection to humans dogs have been selectively bred through generations to pay attention to people and MRI scans have shown that dog brains respond to praise from their owners just as strongly as they do to food. (<http://www.abc.net.au/news/2017-06-21/pet-owners-make-stronger-neighbour-ties-uwa-study-finds/8638432>). Other animals frequently used include horses and dolphins with an increasing use of **small animals or 'pocket pets'** (Hall, 2016; Krskova, 2010).

In Australia the traditionally recognised service or **assistance animal was a 'guide dog' for people with vision impairment**. More recently it has been recognised that assistance animals can provide a variety of supports and this is now so commonly accepted that the NSW Ministry of Health in 2012 set Guidelines on animal visits and services in health services (MOH 2012). In this document they recognise that animals **provide "comfort, entertainment, distraction, solace and a unique form of interaction**. Animals also provide a unique source of assistance in education and **supporting patients through clinical procedures"** (MOH

**2012: 2)**. It covers a range of scenario's and sets out policies for visits from family pets, general animal visits, companion animals, therapy animals and specialised assistance or service animals.

The legislative guidelines pertaining to Assistance Animals are governed at both a Federal and a State level with significant variation among states and territories regarding accreditation and regulation of assistance animals. Under Australian Federal Law, Owner-Trained Assistance Dogs must pass a strict Public Access Test. Service animals are also legally defined and recognised by federal law Under Australian Federal Law the Commonwealth Disability Discrimination Act 1992 which makes it unlawful to discriminate because someone is using an assistance dog as a disability aid. AA must be accredited under state law and trained appropriately by recognised organisation (Rossetti & King, 2010). This website provides information on laws for assistance animals under the *Companion Animals Act 1998* in NSW only.

In Australia, there are generally four options for a person looking for an Assistance Dog. These are:  
Being accepted in to an organisation that will place an Assistance Dog with you.  
Being accepted in to an organisation that will assist you in training your own dog (subject to certain criteria



being met). These organisations require you to pass their own Public Access Test (PAT) however they may or may not be accredited by state authorities. Training your own dog to Assistance Dog standards and applying to sit the PAT through a state government body.

Training your own dog to meet standards of hygiene and behaviour that are appropriate for an animal in a public place.

Note that in all, it is generally a requirement that a General Practitioner AND a Psychiatrist or Psychologist (in the case of a psychiatric disability) must specifically prescribe an Assistance Dog for your medical condition. (Rossetti & King, 2010).

AAT as an intervention is unique and different to pharmacological or traditional rehabilitation methods. Because it complements treatment and affects the way a patient experiences symptoms it is often classified under or considered to be a subset of alternative and/or complementary medicines (Kamioka 2014; Urbanski & Lazenby, 2012; Goddard 2015)

One of the first recorded instances of animals being used for a therapeutic purpose was in the York Retreat that opened in 1796 for the rehabilitation of the mentally ill. Florence Nightingale was also known to use pets with wounded soldiers in the early 19th century to facilitate the healing process (Goddard and Gilmer 2015). **In the 1960's** Dr Boris Levinson a practicing child psychologist noted that his patients were less anxious and had less resistance to therapy when his dog, Jingles, was involved in the sessions (Rossetti & King, 2010; Goddard and Gilmer 2015). Another pioneer in this field was Dr Corson who was labelled the **“father of pet-assisted therapy”** after his death in 1998 (Goddard and Gilmer 2015).

Reports on the beneficial effects of dogs with severely **withdrawn children date back to the 1960's** but it is only since the turn of the century that the field of research has been receiving growing attention (Berry et al, 2013:74). Over the next few decades anecdotal and case-based evidence has continued to grow and **stands alongside a growing “body of evidence showing the overall “de-arousing effect” of human-animal interactions on human physiology”** (Berry 2013: 77).

The positive effect of AAT has been found across a range of settings, with clients who had various health problems: at an inpatients facility for individuals with schizophrenia those assigned to the dog treatment group showed significant improvement; older patients in a rehabilitation unit had a decrease in depression following the presence of a companion bird; interac-



tions dolphins led to a decrease of symptoms for those with mild to moderate depression; animal petting has been found to improve gross and fine motor skills. (Busch, 2016, Kamioka 2014, Gagnon et al., 2004).

A study focusing on children hospitalised on a pediatric oncology unit found 89% of the children who received canine therapy had increased independence and appetite, as well as decreased fear and pain from treatment and procedures (Gagnon et al., 2004). The beneficial effect of canine-assisted interventions on ADHD symptoms was superior to a cognitive-behavioural intervention without canine-assisted intervention, in which only toy dogs (realistic puppets) were **utilised; parents rating of their child's social skills and prosocial behaviour** also increased after treatment. However, although standardised measures were used, parent ratings were not blind, which might have inadvertently influenced the results. Moreover, these positive changes in behavior did not differ significantly from the treatment with CBT alone (Schuck et al., 2015). Child psychologists have found that AAT is especially useful in helping children who have been

abused or neglected and have insecure attachments (Parish-Plass, 2008).

While there is now a wealth of research completed in this area it has generally suffered from poor design and implementation. There has been consistent difficulty with the internal validity of trials; specifically methodological problems in generating appropriate concealment, blinding, and intention-to-treatment (ITT) analysis (Kamioka et al, 2014). In addition, the variation in animals used and subjects reported illness or disability along with the diversity of intervention used make rigorous analysis and retesting impossible. Furthermore “Although there is increasing information available on the effects of trained dogs used in Animal Assisted Interventions (AAI), including Animal Assisted Therapy (AAT)..... **there is little literature available on the effects of pet dogs as an autism therapy.** Indeed, the evidence base in the area of AAI in general is **constrained by a lack of high quality studies” (Hall, 2016: 2).**

A review by Berry et al (2013) investigating the results of six published studies which looked at the effect of assistance and therapy dogs for children ASD. Berry et al (2013) excluded qualitative (anecdotal) studies and only included experimental studies, semi-structured interviews, and case studies, published in the English language in peer-reviewed journals. Burrows et al used the cortisol awakening response (CAR) when examining the effect of assistance dogs on the general welfare of families with children affected by ASD and reported **“CAR was decreased upon the introduction of dogs (acute effect), whereas it rose again when the animals were removed from the families (long-term effects)”** In semi-structured interviews completed with the parents they reported a decrease in problematic behaviours when the dogs were living with them however an accurate analysis of behavioural change would need to be based on systematic observations (Berry et al, 2013:75).

In another study the introduction of a friendly dog into a therapeutic session, with seriously withdrawn children with ASD, showed a sharp increase in the frequency of both verbal and non-verbal social behaviours. These behaviours were directed toward the dog and the therapist and matched by a corresponding decrease in children’s withdrawal. **The improvement was maintained to a lesser extent on a 1 month follow-up.** Unfortunately the research lacked information on the diagnostic criteria used and a control condition, as such it may be that the positive effects observed was due to the introduction of a novel and exciting stimulus (Berry et al, 2013:75).

Taken together, the studies reviewed are encouraging, since the interaction of children affected by ASD with therapy dogs was able to promote verbal and nonverbal behaviours, directed both towards the dog and the therapist. Berry et al note that methodological problems, small sample sizes and a lack of RCT is a **problem for studies in this field but that “intervention strategies, based on exploiting the emotional aspects of the relationship with a dog, can overcome the inability of children affected by ASD to relate and interact with others by targeting some of the core symptoms of this disorder” (Berry et al, 2013:77).**

Kamioka et al (2014) conducted a systematic review of articles published between 1990 and 2012 using multiple databases with no data restrictions. From a cache of several hundred potential papers 57 were assessed but only 11 met their selection criteria where the design was a RCT and one of the interventions used was a form of AAT. Protocols without results were excluded and the primary outcome measure was a cure or rehabilitation effect. The animals used in the studies included dogs, cats, dolphins, birds, cow, rabbit, ferret, and guinea pig. Patients were suffering from a range of physical and mental ailments including schizophrenia, cancer, advanced heart failure, depression, ambulatory motor impairment and neurologic conditions. Of the 11 studies, seven studies were focused on mental and behavioural disorders. (Kamioka, 2014: 5).

**Kamioka et al “... could not perform a meta-analysis.** Due to poor methodological and reporting quality and heterogeneity, there was insufficient evidence in the studies of AAT, and we are therefore unable to offer clearly any conclusions about the effects of AAT based on RCTs” (Kamioka, 2014: 14). **They concluded that AAT may be effective for cancer and other life-limiting chronic diseases and ASD but noted that this is likely limited to those patients who like animals as people who don’t like animals will likely refuse the intervention altogether (Kamioka, 2014: 15).**

Maber- Aleksandrowicz et al (2016) conducted a literature review of studies where AAT was used with people who had an Intellectual Disability (ID) in order to ascertain psychosocial outcomes including, behavioural,

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**“The introduction of a friendly dog with seriously withdrawn ASD children, showed a sharp increase in social behaviours...”**

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social, cognitive and emotional factors. They screened 2750 articles of which 47 were assessed eligible for full review based on their abstracts. Of these full text articles 36 were then excluded because they had mixed patient populations without subgroup analysis for the ID group, were not clear regarding the percentage of people with ID, or participants with ID < 85% of population. The remaining 10 studies generally had low numbers of participants so that there was a total number of 100 participants with ID across all studies, in eight out of the ten studies all participants had ID.

Their review once again noted that study designs were weak, with a failure to control for confounding factors and a lack of randomisation or standardised data outcome tools. Other issues include the lack of uniformity in the AAT and a failure to determine whether the positive results were simply a result of the novelty of the inclusion of an animal (Maber- Aleksandrowicz et al **2016: 333**). **Overall they conclude “Current evidence shows that AAT may be a potentially useful supportive intervention in improving quality of life in persons with ID but good quality research is lacking” (Maber- Aleksandrowicz et al 2016: 336).**

While the evidence grows in support of AAT there are various hypotheses being proposed to explain why interactions between children with ASD and dogs result in positive behavioural and social changes. According to Solomon (2010) **“Dogs highly anticipatory, unhurried, structurally simple and easy to interpret social actions may be generating a locally organised interactional ground against which is easily projected and realised by children with autism” (Solomon, 2010: 157).** **It may be that the “simple and interpretable pattern of movements that characterises dogs might facilitate the engagement of children with ASD in structurally simple social actions that do not require the interpretation of verbal cues and are highly repeatable and predictable” (Berry et al, 2013:74).** **Dogs may be acting as social catalysts or provide a “bridge” by which children can learn how to interpret dog behaviour and then human.** Dogs also provide a strong multisensory stimulus. She notes that for children with autism dogs can generate a **“social universe” without language and encourage interactions much easier than people can.**

If AAT is to be successful there are important factors to consider such as individual patients allergies, fears or phobias. Some patients may feel a natural affinity for animals while others do not like them or are simply uninterested. For children who are diagnosed with ASD age has been found to influence outcomes with older children and those with better conflict management skills responding better (Hall, 2016). Sensory difficulties and arousal levels also need to be considered as

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## “Older children and those with better conflict management skills respond better...”

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this can be especially pertinent in children with ASD (Berry, 2013). As such an individual assessment of the patient, including risk factors and possible contraindication is essential (Hall, 2016).

As a therapeutic intervention the use of animals is in its infancy but this is changing and over the last couple of decades the field has rapidly expanded, engendering growing interest from across multiple disciplines. In effectively assessing the potential benefits of AAT research will need to address difficulties in regard to defining the intervention used, understanding the reasons for non-participation, including blinded studies and RCT methodology. Studies that help us understand in what circumstances and under which conditions AAT is beneficial and what may contribute to adverse effects (Kamioka, 2014). As our society becomes increasingly urbanised and individuals more isolated animals may be one means by which we can maintain our connection not only with the natural world but also with each other.

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